**Know Your Rights Podcast Series**

**Episode 1: Healthcare**

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**Jacob Charendoff:** Hey, well, hello and welcome to the Know Your Rights podcast series. My name is Jacob Charendoff, and I'm the host of this series brought to you by the CNIB. And as the name suggests, the intention of this series is for you to know your rights. We're gonna cover a broad spectrum of topics. And today I'm joined by Lisa Feldstein of Lisa Feldstein Law and Malini Ondrovcik, who is the clinical director at OSR Clinical Services and a registered psychotherapist. Today, we're gonna talk about health-related issues from a human rights perspective, and some issues that some of you may have experienced, from filling out forms and not being the most accessible, to staff who maybe don't understand your needs and also to visible and invisible disabilities. So, Malini, I know that you've kind of experienced some of that yourself. Would you mind telling us a little bit about the type of discrimination that you may have experienced?

**Malini:** Absolutely, so in all sectors, I would have experienced some sort of discrimination. Many times, I find that I'm really great at advocating for myself, but every now and again, there's situations where I'm really taken aback and have a difficult time. There was a particular situation at my ophthalmologist's office that happened pretty recently, that was quite difficult, which involved forms that were inaccessible and just treatment that was really unexpected.

**Jacob:** So, you know, one thing I should kind of preface all of this with is I have a rare form of macular degeneration called Stargardt's disease. And Malini, I know that it's challenging, those forms that you can't see, and to go and ask workers or people sitting in the waiting room, sometimes can be a little bit intimidating. Was this the first time that you've experienced that thing, or has this happened to you before?

**Malini:** Unfortunately, no this has been something that's happened to me in the past as well.

**Jacob:** Okay, and with the inaccessible font size on these forms, how did you progress? Did you ask the staff to help? Did you ask anybody in the waiting room to help with you?

**Malini:** So, in this particular situation, luckily, my husband was with me, so he was able to fill out the forms. And that is typically the work-around that I have - my husband is the one taking me to many appointments, so I have his help, but in some cases if I'm dropped off, or whatever the case may be, I'm usually comfortable enough to ask staff for help when forms are inaccessible.

**Jacob:** Yeah, absolutely. So, with this type of thing, what was the main thing that this was something that really stuck out to you as an issue for you at the ophthalmologist's office?

**Malini:** Well, can I tell the story from the top?

**Jacob:** Yeah, absolutely, please.

**Malini:** Okay. So, it's kind of a twofold scenario. It was two separate appointments, which again, just really took me by surprise. So, the first appointment I arrived with my husband, and like I said, he helped me fill out the forms, which is pretty typical. He left to go do whatever he needed to do, and I waited in the waiting room. So, when I was invited into the examination room by the technician, I was asked to look forward into the machine. So, with Stargardt disease, of course, I don't have any central vision, I only have peripheral vision. So, looking straight ahead is basically, impossible for me. So, I was instructed by the technician to look forward and I advised her, "I'm looking forward as best as I can." And quite rudely she said, "Well, try harder." So that was quite upsetting, but I did my best, as I was instructed, and that was that. So left the appointment, was pretty irritated by that, but, you know, life goes on and it happens. So, follow up appointment after that was maybe a few weeks later. Arrived at my appointment, sat in the waiting room and was invited now by a different technician from the first time, into the examination room. So as is typical, I was asked to look up at the letters and read what I could read so she could examine my acuity. With my vision being as low as it is, the giant E is the only thing that I can see. Anything beyond that is not visible for me. So, she said, you know, "Go ahead and read what you can see." I told her I can see the big E. She said, "Next line, please." And I told her, "Unfortunately, this is all I can see." And she stopped what she was doing, turned her head and looked at me and said, "Really? "You can't read the next line?" And I said, "No, that's all I can see." And she snapped her fingers in front of my face and said, "Can you even see me?" So that was understandably quite upsetting and quite shocking to me. And it was really surprising to me as well, not only her behavior, but my own reaction to it, because I guess that typically, I'm really comfortable advocating for myself. I mean, it's been a lifelong journey of doing so, but I've gotten to a point in my life where most times I'm pretty comfortable advocating for myself and speaking up when I'm treated poorly or not accommodated. I think what was most upsetting about this particular situation is it was in such an unexpected place. You know, when I go renew my health card, or if I'm at the store, it's unfortunately almost expected that people aren't gonna really understand the scope of my disability, but at the ophthalmologist's office, where I am treated for that very disability, I kinda go in with the expectation that they, to at least a greater degree than others, understand my needs. So, I think it was just very alarming to me. And again, quite upsetting.

