Better dead than disabled? The consequences of extending access to Medical Assistance in Dying (MAiD) to disabled people

April 25, 2023

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<u>scs.ca/files/webapps/csapress/webinars/2023/06/08/better-dead-than-disabled-the-</u>consequences-of-extending-access-to-medical-assistance-in-dying-maid-to-disabled-people/

14:06:22 After the webinar we're recording them for keep track.

14:06:26 You could also ask the panelists questions, using the box or reach technical support.

14:06:32 If you're having trouble next I'm going to do a brief background are on MAiD in Canada.

14:06:39 I'll start with some surprising numbers from statistics.

14:06:43 Canada. Disabled people are Canada's largest minority group.

14:06:47 At 22%. And some say this estimate is too low, depends on how you define disability and what people's self report.

14:06:56 Yet our issues and viewpoints are often ignored by politicians and policymakers.

14:07:01 Track. One of MAiD was legislated in 2016.

14:07:06 At that time only people with terminal illnesses and who were near death, qualified that 2 was enacted in 2021.

14:07:15 This extended, made to people with medical conditions and disabilities, who are not near death, that's what we're talking about today to qualify.

14:07:26 Applicants have to have irremediable intolerable suffering from a medical condition or disability.

14:07:33 Nope that made was not extended to other marginalized groups.

14:07:39 For example, those suffering from racism or transphobia applicants for made must be approved by a made assessor, generally a position.

14:07:53 Once they're approved for me, the recipient must give approval again just before the injection or drug that kills them is given by the physician.

14:08:03 MAiD is based on the medical view or model of disability.

14:08:08 It totally misses the role of social context in disabled people's suffering.

14:08:13 That is the social model of disability. For example, discrimination in employment, poverty, level disability supports being forced to live in segregated institutions for lack of community-based supportive housing, or for inadequate support being available attendance support or inadequate

14:08:35 healthcare, home care, Palliative Care. Among many other social factors, this social context reflects government policy choices.

14:08:44 But policies and programs can be changed. There are more tracks coming on.

14:08:50 Hold. It was supposed to be enacted last month is MAiD's extension to anyone with a mental illness as the sole condition, and to make sure, children also being discussed are advanced, requests were made in cases of dementia.

14:09:08 Other neurological conditions which also MAiD result in disability. So that's the end of my background.

14:09:17 I'd like to dedicate this webinar to disabled Canadians who suffered from their social contexts and who were not mere deaths, but nevertheless died by MAiD I gather these names from media stories and the Vulnerable Persons Secretariat website the list includes only

14:09:36 people reported by the media. It doesn't include disabled people who media interviewed, who were considering or had applied for men.

14:09:45 Haven't yet received it, and they had done so for reasons of poverty, lack of adequate healthcare, and living in institutions.

14:09:55 There are many stories in the media of such situations, and people give these reasons as seeking death for seeking death.

14:10:05 Physical or mental health situations, and likely more people have died whose deaths are applications for made were not covered by the media in total.

14:10:16 In 2021, 221 people who were not near death died by MAiD.

14:10:22 We don't know the numbers yet for 2022 or 2023.

14:10:28 I'll give you a minute to reflect on these names.

14:10:44 Our first speaker is Dr. Diane Driedger, she's an assistant professor in the Interdisciplinary Masters Program in disability studies at the University of Manitoba.

14:10:56 She's published 11 books. Her latest is Still Living.

14:10:59 The Edges of Disabled Women's Lives. SHe's been involved in the disability rights movement for 40 years and has worked with disabled People's International Council of Canadians with disabilities and the Disabled Women's Network Canada for more information on Dr.

- 14:11:17 Driedger. Please see her bio on the CSA website.
- 14:11:20 I'll leave you to the side yourself.
- 14:11:25 Okay, thank you so much. Margaret. Hi, everyone welcome. I am a white woman with long blonde hair, and I am wearing glasses, and I have a rust color top.
- 14:11:42 Today, I'm gonna talk about the disability rights movement in Canada and MAiD.
- 14:11:50 MAiD. Isn't a recent thing for the disability rights movement we've been working on this for 30 years trying to hold it back as a movement, and May be folks don't know much about who we are as a disability rights movement.
- 14:12:05 But after the Second World War we had a lot of technologically that helped disabled people live longer and more quality lives and disabled people started looking around and saying, Hey, the environment is not built for us.
- 14:12:21 Nothing is accessible for us physically. How are we going to make changes when doctors and social workers?
- 14:12:31 They are, and our parents in some cases are telling us what to do.
- 14:12:37 So people with disabilities got together into their own organizations in the early seventies in Canada, and formed all across Canada for venture.
- 14:12:50 Provincial affiliates of people with various disability, they rejected the medical model which Margaret mentioned, saying that the problem is with us as people with disabilities.
- 14:13:03 We need to be fixed. We rejected that and said, No, we are going with a social model, saying society was not built for us, and we are citizens.
- 14:13:14 With disabilities, and we need to have equality, like all other citizens in Canada.
- 14:13:24 So our organizations were founded. We had founded an organization at the national level as well, which is now called the Council of Canadians With disabilities, and in the early eighties we had a lot of victories.
- 14:13:39 We got people with disabilities, rights enshrined in the Charter of Rights and Freedoms in the new Constitution.
- 14:13:47 In 1982. We also got disability as a grounds for protection under the Canadian Human Rights Acts and the different provincial Human Rights Acts.
- 14:14:00 So we had presented ourselves as citizens with rights. In the early 19 nineties something new started happening all of a sudden.
- 14:14:12 There were 2 cases which we worked a lot on. One was Robert Latimer.
- 14:14:21 You May remember he's the father who murdered his disabled daughter, who, I believe, was 10 years old.

- 14:14:28 And said that it was a mercy killing pretty much, and through that Council of Canadians With Disabilities said, intervened in the Latimer case to say no, he should be tried for murder.
- 14:14:43 This is not something that was done for the good of Tracy, his daughter, who did not have a say in whether she was living or not.
- 14:14:59 And so through that we found out that most Canadians agree that Robert Latimer was correct in murdering his daughter because he was being merciful.
- 14:15:08 She was suffering. She was very disabled, and she didn't have a good life, so this, of course, was discouraging, because we had established ourselves as citizens with rights that we're gonna be protected and are being protected.
- 14:15:27 Secondly, Sue Rodriguez, a woman who had a ALS from British Columbia, a person with disability wanted to have assisted suicide.
- 14:15:40 Have a doctor assist her to take her own life, and again, disability, rights, movement.
- 14:15:49 The organization's intervene, saying, No, we don't want that, because there is a slippery slope.
- 14:15:56 We can see it come first. It's people who are terminally ill.
- 14:15:59 Then it will go on to people with disabilities, because they are not seen as valued in society.
- 14:16:07 Well, that's exactly what has happened. 30 years later we were able to intervene in a number of cases over the last 30 years, to hold back medical assistance in dying, as it's called.
- 14:16:21 And now we have tier 2, saying that if you, as a person with disability or chronic illness, feel you are suffering too much, you can have a medically assisted death.
- 14:16:36 Well, we find out that it takes less time to apply for made as a person with disability.
- 14:16:44 About 3 months. Then it does to get to see a psychiatrist.
- 14:16:50 So if you're a person who has mental health disabilities, you are on a waiting list.
- 14:16:55 You're not seeing anybody for a year, but you can imagine you hear.
- 14:17:00 Oh, only 3 months! If I want to die! So the unfortunately there are people with disabilities who are choosing this option.
- 14:17:09 And again, we as a myself, as a person with disability, who's been involved in this movement for 30 years.
- 14:17:17 I simply can't stand by and have people choosing deaths on their life.
- 14:17:26 We need services. This is what we had to establish through our citizenship rights.

