

## **Full Transcript of Panel 5:**

“The Systemic Ableism Within the Context of COVID-19 and Medical Assistance in Dying”

[Video Link](#)

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### **Full Transcript**

**00:00:04 Master of Ceremonies, Jennifer Cox**

So, as I indicated, the next panel is called the systemic ableism within the context of COVID-19 and medical assistance in dying, and we have Justice O’Reilly, substituting for Justice Suche, who had to leave as the panel chair. We also have Michael McNeely, government lawyer, and self-advocacy instructor at Canadian Helen Keller Centre accessibility consultant and project developer, Inside Out and he’s online. We have Dr. Heidi Janz, PhD, associate adjunct professor, John Dossetor Health Ethics Centre, University of Alberta, here on stage. And we also have Dr. Nancy Hansen, PhD, associate professor and director of Interdisciplinary Master’s Program in Disability Studies, University of Manitoba. Nancy is also online. So, if we are ready to go, Justice O’Reilly?

**00:01:03 Moderator, Justice James W. O’Reilly**

Sure, thank you Jennifer. Welcome everyone to this panel. Obviously, we’re changing our intellectual scenery again to a different aspect of dignity, and we have very special panellists whose impressive biographies are in your materials, but I’ll just add to what Jennifer said, and that is that Michael, who is joining us, is the first deaf blind lawyer to graduate from Osgoode Hall Law School. He teaches advocacy skills at the Canadian Helen Keller Centre, and he’s also a film critic. So welcome Michael. Dr. Janz, who’s to my left here. She’s an active advocate for disability rights. Michael, I should have mentioned, is also a film critic and Heidi has a creative side as well as a writer, playwright and filmmaker. Dr. Hansen you’ve heard is a professor and director in disability studies at the University of Manitoba, and she writes widely on subjects related to the experiences of disabled people. Some of you who are late to come into the room will notice that I’m not Colleen Suche, who was meant to chair this panel. I’m James O’Reilly, a judge of the Federal Court and past president of the CIAJ. It turns out under the Constitution of the CIAJ, if the president is unavailable, then the past president is meant to step in. Peter Wilcock, would like to put that on the agenda of the Governance Committee for an amendment for future purposes? But here we are and we’re all present. Michael and Nancy are online, Heidi to my left. Michael are you ready to go?

**00:02:58 Speaker Michael McNeely**

Yes, I’m ready to start. Thank you. I’m just waiting. I just wanna make sure that we’re not on mute, OK? So, hum. My name is Michael McNeely. Thank you very much for having me today. I’m happy to be here with my friends whom I now consider my family and persons sort of having to fight for our continued existence as people with disabilities. You know about 30 or 40 years ago, I wouldn’t be in this position. I would probably be in an institution and would be segregated. I would probably die as a result of being

segregated and receiving less than adequate health care. I am deaf and blind as some speakers have mentioned. But those are, those would have been enough to institutionalize me. As you know, I'm a white young man, so the fact that I'm here speaking to you and somewhat concerned about my existence on this planet should be concerning to all of you, because as we know, the further away you get from being a white man, the worse it gets. So, I'm, I'm ready here. I'm telling you it's really bad right now. I'm telling you that I've lost a lot of friends who had disabilities over the last two years. I have had limited support. I've had all sorts of things happen to me as a lack of accommodations.

But I should back up and start with the presentation that I was planning to have, which is essentially that I am here on loan from the Department of Justice. My colleagues and my manager are very happy for me to be here, but I am not speaking on behalf of the Department of Justice. I am speaking for myself and others with disabilities. So, what I want to do is just go through a few permutations of the word dignity. I want to establish that dignity is a double-edged sword. Yes, we all have dignity. We all should have it. But the question is, if I stick this Post-it note on my head, do I still have dignity? Am I still doing a dignified presentation? If I have tics, if I have Tourette's syndrome, if I have a feeding tube, if I have one eye, do I still have dignity and am I still considered dignified? If I can't speak without the assistance of a machine, am I still in possession of dignity? Those are questions that we need to answer. We need to draw out a line between who had dignity and who does not. OK, so that's the first step.

If you take a look at the Fetterman versus Senate, Senator debate that's happening this week, it's very interesting to read the media responses. Especially about Democrat and Republican leading publications. As you may know, Mr. Fetterman had a stroke about five months ago and it has affected his ability to participate in a debate for his office. No, I'm not an expert at all in the US. Politics and the US political system, but I am reading these publications that say he's not fit to win. Because he snores his words, because he put 2 words together, because sometimes he doesn't understand what he's saying. That troubles me a lot. And it reminds me that we need to get beyond the physical body. We need to get beyond the physical body and that includes mental health as well. Because mental health comes from the physical body as well. We need to get beyond that. We need to look at people as their, as if their self-value or their worth is, is not part of their bodies. OK we need to look at people for their ideas or their expressions of value. So, as I mentioned, dignity is a double-edged sword. When we say people have dignity or excluding those people, what we say is they don't have any dignity. And what I want to do with that idea is when it stops for them? I want to say that there's no dignity with death. There's absolutely no dignity with death, OK? My, my assistant is here today. Their name is Alex. They're a good friend of mine and I asked, I asked if I could hypothetically kill them. Just to show that there's no dignity in death, so what I could do is put a pillow on their face and suffocate them. And I could tell you that they died with dignity. But that doesn't mean anything, does it? The person's dead. OK, I don't, I don't want to hear any conversation about dignity and death because the person is dead. That means the person doesn't exist anymore. I don't think there's any dignity in the death of Tracy Latimer. There's no dignity in death of my grandparents who died in the senior home. There's no dignity in the death of my best friend who took his life because then he didn't have any mental health support. So, I don't think there's any, any conceivable way that you could say there's dignity in someone dying, so I don't want to hear it anymore. And that's a challenge to the panel coming after us tomorrow. Because they're going to talk about dignity in death. So, I am asking them not to use that phrase anymore.