**Jacob:** Yeah, I mean, it's so frustrating hearing that type of treatment, especially at an ophthalmologist's office where presumably, and presumably is an assumption at this point, the staff are aware of the condition. And it's funny, when you were talking about the big E, I'm in the same boat. They can cast that big E as far as it can get, but, I mean, the reaction is just, is challenging and unfortunately, that seems to happen more often than not. And, I guess at this point, I can only imagine how you felt after that second experience at the same office. What was the response you took to that? Did you speak to the doctor? Did you talk to the administration at the office? What were the next steps on your end?

**Malini:** So, sadly, in this situation, there weren't really any next steps. Ordinarily, again, and side note, especially because in the work that I do, I do work with a lot of people who have acquired disabilities, and a huge part of my role is helping them to not only get used to their new disabilities, but learn to advocate for themselves. So not only is it something that is personally incredibly important, for me professionally, it is as well. So, you know, to my surprise, I didn't do anything. Ordinarily, I would've said to the doctor or complained to whoever was in charge. I just let it happen. And I grumbled about it, and I was pretty mad about it after I left the appointment, but that was the end of it. I haven't gone back to that doctor, to be honest. And at this point, I'm working under the care of my optometrist, they're amazing at that office and understand my needs, but that's been my very unusual response to it.

**Jacob:** Yeah, I mean, it's yeah, really challenging to hear, but I think it's common for a lot of people who feel that they were not treated fairly and perhaps even discriminated against to just have such a hard time with those next steps. I mean, that draws right into the topic of what are our rights, our human rights under this type of circumstance. So, I don't know, Lisa, is there anything that Malini could've done or maybe understood or something that the office of the ophthalmologist should be aware of in circumstances like these?

**Lisa:** Yeah, so I could go on for a while, so I'll start and you may need to jump in or cut me off. So, I'll start with a basic part of, it doesn't fall under human rights law, but health law, and this applies to all patients. So absolutely, there is a right to informed consent. So, I didn't catch what was in those forms, what the content of those forms were. But sometimes the forms that healthcare providers have people fill out are actually consent documents. And depending what's in those forms that may be seriously problematic, if somebody can't read what they are or understand what they're, even due to a language barrier. It's not always about disability. So, the right to informed consent is something all patients have when interacting with all healthcare providers. In Ontario, for those who like to know the law, it falls under the Healthcare Consent Act. The law actually tells us we all have a right to certain information about treatments. So that is what are the risks, side effects, benefits, alternatives, what happens if I don't do this? And that could be treatment like medication or a procedure or test that's being done as well. So that's sort of one bucket of rights that applies to everybody listening regardless of whether they have a disability. And so, the law there doesn't talk about how that informed consent has to take place. It can be in a form, but the person signing it has to actually understand the information and have the opportunity to ask questions. Informed consent can alsocome through a conversation. It does not have to be documented. So, one thing I flagged is if any of those forms had been consent forms, the duty is on the healthcare professional to make sure the patient provides true, meaningful informed consent. So just signing without actually understanding the material and having that opportunity to have those risks, benefits, side effects, etc., all of that covered, is depriving patients of their right to provide valid informed consent.