- 14:17:30 We are supporting in the charter of rights and freedoms as vulnerable persons, and we are not being protected here.
- 14:17:40 In fact, it is the opposite. So, and for myself, personally, I'll just say there are several times in the last 3 years that I have been close to death myself with my chronic illness, and I am fighting to stay alive.
- 14:17:59 And therefore, you know I see it as all people with disabilities have valuable lives.
- 14:18:07 The disabled life is worth living and I would just like to read a short poem from Jim, who was one of the individuals who were worked.
- 14:18:19 I on this issue as a person with disability for 30 years, and he recently died last year from natural causes, and I just want to read a poem that he wrote about this issue.
- 14:18:37 It appeared in the Rhubarb Literary Magazine in 2016, in the deaths, Resistance, bye, Jim Dirksson, I am not ashamed.
- 14:18:48 Have learned not to be of my body, being different in shape and function.
- 14:18:54 Large head and stomach, crooked fingers, thin arms and legs, I'm not embarrassed to ask for help to cut the meat on my plate, put on my clothes, wash my body, lift me in and out of bed on and off the toilet wipe my
- 14:19:13 bum all things I know I could no longer do is that the blood smell of the death being stirred up by your offers of dignity and fear, proof, pain, free endings.
- 14:19:27 I will not go away, and I will not die to reassure you, not to humor.
- 14:19:32 Your illusion, so how we are or should be, nor to satisfy your advertising images or your cold convenience, I will not die for your fantasies.
- 14:19:44 You fearful, desperately unwilling learners.
- 14:19:49 I will teach you the complex immensity of our so common true humanity.
- 14:19:56 I am not afraid to invite my lovers to spoon or climb, to ride on top of me.
- 14:20:02 Naturally dancing to crescendo in our potent, most levely actuality.
- 14:20:10 Thanks, so much.
- 14:20:30 Thanks so much, Diane, for your compelling presentation, and showing us the power of Cory.
- 14:20:39 Our next speaker is Dr. Gregor Wolbring, he's Professor of community rehabilitation and disability studies at University of Calgary.
- 14:20:48 A member of the Institute for Technology Assessment and Systems, announced in Carl through Germany and a Fellow of the Institute for Science Society and Policy at the University of Ottawa.

- 14:21:01 For more information on Doctor Wolbring's research interests. See his bio on the CSA website.
- 14:21:08 I leave you to describe yourself. Brick
- 14:21:16 Yes, Hi, everybody. I'm just trying to move things around here with a different.
- 14:21:25 And let me get okay. You should see everything hopefully.
- 14:21:38 Margaret thanks for organizing it, and CSA.
- 14:21:40 For hosting us. My talk is about disability burnout, disabledism, burnout.
- 14:21:48 Before I go to my content, I want to thank my students.
- 14:21:52 All my students are undergraduate students when they start with me.
- 14:21:54 So bachelor, and many start with me right in year.
- 14:21:58 One, and I show quite a bit of data which comes from their work.
- 14:22:05 Disability burnout. Let me use a phrase, home carav gill, a disability studies scholar from Chicago.
- 14:22:13 This term refers to emotional despair, engendered by sorted opportunities and blocked goals, it is aggravated and intensified by years of exposure to disability.
- 14:22:25 Prejudice and devaluation. In fact, a frequently repeated seem in research interviews with persons, with disabilities and illnesses, is, I can live with my physical condition, but I'm tired of struggling against the way I'm treated and I show a few examples.
- 14:22:42 Of the disability privilege of prejudice, and evaluation.
- 14:22:47 So I myself will not talk a lot about mate, if at all.
- 14:22:52 But you can see this article is linked to the right to die.
- 14:22:57 That's why it was witnessed. Hey? That's a historic one in the sixties people were born.
- 14:23:05 This non mainstream body morphologies when their mother took the drug. Thalidomide like I'm one of them, and I was born with shorter legs. Others had shorter arms, and so on.
- 14:23:22 Throughout the sixties to today. There's, of course, a negative imagery related to Thalidomiders.
- 14:23:30 This is just from a book from 2,001 parents and daughter shocked of their saloon, my baby collateral damage to their lives.
- 14:23:37 Special, peculiar horror at the side of their children, produce an even their most compassionate.
- 14:23:43 You're finding ordeal of their family life leaving us site for now the caution.

- 14:23:47 Burden on their financial resources from now on, now, beyond that, this is a negative imagery.
- 14:23:55 It also blames the child for the financial resources which are used instead of the Society for not supporting the fact.
- 14:24:03 Interestingly, there are over time where variety of academics who said that the Thalidomide appearance changed the abortion.
- 14:24:12 Debate. For example, Peter Singer, philosopher from Australia, now Princeton, so not the two-to-one.
- 14:24:21 In his book re synching life on, just talked about that this change, the abortion law because it was moved away from women rights issue to have a utility far beyond women rights.
- 14:24:34 Hey, study Canadian universities. This is a 2019. Statistics from statistics.
- 14:24:42 Canada about the reality of hey academic staff around unfair treatment, discrimination, and harassment. You see.
- 14:24:50 In yellow, 47% of disabled academic stuff expands harassment.
- 14:24:58 And 35% unfair treatment or discrimination.
- 14:25:03 That's the highest of all the groups, and it's more than double.
- 14:25:08 Then, if you don't report a disability, that, of course, is a factor in systemic disabledism, it's in this systemic disabledism.
- 14:25:19 And no wonder if that is a cost, if you do not have to disclose yourself, you don't, and indeed you can see right on the faculty level.
- 14:25:29 There are 6.7%. But obviously the numbers are much higher or we do a really bad job of hiring them.
- 14:25:36 But if the cost of outing yourself is higher than the cost of masking, as in type, putting up a front, what you are, but why would you do it?
- 14:25:51 Biased coverage, including in research questions and studies.
- 14:25:57 When you are getting pregnant at the later age, you have a higher probability to have a child with downstream.
- 14:26:04 That's a reality. That's a fact. But Hi set probability.
- 14:26:09 But when you look at the literature, Google, Google Scholar, it's linked to risk, it's seen as you have a higher risk of having a child with down syndrome.
- 14:26:20 And the risk, of course, is not a fact. Risk it's a judgment.
- 14:26:24 And if you use a list language, then you simply preclude a positive imagery of the person, because risk is something we want to get rid of.

- 14:26:36 Transforming our world. A 2030 agenda for sustainable development point 26.
- 14:26:42 We are committed to the prevention and treatment of non communicable diseases, including behavioral developmental neurological disorders, to be clear this would include down syndrome.
- 14:26:52 This would include neurodiverse people and so on. But what I want to highlight is that in that sentence they add, which constitute a major challenge for sustainable development they do not pushing that sentence anywhere else like under that we have to improve well-being and that that is a challenge for
- 14:27:13 sustainable development question as well.
- 14:27:18 When we're looking at the academic literature newspapers and Twitter tweets, how they cover artificial intelligence and machine learning in relation to disabled people.
- 14:27:28 You'll find that the patient Medical health angle is 20 times more covered than the social and disabled people.
- 14:27:36 People, with disabilities.
- 14:27:40 It's purely optimistic. We found no content covering negative effects of AI used by society on disabled people, or the negative effect of autonomous AI on disabled people.
- 14:27:56 Robotics, the same thing, purely tested, optimistic, we found not one article that symmetries in negative impact of robots on the employment situation of disabled people just by the fact that there are buckets of papers who actually covers that in relation to
- 14:28:12 non-disabled people, and we have even lists of which Job goes first right? Take over by robots and automatization, and so on.
- 14:28:20 That's also, despite the fact that most of these easy, low-hanging foods for robotics and robotization are the job disabled people are in such a service workers, administrative support sales workers and so on.
- 14:28:33 Invisibility. Another thing which supports systemic disabledism just come from the Kevy Foundation.
- 14:28:42 Vital signs 2019 that it's the same thing in 2012.
- 14:28:45 We can feel sweat on because of our difference.
- 14:28:50 And then you see production, ethnicity, skin, color, culture, language, accent, gender, sexual orientation, disabled people are missing they were also missing from the 2012.
- 14:29:01 And indeed we don't. When I look through all of their yearly reports.
- 14:29:05 You see a little, actually nothing about the justice impact of for disabled people and the equity situation.