OK, so we're having so much fun today. Let's move on to the next topic. People, people with disabilities have been traditionally segregated. Uhm, so let's look at Canadian history. Canada has eugenics program or had a eugenics program that almost rivalled Nazi Germany. The eugenics program was evident in the 1920s and 30s. We were experimenting how to make the perfect body. We were also against the mixing of races and may consider that those who wanted to marry someone of different ways were mentally ill and therefore needed to be institutionalized. Even to this present day, we still have academics that believe that people need to be castrated, at least chemically castrated, so they don't pass on genetic material to the next generations. Even to this day, we still have professionals that argue that people with Down syndrome or other people with intellectual disabilities should not be, period. In fact, those people that spoke in the last panel to talk about children's aid societies. Children's aid societies also have a high reference weight when it comes to parents with disabilities because they're often monitoring those parents. Parents with disabilities have to prove time and time again that there are adequate parents. And there is, perhaps not dignified, if you want to use that word. This segregation and institutionalization and isolation that are faced by people with disabilities, it's a historical phenomenon that has been with us since forever. Uhm, Miss Devandas, who was the rapporteur, the UN rapporteur who was for people with disabilities. She visited Canada in 2019, just before the COVID-19 pandemic. And in her report, she highlights that segregational institutions should be abolished altogether. So, things like senior homes or care facilities that primarily target one specific disability that make those people with disabilities out of sight, out of mind. Those things should be abolished. I believe that she was ahead of her time because we recognized that very quickly when the COVID-19 pandemic happened. We recognized that with the high, high numbers of people with disabilities that died.

But what I want to do is highlight the importance of information, information gathering and sharing because I think if we want to look at dignity, we need to take a step back. And yesterday we were talking with Jacob Weinrib, as you heard, Weinrib. So, he was bringing about the difference between economy and dignity. I would just like to say there's not really much of a difference. But when we're looking at people with disabilities, we need to look at having dignity and autonomy as being tied into accessing information. So, people with disabilities require the same amount of information as everyone else. This is a justice issue. This is, you know, a way to avoid discrimination. So, I can speak personally because I did not feel informed about what was happening. As a result of COVID-19, I did not understand what was going on in March 2020. I still don't really understand what's going on now. But in March 2020, I did not feel safe to go out of my apartment. I moved home to live with my parents in Kingston, Ontario, from Toronto. So, I gave up a lot of my independence. I moved in with my parents because I thought that they could inform me about what was going on more than what the media could inform me of, more than politicians that were tasked with my care, more than social systems that were supposed to keep me informed. Alex, who was brought back from the dead since I hypothetically suffocated them with a pillow, was supposed to be my support person in person. But as a result of the pandemic, uhm, we were not allowed to spend time together. We were not allowed to see each other face to face so, we devised a system where we would work on zoom. We would work on zoom together every day. So, if I have any personal tasks that I need and they do, they need to show them with this webcam. I need to show that my apartment, I need to show them OK, this is my issue today I spilled something on the floor. Can you help me find it with the webcam? It's not the most effective way of helping somebody. And it leads again to the segregation and the isolation that people with disabilities face. Nobody is really going out of their way to

help people with disabilities because of the restrictions imposed on them due to the pandemic criteria and lockdown, lockdown specifications.

So, I think I should wrap up my presentation soon. But what I want to mention is that due to the lack of information that people with disabilities get, we are deemed not to have an opinion. We are deemed not to have any stake or value in decisions that affect us in day-to-day lives because simply we're assumed to be too stupid to understand the information that we didn't get. If we didn't get the information, how can we make an informed choice? How can we have the dignity that we're supposed to have? So, the question is, then you know, if I'm given a choice between dying with dignity, as I just mentioned as a load of bulls\*\*\*. If I'm given a choice between dying with dignity and using a care system of finding some support services, how am I going to know that I have a choice? If that choice is being taken away from me. So, that is one of the last points that I have to make.

I also have to give you all some homework. Because I was a teacher in my past life and I believe that everyone needs homework so, I don't think you need to do it right now. But I would like you to do it when you go back to your offices. I would like you to find your emergency plan, the emergency plan for natural disasters, fire lines, pandemics. I would like you to make sure that it includes people with disabilities on it. Because that research has shown that emergency plans do not acknowledge or do not count for people with disabilities. So, what do we do in an emergency? We've seen what's happened in the last two years. We don't do anything in an emergency. We focus on, you know, scattered social support for those people with disabilities to help those people with disabilities. But the rest of us may don't know what's going on with people with disabilities. Again, that's a reference to the segregation, isolation, ostracization, lack of information or lack of dignity for people with disabilities.