**Jacob:** Yeah, that's interesting you say that. I didn't know, I mean, obviously, you kinda sign a consent form, but in the era that we are, with all of the Apple iTunes agreements, and things like that, we kind of just give consent. We don't really ever take a second to think about that. And I know personally I've signed medical forms, probably not the smartest thing, without reading them because I just didn't wanna bother the administration staff to read me those long pages with tiny font. So yeah, really interesting, and I think really just good information there. Anything else that would be kind of relevant to this, particularly to Malini's situation?

**Lisa:** Mm-hmm, there's more, and I do wanna say one thing, because I know advocating for yourself can sometimes be intimidating. There's something psychological for a lot of us, advocating for ourselves is very different than advocating for someone else. So, on the informed consent side, it actually benefits the healthcare provider. If they're asked to do it, it actually is in their interest, because sometimes there are lawsuits where consent wasn't provided. And if it wasn't provided, the healthcare provider can be found negligent, for example. So, it really is in their interest as well to make sure that law's being followed because otherwise, if they are challenged later, they can face a lawsuit. They can owe money to another side if they lose. So, for those who are sort of unsure about advocating, remember, it actually can help them too, in a way. In terms of other aspects of the law. So yes, lots more to cover. One is just there's the basic right to receive the equal treatment same as anyone else, regardless of discrimination. And this is where we get more into human rights law. So, in Ontario, I'm sure you've heard of it, we have a law called the Human Rights Code, and it's a very, very important law. The Human Rights Code, it's on a bit of a pedestal. It's treated in some ways as more important than other laws that we have in our province. And a key part of the Human Rights Code is we all have the right to be free from discrimination, and that's discrimination on the basis of disability, as well as age, race, gender, sexual orientation, and so forth. It's the same law that applies, based on the circumstances. And that right to be free from discrimination, what that segues into in that law, is we all have a right to be accommodated. So, if someone has a disability, there's a duty on the healthcare provider to accommodate. And I can say a little bit more about what that means, but basically, that duty to accommodate means they may have to do things differently and bend their policies or procedures, do something that's customed for the patient. Even if that means it's inconvenient for them, or they have to spend a little bit of money, that's actually their legal obligation, that duty to accommodateis a pretty high bar. The only time they don't have to accommodate is when it reaches a point of what's called undue hardship, which is a very legal jargon phrase, but it basically means it's very, very difficult or very expensive, like putting an elevator into a very old building. Some small business, that would put them out of business. They may not have to do that, but some hardship can be required actually by law.

**Jacob:** Just out of curiosity, 'cause I think that that's a point where a lot of people are unclear as to what is a reasonable accommodation and just to kind of sidestep from the specific situation, I mean, how does someone deem what is a reasonable accommodation for themselves? That's a fully loaded question.

**Lisa:** It's such a great question. (chuckles) It's such a great question. My answer is going to be such a lawyer answer. (laughs) Because the law doesn't tell us. This is where the law is helpful and challenging. The law has to be written in a flexible way, because our legislatures, they can't write every scenario into our law. So, so much of our law is written in this kind of ambiguous way intentionally. And then only when a matter is brought to court, a judge ultimately decides what was or was not reasonable. And to tell you how you know that there's differences of opinion is that this is how there are lawsuits. There's at least two sides with very different opinions in these kinds of cases of what constituted a reasonable accommodation. So how can someone know? I mean, if there's no money involved, and using your common sense, it seems like not a big deal, I think you can rely on a little common sense, if you're not even asking for money or it's just a few minutes of time. I think to me, that's a no-brainer, that's a reasonable accommodation. But undue hardship is a very high bar. It may be that organizations actually do have to really go out of their way and spend some money, that may be a reasonable accommodation as well. But I can't give you a bright-line test, because it actually comes down to each circumstance. What are the means of that business? What are the needs of that individual?

**Jacob:** And just a question, just to put you on the spot here, Lisa, do you think that that's a question of the Human Rights Code being held to this higher standard as you mentioned before? Or is that just 'cause it's such a unchartered territory, as to all the types of accommodations that are constantly changing as the world evolves both from a technological perspective and from the way we interact in society?