14:29:15 On March 20, fourth, 2020 disability rights groups came up with a report of how to deal with Covid in relation to disabled people.

14:29:26 During the acute stage, but also thinking already about the aftermath when I did the search for a block piece, I wrote in MAiD 2020, looked at the English language newspapers in the Canadian News Stream database, which is around 190 not one mentioned that report April seventh 2023, are just Redit to

14:29:46 search. Still the report was never mentioned in the media.

14:29:51 Use environmental activism. We looked at 5,536 abstracts covering use environmental activism, 0 cover children and user with disabilities as environmental activists and 0 the impact of environmental activism or environmental problems such as climate change on children or youth with disabilities

14:30:14 interestingly. A couple of months later there was an ABC.

14:30:16 News Is which talked about disabled climate activist burnout because of the lack of representation, the lack of involvement, the barriers of being activist.

14:30:32 Edi is a main policy framework in Canadian Universities.

14:30:36 DEI. It's in. It's in the Us.

14:30:38 Equality, diversity, inclusion is the okay. So we did in 2021, some searches around Edi policy frameworks, including dimension, equity, diversity, inclusion, and frameworks.

14:30:51 We found along 1,011 abstract 12 covered disabled people in universe, and we are not done.

14:30:59 Another, one generic one. We just came out on Edi, and what is actually covered conclusion given our push for evidence-based policies, this invisibility and the Buddhist bad coverage are factors that strengthens systemic disabledism and with that further disability burnout disabledism burnout and that

14:31:21 includes right, the lack of I mean Edi in the research questions covered within Academia, a tool to audit content.

14:31:31 I want to close with that.

14:31:34 The bias we framework was coined and set up by Margaret Ashley and Mary Enberg.

14:31:41 The framework has 20 questions that indicate biases that help maintain social hierarchies in 3 main sections.

14:31:48 Maintaining an existing hierarchy, failing to examine differences, and using double standard.

14:31:56 Now, if both of the open access, a short Nsp.

14:31:59 Page longer one, and you can use energy for any content to see where the biases are.

- 14:32:04 Thank you very much. Cheers.
- 14:32:32 Thanks, so much Gregor, for your edifying presentation lots for us to think about.
- 14:32:37 Yeah. Our next speaker is Dr. Nancy Hansen.
- 14:32:42 She's direct of the interdisciplinary master's program in disability studies at the University of Manitoba.
- 14:32:49 She's co-editor of the Routlege History of Disability and Untold Stories:
- 14:32:55 A Canadian Disability History Reader. Her latest article is 'Disappearing.
- 14:33:00 Disability: Disability made Invisible'. for more on Dr.
- 14:33:06 Hansen's research interests. See your biography on the CSA website where you register. I'll leave it to you to describe yourself, Nancy.
- 14:33:17 Okay. Thank you very much for the opportunity to speak today.
- 14:33:22 Thank you to the CSA. Thank you to Margaret, and I'm very pleased to be on on this panel.
- 14:33:29 I am an upper, middle aged woman, white, with red hair and blue glasses, wearing a blue top, and I'm also a disabled woman on Treaty one territory in Winnipeg. Manitoba.
- 14:33:49 I think, and I can't talk about this subject dispassionately.
- 14:33:56 I'm a disabled woman in 2023, who is put in the position of having to justify her life under current legislation.
- 14:34:07 So what I'm talking about is the choice trope equity as a facade or eugenics by any other number.
- 14:34:17 There has been a tenfold increase in usage of MAiD since they became lost 6 years ago.
- 14:34:27 And there's a strange form of irony here, because theoretically, we have more legislative protections than we've ever had as disabled people.
- 14:34:39 The UN. Convention is only the latest example, however, in the midst of all these protections made, has been steadily advancing to the point where Canada now has among the world's most far-reaching application of medical assistance in dying COVID-19 has brought into sharp focus just
- 14:35:02 how tenuous, and and how tentative our legal positioning is.
- 14:35:12 Legal Protections for disabled people suddenly disappeared.
- 14:35:17 You had to justify your access to medical care. Programs and services were cut back under the under the pretense of lack of resources, and many of those, how many of those programs and services have not returned as restrictions are alright loosened made this being offered as a solution to poverty lack

14:35:45 of accessible housing ramps, support services and alternative, and as of March 2022, as an alternative to long-term prison senses, 9 inmates that far have been given made.

14:36:06 And this is more than the jurisdictions that actually have, and a death policy for crime.

14:36:21 Oh, just 1 s. Here!

14:36:25 Is there a contempt for the disabled body? How comfortable are we really dying?

14:36:34 During the recent series of committee meetings reviewing MAiD, the head of the Quebec Medical Association advocated for MAiD, being used for infants under the age of one that didn't meet the standard.

14:36:53 So what do we do if we don't fit? It wouldn't seem to me that this the stereotypes and antiquated ideas and thinking around disability are lingering just below the surface, and there's a comfort wrapped in in science that justifies outdated

14:37:19 mis misconceptions, around disability.

14:37:23 Just 1 s drop, have lost my place. Talk amongst yourselves for a second.

14:37:29 Here!

14:37:33 Okay, here we are. The title of this panel.

14:37:37 Better, better than disabled. It would seem that society has yet to develop a comfort level with the presence of disability.

14:37:48 Have we managed to truly address the social yuck factor, the messy, the messiness of humankind.

14:37:58 Or has the safety net of science worked to justify the choice?

14:38:05 But bolster and reinforce the outdated ideas that we have become so comfortable with, or mainstream society rather has become comfortable with.

14:38:16 So? Is there really a choice here, when there are few choices, provided it should be noted that disabled people we're not eligible for first serve protections during the main pandemic, and it was only after intensive intensive advocating on a part of the disability constituency

14:38:39 is that disabled people were provided with a one-time made.

14:38:49 Oh, excuse me! Excuse me a one time, Covid.

14:38:55 Allowance.

14:39:01 It would seem that a lot of legislation around disability has been built around lack of expectation.

14:39:10 There's a residual amount of eugenic thinking again, just below the surface.

14:39:18 The language of the legislation has been neutralized, but who is made more comfortable here?

14:39:23 One of my colleagues in legal studies was called brave for taking for wanting to explore the impact of made and the disability community.

14:39:37 So how far we come really, and what comes next, all I know is that I do not want to be the first in line.

14:39:47 Thank you.

14:40:34 It's Nancy for your eye-opening presentation and your personal passion about this subject.

14:40:41 Our next speaker is Dr. Trudo Lemmens.

14:40:44 He's a professor and the show chair in health, law and policy at the University of Toronto.

14:40:51 He was a member of the Council of Canada Academy's expert panel on medical aid in dying.

14:40:59 An expert witness for the Federal Attorney General in the Truchon and Lamb cases which Trudo will tell you about.

14:41:07 He has testified before Canadian Parliamentary committees mandated to discuss draft, made legislation, and to review it and he's been consulted as an expert on these issues internationally for more on Dr.

14:41:23 Lemmen's publications and other work. They see his bio on the site where you registered for this webinar doctor Limits is unable to be here with us today.

14:41:34 But Trudo finally kindly recorded his presentation.

14:41:38 In advance before he set off for Europe for more conferences.

14:41:44 So Sherry, can you play through those recording? Please?