So, if you just remember one thing from this talk other than how emotional I am. Just remember that people with disabilities need to be accounted for in the emergency plan, and that you do. Because the result of that not happening is something that we're seeing right now with the feeling of emergency rules with a lack of health care, with people saying that he might as well die then to get support services that are rightfully ours because we live in Canada. Canada is supposed to be one of the greatest countries in the world. But if we're having people saying that you can just die instead of getting, you know somebody like Alex to help you day-to-day, that's a little bit ridiculous and a little bit concerning. OK, I think I'm finished for now. Thank you very much.

(Applause)

**00:18:40 Moderator, Justice James W. O'Reilly**

Thank you, Michael. Next is Heidi. She has a PowerPoint that has a voiceover, but just so you know when we get to the question period, her echo or Tyler will be helping with the answers.

**00:18:58 Speaker, Dr. Heidi Janz**

2020 and the advent of COVID-19 ushered in a time of new peril for disabled people in Canada. Government and public health officials repeated their daily mantra: "We're all in this together," while at the same time creating policies and legislation which made it clear that disabled Canadians are not part of the "we." Provinces quietly developed Critical Care Triage Protocols that would prohibit many disabled people from receiving critical care should a surge in severe COVID cases outstrip available resources.

And at the national level, the government pushed through an expansion of Medical Assistance in Dying (MAiD) despite overwhelming opposition from major disability rights organizations, scholars, activists and United Nations human rights experts. In my panel presentation today, I draw on my research and experience as a disability ethics educator and advocate to demonstrate that Canada's COVID-19 response, particularly the implementation of hospital no visitor policies, and its concurrent expansion of eligibility for MAiD, are symptoms of the systemic ableism that afflicts Canadian society. I will conclude with a consideration of the enduring danger that eugenic ableism, disguised as autonomy, poses for people with disabilities.

Let's begin then with a basic question. What is ableism? Ableism can be defined as prejudice and discrimination against people with disabilities, based on the belief that typical abilities are superior. Like racism and sexism, ableism classifies entire groups of people as "less than," and perpetuates harmful stereotypes, misconceptions, and generalizations about people with disabilities. Clear, yet not acknowledged. Evidence of ableism can be seen in everything from the way in which buildings are built to exclude people who do not walk or see. To the way in which students with disabilities are taught that it's better to look, move, and behave as much like their non-disabled peers as possible. To the way in which terms associated with disability are used as insults in common parlance, but unlike racism or sexism, ableism remains, in the words of Canadian disability scholar Gregor Wolbring, "one of the most societally entrenched and accepted isms." Ableism becomes systemic as patterns of discriminatory and exclusionary practices against people with disabilities are entrenched in sectors which are fundamental to societal membership. Limited access and opportunities in one of these key sectors, such as education, often automatically leads to further restrictions in employment opportunities, which, in turn, limits housing options.

Thanks to a severe bout of pneumonia in November 2020, I have first-hand knowledge of the unique role of medical ableism in perpetuating systemic ableism. Moreover, I have seen first-hand how COVID-19 hospital no visitor policies grievously afflicted Canadian healthcare. As someone whose disabilities include a significant speech impairment, I've made it a rule never to go into ER without an aide or friend with me to assist with communication, but that night, as I entered the ER entirely alone in the wee hours of the night, I was quite frankly, terrified. Why was I terrified? Well, there was the whole having trouble breathing thing, but also there were memories of numerous first-hand accounts I'd heard over the years from friends and colleagues with disabilities who have had DNR orders arbitrarily placed on their charts without their knowledge, let alone their authorization. Similarly, more recent anecdotal accounts reported how physicians were asking repeatedly whether they would want interventions considered routine for non-disabled people, such as receiving supplemental oxygen through a nasal cannula and then being asked again: are you sure? All these things percolating in my mind caused me to pre-emptively respond to the ER docs inquiry about goals of care without all the clarity and force that my 82% oxygen saturated lungs could muster R1. Fortunately, during my first 18 hours in ER, two saving graces helped mitigate the potential hazards from my not having an accompanying friend. First, the friends, aids, and "fraids." Combination of friend and aid who would normally have been taking shifts with me in hospital were now calling to check on me. This alerted the nursing staff to the fact that I was connected to a community of support outside the hospital. Second, I had the blessing of an exceptionally attentive nurse who assisted me to make and receive phone calls and text messages. One call was from my brother saying he just received a phone call from my doctor to discuss my diagnosis. With some consternation, I told him that I