**Lisa:** Yeah, I mean, I think that's probably true. As technology evolves, what accommodation looks like evolves. How somebody would've been accommodated when the code first came out is probably different for some disabilities and what accommodation might look like now. And as technology gets better and cheaper, we can probably expect that to change. So there have been a number of lawsuits over the years, but they really are unique to the individuals. But I think what's something that's quite helpful for listeners to keep in mind is it's a high bar. So, if they're not sure, ask, have a conversation. The obligation is on that organization to do some due diligence, not an off the cuff, "No, sorry, we can't do that." They have to try. They have to try quite hard.

**Jacob:** Yeah, definitely. Well, thanks for answering my on-the-spot questions here, but coming back to Malini's story here. Is this discrimination? Where's that kind of line? Is this just somebody having very poor etiquette? Does that kind of infringe on the rights from a healthcare perspective? I'd love to hear your opinion on this.

**Lisa:** Okay, so there's a few things we can unpack there. In terms of whether it isor isn't discrimination, it's kind of like what I said with the reasonable accommodation, a lot of things, in order to say definitively, it ultimately gets determined by a judge or the human rights tribunal, was or was it not? Somebody might say "I've been discriminated against." They bring a case, and they might lose, it could be found they weren't discriminated against. So, it's language that we use, but the final say does, and many cases are not litigated. But the final say really goes to, you know, it's someone with that legal authority. But was this discrimination? So, there's a few things to unpack. So, one part is the rudeness, could that be perceived as discrimination? Potentially, sometimes though the with the cases, poor bedside manner, and when that happens, that's where there's notlegal rights attached to it. Sometimes healthcare professionals are jerks or busy or ignorant, and those don't necessarily mean that they're legal issues, they're patient care issues, but they're not always legal issues, but your language of that fine line is absolutely true. In some of these cases, it becomes a matter of, it becomes difficult to know because how a patient perceives it, and how an individual intended it, can be very different things. Of course, Human Rights Law though is not actually about intention, it's about effect, like the impact on an individual. So, someone with good intentions may actually still be found to have discriminated, even if in their heart and in their mind, they thought they were doing the right thing. The part that stood out to me as most likely as a human rights issue though, is the inaccessible form and the accommodation around that. Because to me, it seems like there's some very easy, reasonable accommodations. So having a partner help can be fine, but in some cases, somebody may not want a family member involved with their healthcare. Sometimes some aspects of healthcare are very sensitive or private, or someone doesn't have a spouse, maybe it's their mother, and they'd rather not have their mother involved in a very sensitive medical appointment. And so, no one should be in a position where they must involve a family member and disclose their personal health information to a relative. That right to keep their health information confidential should be respected if they want it to. And with consent, family can be involved, it's fine, but that right should never be undermined because of the disability. We need to find creative

ways in these situations whether that's an interview with the health professional, they fill it out, making the forms accessible, that would be my suggestion, sending the forms in advance, so that the patient can find someone else they trust. But a lot of it will come down to being creative

and healthcare professionals need to speak with the patient directly to find out what do they want, what do they need? It doesn't have to be one size fits all.

**Jacob:** Yeah, definitely. Malini, have you come across any other offices? You mentioned your optometrist is taking care of you on that front. Do you find that they're more accommodating and kinda more empathetic to your situation?

**Malini:** Absolutely, so like Lisa mentioned, one of the strategies that they've utilized is taking me into a private room and filling out the forms with me, verbally reading out what's on there, and me providing my responses.

**Jacob:** Yeah, I totally, I think that's fantastic, but from my experience as well, yeah, it's challenging. Usually, I do have someone with me. I find, and maybe you find this too, Malini, that if it's on a tablet or any things like that, there's some amazing accessible technology and kind of zoom functions that make it usable. I know myself; I like to be independent. I don't like to rely on others to just complete daily tasks for me. So, I'm somebody who wants to be able to have that equal playing field at all levels of life, and finding these accessible resources, whether it be through

enlarged font or digitization or the staff member asking you the questions and filling it out on your behalf, I think is unfortunately not as common as some might think it would be. It's such an easy and quick solution to this, to level the playing field for everybody. You know, Lisa, I don't know if you've come across offices or situations in your professional work that have had to expand into accommodating in these types of areas. Is that something that you've ever come across?