Technical difficulties prevented us from playing Trudo's recording. You can view it here:

https://www.csa-scs.ca/files/webapps/csapress/webinars/2023/06/08/better-dead-than-disabled-the-consequences-of-extending-access-to-medical-assistance-in-dying-maid-to-disabled-people/

14:53:30 So now we have lots of time for discussion. We've only done 50 min through to our time. Slot.

14:53:51 And at the end of this webinar drop said you could send him questions by email.

- 14:53:59 We haven't yet got written permission from him, but if he gives us his written permission, we'll send you his email address as well after the webinar and along with the link to the to this top.
- 14:54:15 So I'd like to thank all the speakers.
- 14:54:20 So they're wonderful presentations, and I hope that they helped you learn about and reflect on today's topic.
- 14:54:27 As I mentioned, we've now got lots of time for discussion.
- 14:54:32 We want to hear your comments.
- 14:54:45 And your stories and experiences, and your concerns, and particularly your ideas for action and collaboration.
- 14:54:54 You'll notice there's no chat box on the screen, or raise hands.
- 14:54:59 Icon, but you can use the box. You can also ask panelists questions this way as well, and we already have one question.
- 14:55:14 So I'm going to go over some technical tips again.
- 14:55:22 On how to use the box.
- 14:55:27 What for the icon on the bottom of the zoom screen?
- 14:55:30 You don't have to give your name when you ask a question you can choose anonymous, and after discussion with our panelists today I'm not going to share anybody's name when I read out the questions and again, you can use the box to network collaborate share
- 14:55:47 emails, resources and links. Put whatever you want to share with the other members of the audience into the.
- 14:55:54 And we will pass them on after the webinar.
- 14:55:57 You can also ask the panelists questions using the box, or you can reach tech support if you see somebody's already made your comment or asked your question or told a similar story, and you don't want to add to it. You can up vot?
- 14:56:14 So Sherry if you can, what all of us on the screen, or if everybody can unmute and start your video, we can start the discussion.

For the exact wording of the participants' questions, see the file 'Questions, Comments and Resources from Participants', which is available here: https://www.csa-participants

scs.ca/files/webapps/csapress/webinars/2023/06/08/better-dead-than-disabled-the-consequences-of-extending-access-to-medical-assistance-in-dying-maid-to-disabled-people/

- 14:56:46 So the first question we have, I'll read it out in the UK.
- 14:56:52 And I suspect, worldwide those fighting for assisted suicide.
- 14:56:59 Legislation, often lung.
- 14:57:01 Disabled people who oppose this in with pro-life.
- 14:57:05 Christian protesters. It's easier for them to dismiss us by saying we're pro-lifers, which many of us are not, that it is for them to acknowledge that we are disabled people with real concerns.
- 14:57:18 Do you have any experience of dealing with this? So first of all, the panelists, and then we'll ask members of the audience if they have an answer.
- 14:57:31 Anybody wanna bill for this Diane? Yes.
- 14:57:37 Yes, in the early days of the disability rights, movements, interventions against assistance, suicide.
- 14:57:47 We had pro-life groups who did support us as a Canadian disability.
- 14:57:54 Rights movement, and we saw that, as you know, we obviously people are more than one dimensional right?
- 14:58:04 They agreed that we should be killed as disabled people, but not all of us agreed that we were pro-life, and so we tried to stick to the main issue, which was killing of disabled people.
- 14:58:17 Right and so that's how we dealt with it.
- 14:58:20 Other people's definitions of things, again, is is part of the ableism, that we deal with all the time, and we all know all people don't think alike right.
- 14:58:34 So we can differentiate between different opinions at different times.
- 14:58:40 Anybody else on the panel have some remarks on that question.
- 14:58:57 Maybe it's really important to understand. We don't all think it act the same way.
- 14:59:02 I myself, if people want to choose medically assisted, dying, that's fine.
- 14:59:09 I object to being put at the front of the line.
- 14:59:13 Just, and to have special access simply because of my disability.
- 14:59:17 I would much rather be given resources to live rather than speedy access to die.
- 14:59:25 I mean for me, disability, disability, rights, and dignity does not mean getting in the fast lane to X.
- 14:59:34 Thank you.
- 14:59:38 Any comments.

- 14:59:42 I mean, it's often I mean a strategy right?
- 14:59:46 You clump them together with something right mean to write, negate, amend the validity of what's this? What one says?
- 14:59:54 Right. And it's use for disabled people on all kinds of topics.
- 14:59:58 That's not just as a made issue, and whole life.
- 15:00:01 But I mean but even people saying Oh, but I mean you're not all sinking the same way.
- 15:00:10 What if you were, use it with women rights and saying, Not every woman is in favor of abortion, and use it as an argument you would get slaughtered right.
- 15:00:21 But with us. So I mean, it's constantly this, what I call animal farm philosophy, right? Its village is double standard. It's this, I mean some awake with others, and and they use all the time stuff with us.
- 15:00:34 If you would use the same sentence of reasoning and put another social group in there, I mean, people would, I mean, blow up, and with others users then seen totally acceptable.
- 15:00:45 I mean, that's I mean, a standard strategy. Right of double standard. That's why I put in my slide at the bottom right?
- 15:00:51 The biosphere framework. I mean, you can really unmask a lot of things which some basic, I mean analytical questions.
- 15:01:03 It amazes me still. How many people do not understand that access to programs and services I don't include quick access to made among them that access to programs, services and facilities is not seen as a human rights.
- 15:01:22 Are social justice issue as it's applied to the disabled people.
- 15:01:28 The defect, weakness, suffering, element that has been applied to, and disability for centuries is still lurking just below the surface.
- 15:01:42 Like I said before, despite decades of advocacy from the disability constituency, because there's a still, this need to dismiss what disabled people have to say, because we're seen as less than or not equal to despite all the rhetoric around edi
- 15:02:08 we still seem to fall off that continuum.
- 15:02:11 Cool alright. I mean, you, I mean even the very term accommodation.
- 15:02:17 Right. It's all very much ability, privilege. By it, I mean, if I have a wheelchair mushrooms, they call me.
- 15:02:22 I'm getting accommodated, but of course a washroom is no comedy for the human body period.
- 15:02:27 Right, otherwise it would smell quite differently in any workplace.

15:02:32 Alright, so I mean, or saying, confined to the wheelchair.

15:02:37 Well, I mean I'm not. I can actually get out of my wheelchair, but I mean normally, you know, human race is confined to their legs.

15:02:45 Right, or if you call me mobility impaired. Well, the human race can't fly.

15:02:50 So you are flying, impaired. I mean, there is bizarre.

15:02:52 I could give a talk with just on these kind of double standards, of how you use.

15:02:56 And it's based on ability, privilege. You take certain things for granted that you're getting accommodated.

15:03:00 You don't have to use the term, and I have to use the term, and I have to be grateful.

15:03:06 That's why, we are. I think it's a problem with medicalizing student by students in order to get accommodated at university level.

15:03:18 Hmm!

15:03:13 I mean, yeah, I stop you otherwise. But there are so many systemic issues which we haven't solved this.

15:03:23 And I come there with all this new stuff right? And then, of course, you have no one to do that right, because the old stuff hasn't even been solved.

15:03:31 The employment numbers haven't improved in a hundred years.

15:03:34 Roughly, when you look at numbers right for deaf and blind.

15:03:39 For example. Alright, 85% of people who are under neur diverse label are unemployed or don't work right.

15:03:46 And so on.

15:03:49 Thanks very much. Gregor. You're making some great points.

15:03:55 Good.

15:03:52 We have 10 questions now from the audience, or 10 comments, and it just thought of something to respond to yours as well.

15:04:00 Families have been accommodating most mothers. Starting in the 1980 S.

15:04:04 A lot. Family workplace balance. That's one thing you were talking about in yet.