had yet to see said Doctor. However, a couple of hours earlier, a resident had come in to take my medical history, or rather, he attempted to take my medical history. It was clear to me that none of my responses to his questions had registered. This, I surmised, was what prompted my attending physician to call my brother. Now he had to relay to me the information about my rather complex medical condition that had been related to him by my attending physician, whom I had yet to meet. After I finished the call, I exclaimed to my nurse, who looked almost as exasperated as I felt. You know, I'm a professor at the Ethics Centre at the University of Alberta, I can handle conversations about my condition. After uttering an expletive, the nurse said, "I'm going to go find your doctor and make him talk to you." I didn't see this, but I could envision her dragging the doctor by the ear to my bedside. At any rate, the doctor did talk with me about my condition and treatment plan, and I'm happy to report that for the remainder of my hospital stay, everyone on my treatment team interacted and engaged with me as they would with any other patients. Nevertheless, my experience has left me deeply concerned about what happens to people with physical and/or communication disabilities who are forced to go into ER alone due to pandemic restrictions, but who do not have the benefit of either an exceptionally observant and attentive nurse, or the status of having a job that's healthcare related. In my view, the widespread creation and implementation of hospital no visitor policies during the COVID-19 pandemic is clear evidence that, despite all the lip-service Canadian policymakers pay to inclusivity as a core ethical principle, the needs of old, ill, and disabled people can be summarily deemed excessive.

Like many of the healthcare responses to COVID-19, the expansion of eligibility for MAiD in Canada to include people with disabilities who are not at end of life is demonstrably rooted in medical ableism. To begin with, as healthcare professionals MAiD assessors are not immune to the prevalent influence of medical ableism rooted in eugenic logic. This becomes particularly significant when studies consistently demonstrate that health care professionals who provide care to disabled individuals are often more pessimistic and upset about their charges' prognoses than the affected individuals themselves. Some may argue that this is essentially a moot point because people with disabilities meet with MAiD assessors only after they have already applied for MAiD. However, such an argument fails to consider that, among other things, MAiD assessors are tasked with determining "the greatest source of suffering" that is prompting a person's request for MAiD. MAiD assessors afflicted with undiagnosed ableism are likely to automatically view the existence of disability, in and of itself, as the greatest source of a person's suffering. They thus risk conflating suffering stemming from remediable social conditions, such as poverty and the lack of affordable accessible housing and community-based user-directed personal support services with the irremediable presence of disability.

One recent casualty of such ableism was Sophia, a 51-year-old Ontario woman with severe chemical sensitivities who chose medically assisted death after desperately searching for affordable housing, free of cigarette smoke and chemical cleaners. She had multiple chemical sensitivities: MCS, a chronic condition, also referred to as an environmental illness or environmental allergies. "The government sees me as expendable trash, a complainer, useless, and the pain in the a\*\*," Sophia said in a video filmed on February 14, 2022, eight days before her death. Avis Favaro of CTV News reports: "She died after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto. She also left behind letters showing a desperate two-year search for help, in which she begs local, provincial and federal officials for assistance in finding a home away from the smoke and chemicals wafting through her apartment. Four Toronto doctors were aware of Sophia's case and they also wrote to

federal housing and disability government officials on her behalf. In that letter the doctors confirmed that her symptoms improved in cleaner air environments and asked for help to find or build a chemical free residence: “We physicians find it unconscionable that no other solution is proposed to this situation other than medical assistance in dying,” they wrote. A personal postscript to Sophia’s story: Taped to the wall by my computer at home is a letter that she wrote to me three days before her death by MAiD. In the letter, she thanked me for my efforts to advocate on her behalf, apologized that she did not have the strength to fight on, and asked that I continued to tell her story in the hopes that, one day, people with disabilities in Canada will not be driven to seek MAiD as their only option when they no longer have the strength to fight for their right to live. I keep Sophia’s card where I can see it every day to remind myself of what, and who, is at stake in the ongoing disability-rights advocacy work to stop the so-called “right to die” from nullifying people with disabilities’ right to life.

The Parliamentary and Senate Committee studies of Bill C-7, the proposed expansion of eligibility for MAiD, took place in the fall and winter of 2020 to 2021, while the entire country was under pandemic lockdown. Ironically, at the very time when government and public health officials were urging Canadians to make sacrifices for the sake of protecting the lives of vulnerable people, some of these same government officials were pushing through a bill that would make many of these vulnerable people eligible for a state-sanctioned death. The kind of logical and ethical contortions that this required had to be of Olympic calibre, matched only by the logical and ethical contortions that it took to quote from the UN Convention on the Rights of Persons with Disabilities in the Preamble to Bill C-7, when three UN Human Rights experts declared Canada’s MAiD regime to be in violation of that very Convention. Thus, it is clear that systemic ableism in Canada is, not just alive, but thriving, with the passing of Bill C-7, and current efforts to further expand eligibility from MAiD to include people with a sole diagnosis of mental illness and so-called “mature minors,” including kids with disabilities. As someone who had most of my K-12 education at a school for kids with physical disabilities, I find this latest impending expansion of eligibility for a state-sanctioned death particularly chilling. Roughly half of the kids in our school had life-limiting conditions like Muscular Dystrophy, which, at that time, had a life expectancy of 14 to 18 years. Every student in that school grew up knowing that some of us would live longer than others. But we also knew that all of us would live with the best quality of life possible until we died. This is not the message that Canadian kids with disabilities growing up in this Brave New World of MAiD for “mature” minors will receive. Instead, they are more likely to hear: “Well, it’s only natural that you’re depressed and tired of your life, you’re disabled. Maybe you should just go get MAiD.”