**Lisa:** Well, it's now something that's increasingly becoming a requirement, so I'm sure some of your listeners have heard of the Accessibility for Ontarians with Disabilities Act, often called the AODA for short. And it’s basically law that's been rolled out in sections over a number of years, starting with government, bigger businesses and then trickling down to smaller businesses. So, there's different rolling start dates for different organizations, but essentially this is a law where the purpose is to have businesses and the government become more accessible. So that's not an option anymore. And it started years ago with customer service standards that address things like bringing service animals. And it's just been rolling out over a number of years. So, we're shifting from not having anything in place to having more awareness and more requirements with the government having the power to actually issue fines if organizations are not being accessible, as they're required to be.

**Jacob:** Yeah, and just to kind of sway the conversation slightly here, is something that I'd like to cover just briefly in this episode is invisible disability or difference or challenge. You know, I know that a lot of people have psychological kind of disease that does require accommodation, however, isn't visible to frontline staff. How can healthcare organizations address that proactively to be accessible so that it's not necessary for the patient to disclose information that maybe they don't want to, or aren't comfortable with upfront.

**Lisa:** Yeah, and I think that's a great thing to be thinking about it from a proactive perspective. So, it's not always on a patient having to bring something up after they've run into two barriers. So, I think one way is

healthcare professionals putting it either in their website, a welcome package, a different kind of first touch points with the organization to invite people, to reach out and say, "If you have a disability that needs to be accommodated, "let us know, so we can figure that out." And so just making it less intimidating by making it like an invitation. So that feeling a little bit nervous around advocating for oneself, hopefully that can reduce that, because it's sending a message that our doors open. Because the reality is not every healthcare organization will have everything in place to accommodate every disability or know. They will not necessarily know does this software work for certain types of vision impairment? So sometimes it really just, it's exhausting to say over and over, but it does sometimes fall on patients to keep saying, "Well, can you do this, can you get this one?" Hey, there's this software, it's actually free or very inexpensive and it will help your other patients." So, it does often put patients in that position of educator, but I think healthcare professionals, setting that tone from the outset, that they're really open to learn and want to do better, at least creates a much more positive atmosphere, and one where hopefully, people feel empowered to advocate for themselves.

**Malini:** And Lisa, I think you make an amazing point there too, because I think what that accomplishes is it empowers both the patient and the healthcare provider to feel able to collaborate on providing accommodations. Because I think that many healthcare providers are afraid to either ask or get it wrong, and many people are unable to ask for what they need. So, I think that marriage of those two is a wonderful point.

**Jacob:** Yeah, and, Mali, in your practice, are there any kind of, I guess, proactive approaches that you're taking for your patients so that they don't need to be asking you for different accommodations? You'd mentioned that a lot of your patients do have different forms of disability.

**Malini:** Absolutely, yeah. So many of the people that we see are dealing with psychological injuries, physical injuries, traumatic brain injury, or a combination thereof. So, it's our standard protocol with their first contact with our office. It's automatic that we say, "If you require assistance" with any of your forms, the intake, anything that we have "as the preliminary

paperwork, let us know." So just as Lisa mentioned, that invitation has gone a long way where people feel so much more comfortable and confident saying, "You know what, yeah, I do need some help." And it starts that conversation.

**Jacob:** I think that it's great to hear, and setting that standard for different offices, be it optometry, ophthalmologists, psychotherapists, all aspects of health, I think having that really open and welcoming response for everybody, no matter what their needs, is so important and such a warm welcome, especially with health. People feeling comfortable to disclose to professionals why they're coming in, is just going to help everybody in the long run, and that starts with having a very open line of communication for people to get the help they need in order to be at a level playing field or to feel as equal. So, I mean, I guess to wrap this up, Lisa, is there any information or advice that you might give to any of the listeners on getting more information or things that they should consider, when they feel that they've perhaps been discriminated or just general thoughtsaround the health law area?