15:04:08 There's still not called accommodations. Are you allowed to leave work early because your child is you haven't a medical point with your child.

15:04:17 You have to go to school play. These are not called accommodations, but they are for a different reason, they're not the disability reasons they're for family reasons.

15:04:26 So we've got a response from Christina, who's responding to the same question that I read out.

15:04:34 She says, sorry should we mention your name? I wrote an article on my blog about disability and reproductive ice on my activist blog.

15:04:43 Some of it could be helpful when combating the claim that we are all pro licensed and I'll read out the web link just in case you want to put it in your in your search engines right now, Www.

15:04:59 The once and future cripple.com slash, en slash, disabled people dashboards without the hyphen or reason, dash to dash, ban, abortion, so we'll all include this in the list of links that we'll send out after the webinar so

15:05:23 moving on to the next comment from an audience member in 1996, under the leadership of Diane Coleman, I joined, Not Dead Yet, and wrote our theme song at 73.

15:05:40 I am 45 years past the spinal cord issuing injury.

15:05:45 When I was literally stabbed in the back in 1987 I joined ADAPT, which stands for American Disabled, for Accessible Public Transportation, which became American Disabled for Attendance Programs.

15:06:01 Today, after the Ada, which is Americans with Disabilities Act believe was passed.

15:06:10 I can reload your email address. Is that okay?

15:06:15 Gregor, just thinking of your concerns. Confidentiality.

15:06:20 Maybe I'll include it well included in the message that other file that we send out after the webinar.

15:06:28 That's probably better to keep everybody safe, and the person ends by saying, truly, we are in this together in capital letters.

15:06:39 So thanks very much for that comment and contribution. Again, anybody who wants to.

15:06:46 We've got 2 more questions. Good. So 2 more comments.

15:06:50 So I'll keep going.

15:06:55 And this is a question for any of the panelists.

15:06:58 A simple question. Is it possible for a person with a disability to autonomously choose of their own free will to avail themselves and medical assistance in dying?

15:07:11 Or does the social model of disability preclude the autonomy of the individual in making choices about the end of one's life?

15:07:19 Maybe I'll direct that question to Nancy. Since that was part of your presentation. You want to start, Nancy.

15:07:26 Sure I would say whatever a person chooses to do.

15:07:31 Is their own business, but I don't think that a person should be forced into that situation because of untenable living conditions of poverty, lack of service, provision, lack of options, as far as transportation, employment, all of those things having a unequal distribution

15:07:59 of options often makes people feel like they have no choice, because the there are so many barriers to to making those other choices that being said, I would never get in the way of somebody who really wanted to take their own life.

15:08:20 That's all about personal autonomy.

15:08:22 But one shouldn't be driven to personal autonomy because they live in poverty because they don't have access to goods and services that they need to live their lives the way they want to.

15:08:36 Any other comments from the panel. Thanks, Nancy.

15:08:40 I don't think it has anything with the social model of disability.

15:08:44 I think that term is thrown around too much. That film simply means that the disablement originates with the social structure.

15:08:54 Nothing else that by itself has says nothing about whether you kill yourself or not.

15:09:00 Alright, but I mean what it does is that it can question that.

15:09:05 I mean, you focus on disabled people as it will.

15:09:09 And when you look actually, we are a man. That's why I had to salute my one up Sale.

15:09:14 Alright. You use a certain narrative image, but what you have in mind goes far beyond, and indeed, that's what changed the abortion debate, according to Peter Singer and others, and we are used.

15:09:25 What? Because reality is when you look at a Netherlands and Belgium, the push is really to allow for your tired of your to move beyond.

15:09:38 Right, because I mean it started with something. You know that the public is right.

15:09:44 I mean, right, can see that the same as we did that with genetic testing. And then you moved on and on, and you do the same thing.

15:09:52 There. So I think that has nothing with the social model of disability, and it also has nothing to do with autonomy, because if this, if the term autonomy is really so important, then it should not be used in this selective way as it shoots on man.

15:10:09 Right? Right? I mean, certain groups.

15:10:13 Did you wanna say something, Diane?

15:10:18 I'm thinking about the social model, and I think that it actually pertains to the situation.

- 15:10:24 We're at in Canada because of the social barriers around.
- 15:10:29 Housing, Attitudes. Treatment Options, Cost Cutting.
- 15:10:39 These are social issues that are barriers for people with disabilities to make real choices right, make a real choice.
- 15:10:46 If you are suffering really because you have horrible housing, that is, mouse infested and has no locks on the door.
- 15:10:55 How can you make a choice? So the social model effects this decision that's kind of how I see it ideally.
- 15:11:04 The social model for the disability rights movement means. This is our.
- 15:11:10 This is our vision. If all barriers are taken down, then we can participate on an equal base with it.
- 15:11:17 Basis with everyone else but those barriers aren't just been coming up, even as made has expanded in.
- 15:11:26 Who can have made?
- 15:11:29 I'm Stan. I've got some numbers here on employment from Stats, Canada, in 2021 people with a disability had an opponent rate.
- 15:11:41 Of 19.1%. So 19% in contrast, people with no disability, 63.7 or 64% reported being employed.
- 15:11:53 So you can see there's a huge yeah in employment there between people with disabilities and non-disabled people.
- 15:12:02 So I'm gonna go move on to another question. The UK is polarized because of the actions of Humanist UK, so do we need to differentiate ourselves as the disabled people from the reactionary religious right?
- 15:12:20 Is anyone to the on the panel? Right? Want to respond?
- 15:12:27 There's always going to be differences of opinion and and it's not about muzzling any particular group.
- 15:12:35 It's about giving people a platform to speak from.
- 15:12:42 In the first place together, and to let their concerns be heard and known and not diminished or made invisible because of.
- 15:12:50 Of a lack of access to make their concerns known.
- 15:12:54 I think that we have had a very sort of very simplistic understanding of what's involved with the issue.

- 15:13:06 And it's not. It's not simple or simplistic, I think, and that's the problem with the way this legislation has been dealt with from the beginning.
- 15:13:17 There are a lot of complexities here. Very few of them having to do with.
- 15:13:23 Access to dying. What we have to look at is access to resources for living.
- 15:13:30 Yeah, but we are. And other people have the right to make their opinions.
- 15:13:35 Known, but there shouldn't be an exclusivity attached to any sort of opinion.
- 15:13:47 We got your hand up.
- 15:13:50 Hi! Think in general, if you want to put forward the disability rights angle, I mean, you have to.
- 15:13:58 I mean, really put away Korea, I mean. And was this any objectification that others use you for their purpose?
- 15:14:04 And that is, this is not just a little spot. I mean to just singles and out as if there's only ones, I mean, who are, I mean, using us there are many groups to use our images and our how we are right and and so on to sell their own stuff.
- 15:14:20 What and so, as a disability, I'm I mean simply one has to resist being objective.
- 15:14:27 5 periods.
- 15:14:33 You waving your head. Nancy, yeah.
- 15:14:35 I think there's been a very colonial approach to the disabled body for a long time, and it's yes.
- 15:14:44 We'll let you win, but we'll let you win on our terms, and only in a on a very, in a very narrow perspective.
- 15:14:50 There's really to move on from from what Gregor said, there's really very little understanding of what the barriers that disabled people encounter in the chronic, the chronic systemic ableism that we deal with on a daily basis as Gregor also
- 15:15:13 allude to the right to peace, shouldn't you know?
- 15:15:16 Shouldn't be some exciting thing, non-disabled people do it every day.
- 15:15:22 But when disabled people are, have been given a ramp and a toilet that seems to be, you know, somewhat exceptional, and that same exceptionality is sort of shown when disabled.
- 15:15:36 People actually show up because we're not expected to be in most of the spaces and places we find ourselves.
- 15:15:45 Daily, so we're chronically having to make the case to be there.
- 15:15:51 In the first place and made is just the latest iteration.