There is a palpable, if generally unacknowledged, sense of *deja vu* surrounding the eugenic philosophy underpinning the relentless expansion of MAiD in Canada. Washington Post columnist Charles Lane articulated this disquieting *Deja Vu* in a recent article, in which he mused about similarities between the current MAiD program and Canada’s Residential schools: “One of the most haunting aspects of the Canadian Indian Residential School system was that one of Canada’s worst historical crimes was managed and defended by people who fervently believed they were doing the right thing for the Indian,” Tristin Hopper wrote in the National Post last year. As they expand euthanasia today, Canadians should bear in mind that they, too, are subject to the law of unintended consequences and to the judgment of future generations. In quote: Indeed, there is an urgent need for Canadian policymakers to consider “the law of unintended consequences” as growing numbers of disabled Canadians are being driven to end their lives

through MAiD when systemic ableism prevents them from getting the supports they need to live. COVID-19 may be waning, but systemic ableism, turned lethal through MAiD, continues to spread. Thank you!

00:32:23 Moderator, Justice James W. O'Reilly

Thank you. Dr. Hansen, are you still with us?

00:32:36 Speaker, Dr. Nancy Hansen

Yes. Thank you. Uhm, first of all, thank you for the opportunity to speak today. I've been doing a lot of talking about MAiD recently. And it's hard, not because my disability is hard, it's just different. It's hard because I feel a continuing need in 2022 to justify my existence, which is kind of ironic because we are living at a time when, in theory at least, disabled people have more legislative protections than we've ever had. To put some context in here, I'm a proud white, heterosexual, poor legged woman. I've used crutches my entire life. And I'm part of the world largest minority. We are over 1 billion in number. Yet I think, and we're 22% of the Canadian working population. Yet I think I have to ask this basic question: how comfortable is Canadian society, or the world at large, with disability anyway? Because that the discomfort level that the larger non-disabled population has is rooted in systemic ableism, so in until we start to deconstruct that, we're stuck in the mess we are now.

We, as I said, we're the world's largest minority. In my province we're one in five. And over the past two weeks, I've heard that MAiD, has been, medical assistance in dying is an alternative to accessible housing. Medical assistance in dying is an alternative to appropriate home care. For my, excuse me, I'm a bit nervous because this, I'm not engaging in a theoretical exercise. I'm not engaging in disability tourism. Quite frankly, this quite literally hits me where I live. And I find it interesting that in this day and age I'm still faced with having to justify my existence. And I'm a disabled woman of privilege, so I feel it necessary that I go forward and keep talking about this, even though disabled academics and activists are routinely dismissive in the way they approach, the way MAiD is being approached in Canada. What has been most disturbing for me this week is that a representative from the Quebec Association of Physicians and Surgeons presented the option that, infants with significant malformations, whatever that is, under the age of two, excuse me, under the age of 1, I'm nervous, be allowed to be eligible for MAiD. Which means myself, my husband and most of the people I know with cerebral palsy would no longer be with us, which is quite scary.

I realize it is not your usual academic talk, but I can't remove myself from the realities that disabled people are facing at the moment. Medical assistance in dying should not be a viable alternative to poverty. I don't understand why there is not more concern and outrage being expressed. Thank heavens the press is looking at it now, because at least the wider population is becoming vaguely aware of what's happening. Uhm, currently 5% of deaths and, in BC are attributed to the use of MAiD. I'm sorry I'm going all over the place a bit. So, you'll just have to follow me. Also, this week, the Minister of Veterans Affairs described the, the offering of medical assistance in dying to veterans with PTSD as a regrettable incident. As far as I'm concerned, there's been far too many regrettable incidents in this country recently, and it seems to be growing. Just one second here. I've lost my place, uhm. What concerns me too, I forgot to mention, when the representative of the Quebec College of Physicians and Surgeons gave his presentation, there were no questions from the committee, the Parliamentary Committee on Medical Assistance in Dying, and that is the most disturbing of all.



We have to really start to deconstruct what's happening here. We have to, sort of, deconstruct the, the idea that there is somehow dignity in death, that somehow disability is worse than death. I'm still approached by strangers on a regular basis, telling me: I couldn't exist the way you do. And to me, that's deeply disturbing because systemic ableism is so deeply entrenched, it's a, uhm. Excuse me. Disabled people who raise concerns are readily dismissed as extremists. Disabled people have not been present in the places where these discussions around MAiD take place. And I know I'm speaking rather quickly, but it's because I'm nervous too. Uh, yesterday I had a conversation with the head of a disability lead organization in my province. He is receiving phone calls on a regular basis from his membership that are terrified of what's happening with regard to MAiD in this country. And he was told by one of his members, again, who couldn't receive, who was not able to receive home help assistance that medical assistance in dying was an option. I would much prefer that we have regular access to resources that enable us to live rather than resources to give us a fast track to death.

When, I have to relate an experience of one of my students who is a healthcare aid in a care home in Saskatchewan. Saskatchewan people living in care homes were subjected to much longer lockdowns than the non-care home population. She said that people who wanted psychiatric support were required to wait months and months and months for psychiatric support to deal with the depression that they were experiencing as a result of prolonged lockdown. However, once they had requested MAiD they were able to get a psychiatric assessment within three short weeks. She said at the time she was working in the care home, MAiD was being used as a, it seemed like a conveyor belt, and she said it was a very disturbing thing to watch.