**Lisa:** Sure, so I can start with a few resources. One is Pro Bono Ontario, and the ARCH Legal Disability. These are just two different resources where somebody can actually call and get some free legal advice, if they feel they've been discriminated against. And in some cases, ARCH will actually bring lawsuits, but sometimes legal advice is all that people need. So, there are ways to get free legal advice for sure. But in terms of general, strategic advice, I have a few ideas. So, one is to let people know the squeaky wheel gets the grease. I've just seen it so many times. Sometimes, if you don't ask, you don't get, and you do have to be a little bit persistent, but it really makes a difference in our healthcare system. And I mean that across all contexts, the patient who hasn't been seen, or they're advocating for a family member, it makes a difference to be squeaky. (chuckles) Also healthcare professionals have regulatory bodies. There's colleges, and I don't mean post-secondary, but colleges that give out licenses and can take them away and can suspend licenses. And so, they do not want complaints, they don't want trouble with the body that gives them their license to do their work. They don't want to be brought to the human rights tribunal. I never suggest starting with the threat, I always think start nice, but there is a legal context, there can be legal consequences for the health professionals that are not doing what they are required to do. So sometimes those end up needing to be mentioned, it's never where I would suggest someone start, but if they're having a very, very difficult time, it's good to even just know they exist, because sometimes psychologically, if someone is struggling to advocate for themselves, just knowing their rights and knowing there are places they could escalate and get free legal advice along the way can be helpful, and people feeling confident to speak up for themselves.

**Jacob:** Yeah, I mean, those resources, I think are invaluable, especially in a circumstance like this. One thing, maybe we'll save this for another episode, is I've experienced my own kind of human rights issue that I'm currently going through. And I was totally unaware of those resources that you've mentioned. Since getting involved in this project, I've learned about them, but for anybody listening, please look into that, even if it's just, I love the word proactively, to know your rights, I think is great to always be informed and educated so that you can understand how to thrive as an individual and to make sure that you're not being discriminated or treated unfairly. So, I guess, Malini, given the circumstance, I do wanna just thank you for sharing your story. I know that it's challenging and hard to share that. So, thank you, and I hope all of you guys really appreciate hearing this experience firsthand, because I can tell you from my own experience that this is extremely common, not only in health offices, but in all sorts of businesses and organizations. Is there anything that you would tell our listeners who might have experienced similar situations?

**Malini:** Yeah, first off, I'm happy to be sharing these stories. I think it's through sharing these stories that we're able to support one another and make some changes. So, you're welcome for that. Secondly, as far as what advice that I would give, if even I had a do-over, or if somebody else had a situation that they run into, like this, speak up. I think that that's probably the biggest thing and what we're most equipped with is our voice and our ability to speak up when something is wrong, and stand up for our rights.

**Jacob:** Yeah, so that seems to be the general consensus from both of you guys is be the squeaky wheel. Don't be afraid to stand up and to advocate for yourself. If you don't, then nothing is going to move forward. That's the whole purpose we're speaking up about this is so that you guys can be informed to know your rights, to understand some situations that you've probably experienced or may experience. And we really want to provide a platform where it's okay to speak up, it's okay to understand. And we encourage you to learn about how to protect yourself to be treated as an equal.

**Lisa:** When you speak up, you are paving the way for other people too. So, I would remind people too, when you are suggesting, making a suggestion about how something can be done better or differently, or a disability can be accommodated, you are now educating that organization or a health professional, so the next person who comes along does have a better time. So, it really, it's important for making a difference for other people who come next.

**Jacob:** Absolutely, yeah. Great point, Lisa. So, guys, speak up, make change, and we'll see you on the next episode, take care.

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