- 15:15:57 Sort of expediting why we shouldn't be there.
- 15:16:08 Yeah, I just wanted to reiterate what both Gregor and Nancy are saying.
- 15:16:13 You know the reason for a disability rights movement in the beginning.
- 15:16:19 40 years ago, now starting is that other spoke for us.
- 15:16:24 Others who considered themselves experts in our lives, doctors, social workers, parents, other family members, that's why we had to start a voice of our own.
- 15:16:38 And that has is the motto of the Council, Canadians, with disabilities as well as the disabled People's International.
- 15:16:46 Are an international coalition in over a hundred countries of disabled people's groups.
- 15:16:52 This is continuous, we have to constantly reinforce that this is our voice and a voice of person's meeting with disabilities is different than just one disabled person's voice.
- 15:17:06 We have to also understand that a lot of people have said to me, well, there are people with disability who wish to have made so disabled people aren't all against it.
- 15:17:19 No, we aren't all against it. However. Our voice, a larger group that has included thousands of people who belong to our movements.
- 15:17:30 Have seen that this is a slip-free slope.
- 15:17:34 As we predicted, we start with end of life, and then oops quickly.
- 15:17:41 It becomes your suffering too much as a disabled person.
- 15:17:46 So, yeah, as a movement, we have to continually differentiate ourselves from all other voices, especially those of us service providers.
- 15:17:55 Right, which is a fight we had 40 years ago, and we still have that, because who are the experts on the mental health panel?
- 15:18:05 Psychiatrists, and I heard there are 2 or 2 people with lived experience of mental health, disabilities, and one of them resigned because the experts who outnumbered people with that disability it didn't work listening, and so this is very problematic even when you
- 15:18:27 have a seat at the table. How many seats do you have right?
- 15:18:33 This is getting to this is a big issue.
- 15:18:39 It's now 3, 18. Did you want to leave at 3, 30, over 3, 18?
- 15:18:45 My time, or can you hang on for the full 2 hours?
- 15:18:47 I we could hang on. It's fine, or I won't speak for Diane.
- 15:18:53 I can hang on Diane's giving a thumbs up so.

- 15:18:50 Okay. Hey? That's good, too. Good. We've got 14 questions, and I wanna make sure I get to the ones that don't ask for the panel.
- 15:19:04 So people get heard. The next question is, Thank you for your session.
- 15:19:10 Today I worked for a disability organization and I'm a DST student at TMU.
- 15:19:16 I worked for a disability organization, and I'm a DST student at TMU.
- 15:19:19 I think that sounds for disability studies student at Toronto, Metropolitan University.
- 15:19:22 Can you speak to the current? Pause in extending made to people with quote mental illness, unquote, and any changes that MAiD occur.
- 15:19:31 Or will the fed still push it through, as if certainly gives us a window for wrapping up action?
- 15:19:37 Okay, that sounds like a question for the panelists and also for Trudeau.
- 15:19:41 So Maybe we'll pass that on to him when we're done.
- 15:19:44 Any of panelists want to answer that question?
- 15:19:49 I'm gonna read it again.
- 15:19:53 Oh, you've got the up on your screens, I guess.
- 15:20:02 I would just reiterate what I had just said, even when we do have representatives, we people aren't listening on the issue of of this issue.
- 15:20:15 It seems that in from what I've seen is that the folks who want to have made you know are just ignoring other voices that are more vulnerable to theirs in many cases, and I'm not, saying about people with disabilities, but people who are able-bodied cannot
- 15:20:38 think of having pain and disability. They'd rather die.
- 15:20:43 There'd rather be dead. I've had people say that to me, and I've also said, had people say to me, boy, I could never live like you with constant pain and fatigue, I don't know how you do it.
- 15:20:55 I never would do it. And so, yeah, how the question is, how do we get around this ableism?
- 15:21:05 This is really where I think it has come. 2. We are so ableist in our society that we ignore these disabled people's voices.
- 15:21:17 We're just ignoring them.
- 15:21:19 Well, if if we don't agree with the status quo, and I mean of the majority status quo, then we're routinely discounted as some kind of extremist who likes to.

- 15:21:33 Overblow the, you know there's this constant trust us, approach to to legislation related to disability.
- 15:21:45 And there's I have a problem trusting people who are inherently uncomfortable with the way I live my life.
- 15:21:55 When I was out and about in the world of non-disabled people more than I am now, I would be routinely approached by individuals who couldn't understand why, was happy, and how could I be happy?
- 15:22:11 In my particular situation, and they would routinely tell me that they couldn't live the way I do, and I thought to myself, Then you really don't know the way I live.
- 15:22:23 You know there's a there's very little creativity when it comes to the way humans think, move, and perceive the world.
- 15:22:34 You know, I think diversity is a spice of life.
- 15:22:41 We just have to make people understand that disabilities, a lot sexier than a lot of people think it is right.
- 15:22:47 But then anybody that's been marginalized, for whatever reason, and it's important to recognize that there are candid numerous marginalities working in the same time.
- 15:22:58 I've also been subjected to this kind of lack of progressive thinking throughout centuries.
- 15:23:07 We're just. This is the latest iteration.
- 15:23:10 And unfortunately it's 2023. You think we could get beyond this by now?
- 15:23:16 That's that's it. You start an idea, and me, or reaction when somebody makes those extraordinarily rude province about the quality of your life, all they've seen is you in in Maybe a a couple of minutes.
- 15:23:31 They have no clue. What the rest of your life looks like in the case of people with invisible chronic illnesses, for example, like Diane and I have.
- 15:23:44 People don't see anything. So they deny they often deny it.
- 15:23:50 You can't be sick. If there's nothing wrong with you, you don't look and save so there's 2 sides to that coin.
- 15:23:53 Make people making a assumption based on a very short moment, of seeing you making assumptions, of the rest of your life, and then people also, because they can't see what the problem is, not believing.
- 15:24:07 You so Maybe we better move on. We've got.
- 15:24:12 Oh! Another one came in. This is someone who writes it.

- 15:24:16 This is more of a common rather than a question. That's great.
- 15:24:22 Have any comments welcome. I'm a disabled person, who is also a great supporter of death, causes.
- 15:24:27 I desperately want to see MDs Removed from the MAiD process.
- 15:24:32 As they are usually among our greatest abusers and gatekeepers.
- 15:24:36 Especially for disabled people with multiple marginalized identities.
- 15:24:42 What I want to see is licensing of homeless, dying care specialists from outside the medical system, who can work with people who are seeking maid to help them with their decision, to end their lives without giving even more undeserved power to MDs and the biomedical system
- 15:25:01 oh! Oh! This comment had 4 up votes for the 3 other people who agree with this comment, does anybody want to give a response?
- 15:25:14 Welcome!
- 15:25:23 I mean, there are many studies which show the difference. I mean in perception between medical profession and I mean and disabled people.
- 15:25:34 I mean start is going right? The phone, the nineties, and even earlier, I mean, this is constant.
- 15:25:39 The difference in perception is just. I mean, it's just a and reality is.
- 15:25:46 Look at this little-mode quote, if this is what you're exposed to throughout your life, if this is the clamors, I can't even blame people.
- 15:25:57 Alright, if this is what it is, I mean you are only your product of your own I invite what you are exposed to, and if this is what the narrative is right, where would you get something former or like I mean oh, this is totally not white short of that, you are yourself, then or I mean, we have
- 15:26:18 this women wise. We have a term like called niche.
- 15:26:24 I mean, you internalize your question. Right? That is the same.
- 15:26:27 If you're exposed constantly about yourself, that I mean you're worse, worse, and that your life is not worthy, and end you have all this systemic disabledism.
- 15:26:38 It's very easy then to I mean, internalize so question also to yourself the same as we do use that term for women.
- 15:26:45 Is insulin. We use very little that term in relation to disabled people, but so it's just as applicable.