I realize that my presentation this afternoon is somewhat disorganized, but that's because I'm so passionate about this issue. We have to start taking MAiD seriously as it results, as a result, as it impacts people with disabilities in this country, it's not some kind of theoretical process we're talking about death, and I think we should be talking about resources that disabled people need to live in a society that ostensibly presents itself as one deeply concerned about human rights. I think that we need to understand that only certain groups of people are accorded the rights that they have, supposedly have, on paper, and I think that we have to have serious conversations and look at existing policies, programs and services with a disability lens, because whether or not disability is recognized it is always present and we have to look at disability as simply different, and not something that's weakness or diminishment and that way, we can really see dignity in people's lives, as opposed to so-called dignity and death. Thank you.

00:42:44 Moderator, Justice James W. O'Reilly

Dr. Hanson, I don't think you needed to apologize for being passionate about this subject. We've gone from talking about dignity in some panels in a fairly abstract way, but now we're talking about it as a concept that it affects the quality of life of many people, especially people with disabilities. So, thank you for your presentation.

We have time for questions with all three panellists who are with us for another 30 minutes. I see a question in the middle.

00:43:19 In person participant (Question 1)

Hi, thank you very much for your presentations. They were really moving. My name is Lan and I am a student here at Dalhousie University School of Law. I am also the President of our Disability Alliance, a new organization that we have put together in the last three years as a result of the systemic ableism that we are experiencing throughout all of the law schools in Canada.

Disabled law students are struggling. Please hear our cries for help. We are combating constantly with systemic ableism, the bureaucracy that is the law institution is not one that is inclusive. I have had more accommodations offered to me in the one day I have been at this conference than I have the entire time I've been in the law school. It is not an easy time. We are trying to be in meetings and involved in important conversations to better the lives of disabled people within our communities, but also throughout the country. But we can't sometimes even get to the meetings because they are held in inaccessible spaces. As someone who deals with a mental and physical disability, I am struggling in law school, and, the law schools continually are denying people and my peers accommodations that are guaranteed to us or should be guaranteed to us by legislation.

So, my question to you all, as people in higher education and who have been through the system, of some sort, what would you do if your institution was preventing you from succeeding? Thank you.

00:45:07 Speaker Michael McNeely

I, can I take this? I don't know...

00:45:09 Moderator, Justice James W. O'Reilly

Go ahead, Michael.

00:45:12 Speaker Michael McNeely

Yeah, I just graduated from law school, so I graduated in 2020. I'm a baby lawyer (...). In 2020 I saw a lot of things that I wish that I hadn't seen because I, I graduated from Osgoode. And I thought Osgoode was going to be, you know, a great place to study. But just at the, when the pandemic was started in March 2020, we all had to vote on whether or not we wanted, we wanted our courses to be pass-fail or we wanted our grades on our transcripts.

So, at that point there was a lot of hatred being passed to us. Because we had some students that were saying that, that people with disabilities just weren't trying hard enough to get to classes. That, that, you know, we just had to work harder, or that we should just do the grades because the grades would allow people to get into articling and get good jobs. And so, it I just realized that a lot of people just don't when they take into consideration the needs of people with disabilities.

So let me answer your question. No. Number one, I would take this recording, the recording of this talk. I would take this recording and I would use your, your question to us. I would, I would find a way to broadcast that across the entire country. Uh, I mean, I'm, I'm perhaps naive because I, I wonder if people were actually listening at this point, but somebody has to listen. You were here today, you made it to the CIAJ, you made into one of the highest places of institutional learning and you asked that question so. Just, just remember that that you did ask that question and use it now.

00:47:10 Moderator, Justice James W. O'Reilly

Others wish to address the point? Heidi?

00:47:21 Speaker, Dr. Heidi Janz

One thing that I am constantly discouraged by, a lot of the barriers that existed for disabled students, back in the 1980s when I personally started in school in university, continue to be barriers that are going, that are in universities right now.

My best practical answer is, because it works for me, find a couple, I hate the word champions, but a couple of champions on the faculty. It will help amplify your voices, that's how I managed most of my career. And that's not the way it should be. But sadly, that is what works.

00:49:11 Moderator, Justice James W. O'Reilly

Nancy, did you wish to add something?

00:49:13 Speaker, Dr. Nancy Hansen

Yes, just to say that I echo just what Heidi just said because it's a real problem, no pun intended Heidi. Uhm, but the academy is rife with systemic ableism. And just by being present that's resistance, and you have to keep pushing. And you have to ask why things are done the way they are, because there's this sort of myth that the academy thrives on collegiality and, and, and it is not the case at all. Marginalized groups and, and disabled people are just one along the continuum and it's important at this point to remember that every, not everybody is just one thing, but you have to keep pushing the Academy, uh, to get over themselves.