- 15:26:58 I totally totally agree with that. That's why I think we have to get at the issue of Ableism.
- 15:27:05 It's insidious in society. I myself am able to every day to myself.
- 15:27:12 I get up in the morning and think, oh, how much am I gonna get done today?
- 15:27:17 I wanna do more. Why can't I do more? And then, like, Go there is that able?
- 15:27:24 Is tape running in my head about more and faster and better, and hey, I I know that that tape doesn't work for me, so I have to get myself readjusted for the day.
- 15:27:39 And this tape is going on in everybody's head, and it has nothing to do with whether you are a progressive person or not.
- 15:27:47 Some people feel quite offended because they they said, I'm doing my best to be an ally.
- 15:27:53 And now you're criticizing me because they see themselves as a progressive person.
- 15:27:59 And yes, you are. But you know what all of us are able. So it's like all of us are working in our society because we have grown up that way. So we have to get at dismantling this system of thinking as well.
- 15:28:17 Yeah, we have to stop tinkering around the edges right?
- 15:28:23 There's been no real dismantling of the insidious endemic systemic ableism that we have to deal with.
- 15:28:33 All the time and that's the part that's tiring is that we have to deal with these micro oppressive kind of things.
- 15:28:44 There's a as Diane alluded to, and Greg or earlier, there's this kind of averse of Ableism that we have to deal with.
- 15:28:53 So my best friend, are disabled people. What do you mean?
- 15:28:59 I'm encouraging, but we are what we have to deal with is the social yuck factor, and how people often project their levels of discomfort on to us, right?
- 15:29:14 So they have to get comfortable with disability and disabled people.
- 15:29:19 We're not going anywhere. And you're around us every day.
- 15:29:23 Anyway, you just might not realize it. So I think we just as a society, we need to have more real concrete education as to what's actually happening here.
- 15:29:34 And that we we can't put lipstick on a pig.
- 15:29:39 We have to do some real serious work here, and Maybe there are some difficult conversations ahead.

- 15:29:46 But I say, bring!
- 15:29:58 Justice is interracial, multicultural, intergenerational, gender fluid with cross disability, solidarity.
- 15:30:08 Have you moved towards disability? Just?
- 15:30:19 I think you talked about racism, Diane.
- 15:30:26 We're on a path towards this disability, justice in our disability rights movement in Canada.
- 15:30:35 In fact, I know, for instance, that Disabled Women's Network of Canada, our national disabled women's group has been looking at intersectionality for the last 10 years in terms of gender race ethnicity, and including those folks in our work, one of the criticisms of
- 15:30:57 course of the disability rights movement from 40 years ago is that the primary actors were white men in wheelchairs in Canada and in other Western countries, and that is that that is true.
- 15:31:16 They were people who were in a position they had more power at that time, because they were men, and they were white, and they were able to push the agenda forward.
- 15:31:25 Now, of course, we have to include everyone, and we can't just have the white distinction rights movement of mobility impaired people.
- 15:31:34 I know as a person with invisible disabilities.
- 15:31:38 You know there has has been the issue of visible versus in this visible disabilities within the disability rights movement, too, and some feelings that well, those you know from some that these invisible disabilities are not really disabilities, not like not like we experience as those who have visible
- 15:32:01 disabilities. And so there hasn't been a bit of tension.
- 15:32:04 But I think that has mostly resolved. Now we have to in of course, the tension around the the participation of women, because men were very much in leadership in the early years, and you know that's why Disabled Women's Network Canada was founded in 1986
- 15:32:24 because there was not a forum for women to speak within the larger movement.
- 15:32:29 The men wanted to sit down and speak on the women's issues with them.
- 15:32:35 And this is what forced the creation of a separate group, and and they work in coalition with other disability groups as well.
- 15:32:47 Thanks. Dan, I wanna move on to make sure we cover everybody's contributions from the audience.
- 15:32:55 Here's another one. How do you think MAiD will, or has created barriers for deinstitutionalizing long-term care which often houses the disabled folks as well as older adults,

who I might and awesome are all in long term care because they have something that impairs them

- 15:33:18 often dementia. That's it.
- 15:33:23 This isn't exactly touch on it, but the government reports relating to MAiD make a focus on the idea what a cost saving measure medical assistance in dying.
- 15:33:37 Is right. So how do you cut costs of?
- 15:33:44 Institutionalization and institutionalization. Remove the issue from the beginning.
- 15:33:50 But and I found it really deplorable. That was, that was the big thing that the latest government reports on MAiD we're focusing on was the cost effectiveness, and how much money that made was saving people.
- 15:34:07 But again, this is a very narrow approach to what cost effectiveness really is.
- 15:34:16 I could add something there. I read a report that Nancy, I think you forwarded.
- 15:34:22 It was embedded in in a block. It was the setup.
- 15:34:28 It was parliamentary. It was a part of the problem with Canada.
- 15:34:34 Senator asked the.
- 15:34:37 Economics, analysts to calculate the cost savings with MAiD or the cost.
- 15:34:46 The sector actually has for the cost of no, and the analysts found out that it was going to save money.
- 15:34:53 For most of the provincial governments who are responsible for healthcare budgets, and most of them.
- 15:35:00 But it wasn't large amounts. It was only 2 billion dollars, I think, out of budgets that are way bigger than that.
- 15:35:08 And it. It was a small percentage of costs.
- 15:35:12 So the people who are citing this report might want to look back or they're using another report.
- 15:35:20 But the conclusion of this the Senator of the researchers was that it'll save money for the provinces, but not a lot an update on that one.
- 15:35:36 I'm someone who looks at the institutionalizing, long-term care using the lessons that come from the institutionalizing younger people.
- 15:35:47 And I think it could be a barrier, because what's coming up and what I've heard physicians, advocate and organizations at the call, for example, dying with dignity.

- 15:35:59 Advocate is before you become, you lose your capacity when you have advanced dementia, ask for, made in advance before you get to that stage.
- 15:36:10 So this is an attempt to avoid long-term care.
- 15:36:15 In some cases, or one of the media articles that I found when I compiled the memorial slides, was a woman who was you didn't want to go into long-term care.
- 15:36:25 She had early onset dementia, and she didn't want to live the life that she envisioned for herself, going into long-term care, because that's what we offer people in Canada with dementia.
- 15:36:36 We don't offer community based support of housing. We don't offer attendance, support.
- 15:36:42 The way we do is younger people not available to older people with dementia.
- 15:36:45 Oh, and so this solution is, let's see right now is you go into an institution which is a nursing home and a lot of people aren't aware of conditions in nursing homes because they haven't spent time there and we're not really paying attention to this issue which affects people
- 15:37:03 with disabilities as well, people that's living domestic with dimension and frailties and hard conditions, and so on, that lead them to the institution we're also cutting home care in Ontario.
- 15:37:20 We in Canada, we spent a way less on home care.
- 15:37:23 Then countries in Europe do United States and Canada one of the 2 countries in the OECD who's been a very low proportion on homecare, and that is, supports for people with disabilities that might end up in long term care including of course now younger people who can't get the
- 15:37:45 attendance that they need and can't get into communities supported housing, because there's not enough of and it's it's been cut.
- 15:37:53 It hasn't been. It doesn't meet demand.
- 15:37:55 And so people end up having to live in long-term care, which is an institution that the whole idea of deinstitutionalization was created to avoid so there's some more comments.
- 15:38:08 Maybe we should move on to the next audience contribution. I'm looking for the upvotes to see if this questions have been asked more than once.
- 15:38:24 Thank you for putting together this excellent panel, and for sharing your insights.
- 15:38:29 Do you think? Radically expanding, made to all humans, regardless of their situation?
- 15:38:35 For example, to the non-disabled as well.
- 15:38:39 Would get around the discrimination. Currently, in these policies or make them worse.
- 15:38:45 Any comments, panelists.