There's a, here's an assumption that the "elite" nature of the academy is somehow compromised when marginalized population groups show up, which is not the case at all. Uhm, people from marginalized population groups, disabled people among them. It's always a surprise when we show up. We have to be chronically creative from necessity, because that's the only way we can manage in environment, either attitudinal or physical, that were built without us in mind. We, we have to deal with policies, programs and services within the academy that are messed up and we have to, sort of, deconstruct them. There are positive things that are happening in my own institution, that's being, they're being, there's a, taking down ableism initiative that's ironically being led by the school of rehab. We're dragging the rest of the institution in the 21<sup>st</sup> century.

So what I would say is keep pushing and keep asking questions, and, as a point of interest, my husband is a recently retired disabled legal aid lawyer and he's engaged in a human rights case with several other disabled lawyers dealing with a lack of access to his workplace. Just to say it's... We have a lot of work to do, but the fact that we're here talking about it is a step in the right direction.

00:51:50 Moderator, Justice James W. O'Reilly

Thank you. Nathan, do we have a question online?

00:51:54 Nathan Afilalo, CIAJ (reading question 2 - online participant)

This is from Jasmine online. It says, what a thoughtful and emotion-provoking panel. What are tangible ways you would see physicians in the MAiD sphere address ableism? In light of what is mentioned, that once patients seek MAiD, they do see it as the final option, and have to be confident and certain to have MAiD?

00:52:16 Moderator, Justice James W. O'Reilly

Who would like to answer that?

00:52:22 Speaker, Dr. Nancy Hansen

I'll start. I'll make it quick. I would say that, hum, the, that may, that I would ask questions as to why they're seeking it in the 1st place and see if there are other options. Uh, they have been made available, no... Perhaps, perhaps that's not the best word but made available to people other than death. I mean, we have to stop talking about medical assistance in dying and talking, we're talking about death as an option as opposed to accessible housing, as opposed to support services, as opposed to income levels that bring people above the poverty line, the present level of disadvantage is not natural as experienced by people with disabilities. It's experienced by systemic ableism that's built into the program, services and policies, policies that have been directed toward people with disabilities. And I would hope that people would get as much counselling and support to live as access to death.

00:53:38 Moderator, Justice James W. O'Reilly

Heidi, this goes to your presentation. Do you want to address that point too?

00:53:48 Speaker, Dr. Heidi Janz

I just want to echo Nancy. Systemic ableism, I think that there's a tendency to complain the existence of people with disabilities with the actual reason as to why they're seeking MAiD. I had a close friend of mine who lived in the community for several years. As she got older, her care needs increased, to the point where she was deemed "unsustainable" in the community. She was forced to go into an institution. After several years of living in this institution she got aspiration pneumonia, which is perfectly treatable, but the doctor asked her, do you want oxygen? And she was so tired of not being able to live her life the way that she wanted to that she declined the oxygen. This is what internalized ableism does. It has become a thousand times worse in the era of MAiD because disability is assumed to be worse than death.

00:57:11 Moderator, Justice James W. O'Reilly

Thank you. Any other questions? But I want oh, I see one in the back. Yes please.

00:57:22 In person participant (Question 3)

Hi and I just want to thank all three of you, four of you I guess for, for this and for you know these really extraordinary first-person commentaries on the topic of dignity. We've been talking about worth. Whether worth is dignity or worth and dignity are two separate things. And one of the things, of course, that seems to me to underlie dignity, is the ability to, to be accorded self-worth. And one of these, one of these freedoms, or the right to be accorded self-worth I and...

Michael, you were talking particularly about something which interested me and that's the question of access to information in the context of disabilities. You know, one of the greatest ways to objectify a person is to render them third person. We know we have several transitions in life, people between birth and the age of, sort of, whatever the age is, which children are deemed to have a viable opinion about their own, about their own destiny and life circumstances and the age at which people's physical abilities to begin to decline. It's between for most of us, it's during that period of time that we seem to be accorded dignity of not being the object of others, the object of discussion, and therefore, accorded the right to information which affects us, either you know generically or as individuals. You spoke Michael about the difficulty of accessing information, and I think it was you Heidi who spoke about people discovering that DNR orders had been written onto their charts. I mean these are. These are absolutely fundamental to the rights of autonomy and of self-worth. Could you talk a little bit more Michael about the barriers to access to information and privacy barriers as you have experienced them?

00:59:40 Speaker, Michael McNeely

Yes. Uhm, so, I'm reminded of a study that I enjoyed reading about, uhm, dietary changes in Australia. So, it was a study about homeless youth that were being asked, uhm, they were being asked to go on special diets by social workers and they were supposed to give opinions about, you know, the food that they were eating. And one of the things in this study was that the homeless youth all had intellectual or developmental disabilities, and they could not provide opinions about the foods that they were eating. So, they, nobody had ever asked them to provide an opinion about their life circumstances, about what they wanted to do or what they like to do. So, I think, I think a lot of information processing is having an opinion about the information, so as Heidi, Nancy and myself have done, we've had opinions on MAiD because we had the information provided to us to have an opinion on it.

So, I think first you need to get the information and, then secondly you need to have an opinion about the information that you're being provided, so that you can say, you know, it's not good enough or it is good enough or I'd like to have more information, or who could I ask questions about? I think that we simply just don't talk enough to people with disabilities or to have these conversations. I really do feel that because, uhm, I don't recall being asked a lot about my own needs and my own desires in terms of my life and what would I achieve in my life. I, I chose to become a lawyer, not because anybody believed I could be on a lawyer but because I had to prove other people wrong. So, you know it's, I hope that's a kind of answer to your question.

01:01:42 Moderator, Justice James W. O'Reilly

Thank you, Michael. Nancy, I see you nodding your head. Did you want to add a point?

01:01:47 Speaker, Dr. Nancy Hansen

Yes, please. What we're talking about here is arbitrary bodily privilege and our society has determined that certain ways of being and doing and, and moving in the world and, and, and sensory experience in the world, we privileged those and accept those as the way of being, and we have to recognize that those are arbitrary mechanisms, of, of privilege that have been determined by a group of people that have sort of directed value toward standing up, communicating in certain ways, seeing the world in certain ways, and recognizing that this is arbitrary privilege and that we have to get more creative in the way that we

value people moving and experiencing the world, right? And, and we have to put, stop putting a label of dignity around stuff just and ask ourselves who are we really making comfortable here around disability? It's not the disabled person, it's people who are uncomfortable with disability to start with, so we have to get over the social, social yuck factor that the majority seems to be experiencing around disability and deal with that and education, knowledge is power, real power to have a better quality-of-life. And oh while I think of it, the quality-of-life argument is always presented to disabled people. And what does that actually mean anyway? It gets back to, to bodily privilege, because if people, toilet or eat or, or move in the world differently there's somehow a lack of value attached to that, so we really have to get in touch with arbitrary bodily privilege and get beyond if you will body colonization where disabled people are chronically being told what to do rather than being listened to what they actually want or need.

01:03:57 Moderator, Justice James W. O'Reilly

Thank you, anything to add Heidi?

01:04:10 Speaker, Dr. Heidi Janz

I would like to add that in my day job I regularly teach disability effects to medical students. I introduce them to the word "tab," which means temporarily abled body. The idea behind "tab" is that if a person lives long enough, at some point they're going to acquire some sort of disability. I have had some students go "Oh yeah, that makes sense." I also have had some students take some great offence within that word. I think that speaks to the lack of value, but not only medicine, but society as a whole attribute to people with disabilities.

01:06:06 Moderator, Justice James W. O'Reilly

Thank you. I don't see any other questions, but I wondered if we have a couple of minutes. Michael, I was intrigued by your, your comment that dignity, dignity is a double-edged sword and I was curious what the panellists...

01:06:20 Speaker Michael McNeely

Sorry, you do have a question in the chat, but you can go ahead with your question first.

01:06:27 Moderator, Justice James W. O'Reilly

Oh. Nathan, do you have that? OK.

01:06:32 Nathan Afilalo, CIAJ (reading question 4 - online participant)

Kathleen asked: Today, a new national organization is launching the Canadian Association of Lawyers with Disabilities. What message would each of you bring to members of the legal profession as they begin their collective work?

01:06:51 Moderator, Justice James W. O'Reilly

Anyone?

01:06:55 Speaker Michael McNeely

I can start, I guess. I would like you to ask me to do some of that work. I'm, I'm here, so just email me. Uhm, I think I'm actually part of the Facebook page too, but I'm also happy to get going on the work in question. And I hope that person from Dalhousie University can be a part of this too. She's the one who asked the question at the beginning. I think yeah, we have a lot of work to do. And so, I think one of the main issues is that if, if you live with a disability, you live in the closet because most people don't want to talk about having a disability in the legal profession, it's very frowned upon. So, it's, it's something that we seem to be ashamed of, even though the legal profession does have the highest prevalence of addiction and mental health, disabilities of most provisions. So, I'm, I'm here. I'm happy to start doing the work, so please let me. Thank you.

01:07:58 Moderator, Justice James W. O'Reilly

Thank you. Nancy?

01:07:59 Speaker, Dr. Nancy Hansen

I, I think that, first of all, I'm very pleased that this organization is coming to fruition. And I have been married to a lawyer with a disability, so I hope that the information is circulated far and wide, so people that want to be involved can be. And I would, I would say that, really one has to take a step and look at what is, what society thinks it knows about disability and recognize what is known about disability, has very little involvement, again from disabled people. So, I think the first thing to do would be to listen to the experience of disabled people and move from there. And I'm very excited that this organization, it exists. It's in existence now. Because it shows things, there are positive things out there.

01:08:58 Moderator, Justice James W. O'Reilly

Right, thank you. Heidi, anything to add?

01:09:02 Speaker, Dr. Heidi Janz

Just that I applied any and all efforts, to show the rest of society that we are here. We belong here.

01:09:40 Moderator, Justice James W. O'Reilly

Thank you all. Please join me in thanking our panellists, I think that (applause) I think that we'll agree they've made a profound addition to our program, and we're very grateful for that.

01:10:02 Master of Ceremonies, Jennifer Cox

Yes, and I want to personally thank you as well. I learned a tremendous amount from all of you, so I really, really appreciate hearing and being here and having the privilege of hearing this, the first-hand experience. So now we're going to take a break until 4:00 o'clock and we'll be back for our last panel of the day entitled "Prisoner Justice, dignity through decarceration." So that's 20 minutes. Thank you.