- 15:38:49 I don't know why people are so keen to exit.
- 15:38:52 I would rather much rather see people have resources to live to the fullest.
- 15:39:00 Oh, H. Wages, for example, affordable housing food that people can actually afford to buy basic stuff like that.
- 15:39:13 People can actually afford to buy basic stuff like that rather than having wholesale exit.
- 15:39:17 Poll, that's my opinion.
- 15:39:23 Thanks, Nancy. Well, we've got more questions coming in, and more cost.
- 15:39:26 So, I'm gonna go to the most recent one.
- 15:39:31 How can we? How best can you lobby government as an ally to all of you? It's an action idea.
- 15:39:46 Anybody on the panel have any thoughts?
- 15:39:54 I don't think session easy answer was obviously, look at our advancements over the decades.
- 15:40:01 But I mean independent of made a mean. We have to deal on so many topics with governments, and it really changes.
- 15:40:10 Next one comes in and you're starting at 0 again right and the flavor of the months who was in who is out with what we cover.
- 15:40:19 I mean there's no consistency, I mean, like, otherwise we would have solved.
- 15:40:25 I mean, we know what it takes to employ disabled people it's not like we don't even have knowledge.
- 15:40:31 It's really an implementation issue. We know how a building should look like.
- 15:40:37 And so on, and we still built new buildings who are not accessible.
- 15:40:41 What? Because building code in the way it's witnessed water down so much that it's actually not accessible.
- 15:40:47 And so on. It's very hard and it's not one government, I mean, because it changes, and then I mean, do you deal with the middle management?
- 15:40:56 And how much do you get really through the top and to the top?
- 15:41:01 100. But if it changes every 4 years or so, or in between even you're starting all over again because the literacy is just not there.
- 15:41:11 The political will depends on so many amendments. I mean different factors.
- 15:41:15 There is no easy answer. Oh, I MAiD invite I mean strategy.

15:41:21 I think.

15:41:29 So we've got 20 min left or so. Yeah, Diane.

15:41:33 Just briefly, I think the only way to get at this issue right now is through the courts, and what I think needs to happen is that a court challenge needs to be made to the current made legislation phase 2 and I have heard rumors that there are folks who are

15:41:54 preparing that I think that within our system, as Gregor was saying, Yeah, our governments change.

15:42:00 I think the only way that we can fight back now is through the courts, because we also had people at the parliamentary hearings on on MAiD, disabled people from our organizations, and they felt very much discounted and heckled by members of parliament who weren't

15:42:21 taking them seriously.

15:42:23 Thanks, Diane, here's like.

15:42:30 I just lost it.

15:42:34 It's got 6 up the up. So it's common issue for people.

15:42:39 Comment? Isn't every life inherently both equal, unequal?

15:42:44 Hi am black, and the parent of an adult son. Born in 1982, is Down Syndrome.

15:42:50 The genetics is to confirm his diagnosis, remind us, reminded us, as parents, that our son inherited all of our genetic doctors, told us our son would not walk pop, ride a bike, or throw a ball.

15:43:04 He walk within the quote, Norm began expressive language quite early, excelled in Eq.

15:43:12 Not sure what that means. And was fully toilet, trained by 3, and is now employed as a self and as a self advocate, has started his own DJ.

15:43:22 Business. It breaks my heart to know he and others are considered discardable when we all believe in saving all lives and decide to work as one volunteer.

15:43:33 To this end things will never change for any of us. Let's join forces and honor all life without exception.

15:43:42 Well said.

15:43:45 So, I'm just looking for the next popular comment. Here's one.

15:43:52 I'm a social worker working towards my BSW.

15:43:55 At the University of Manitoba. I appreciate this panel, and your time and opinion.

15:44:00 My question is, what would you need, and like to see from emerging social workers in this profession?

15:44:07 So what can social workers do about our issue of today?

15:44:20 Yes, I think in general, social workers need to listen to people with disabilities, and that has been an issue between the social workers and people with disabilities for many years, and still is for some people whose services are are worked out with social workers and the social worker has control over the gig whether they get it or

15:44:47 not right, so I think the most important thing is, listen to the people with lived experience, and I don't know if social work does talk about disability and disability rights or not at university.

15:45:02 Manitoba, but we encourage social work students to take an elective with us in disability studies at university, in Manitoba.

15:45:12 We can then unpack models and have a real good look at what the role of social workers and experts have been.

15:45:21 We don't want to just say all of you are mad.

15:45:26 We. We need to work with you. You have access to resources.

15:45:30 You have access to to credibility. Right? And we need you to work with us.

15:45:37 That is the most important thing to remember.

15:45:41 Nancy, can you give that over Steve Gregor? Want to speak?

15:45:45 Just noticing it's we've got 15 min left, and lots of questions to go.

15:45:50 I'll make this really quick, well informed allies are priceless.

15:45:50 That's very brief, very quick. Here's our next question in popularity terms, is the topic of killing people with disabilities really solely a disability rights question.

15:46:08 Isn't there room for the larger question of creating a society in which it is easier for us to care for one another, especially when we are vulnerable?

15:46:17 MAiD has no place in such a society, whether people want it or not, so I'll just leave that.

15:46:24 It doesn't matter. I just like to make sure that all the questions get and the comments get on our recording.

15:46:33 I think Gregor wanted to say something.

15:46:35 Okay. Gregor, yeah.

15:46:37 Social work. I think I have to. I mean, one has to really audit the curriculum and and the material.

15:46:44 A lot of them is still very medicalized. I mean, there's a reason why, in many universities the mainstream is clinical social work which comes from a totally different premise than the community building social work alright.

15:47:00 So even with stream. You are, you all get totally different content.

15:47:04 Very likely, and I mean social work has, like occupational therapy.

15:47:10 They have beautiful language. Right? When you really look at it, that beautiful social justice, language, even occupation, ____ talks about occupational rights, occupational oppression, occupational apartheid, beautiful language.

15:47:25 But the language never makes it to actually in this implementation there seems to be something lost in translation.

15:47:31 What I mean. They don't apply the language they have for disabled people.

15:47:37 And that wouldn't. I mean, it's just a man.

15:47:40 So a lot of issues around impact on the social of marginalized groups.

15:47:46 Social work, just doesn't teach it like science and technology.

15:47:49 I mean. So the curriculum is simply not up to snuff on the new things.

15:47:55 Ecosocial work does not cover disabled people within environmental activism and impact of right environmental demands and environment activism.

15:48:05 Right. So the future has to modernize. And really, I mean the disabled, or whatever you want to call these terms right?

15:48:14 I mean around disabled people, away from the medical and.

15:48:19 Thanks. Gregor, we still have 12 questions to go.

15:48:24 Is everybody on the panel willing to stay in a bit longer, and including Sherry?

15:48:28 I have to go to another one. I'm already 40 min.

15:48:31 I mean intuitive where I have to. Other one had to go, so I have to see the second half.

15:48:34 Okay, so, Maybe what I'll do is read out the the comments, and then we'll we'll I wanna get them all on the recording, at least.

15:48:45 And there'll be things for people to think about so here's another one.

15:48:48 I'm appalled that in the Truchon decision, according to Dr.

15:48:52 Trudo, Dr. Lemons that our concerns were dismissed by lawyers as quote value laden, how can our disability justice, concerns, be truly heard when an illegal setting unbelievably they are dismissed?

- 15:49:05 So effectively, I think, with the general public is ignorant of our concerns, and subscribes to deeply ablest assumptions, that, like with disability.
- 15:49:14 So the politicians just support the status quo.
- 15:49:17 Probably all agree with that panelist. So let's yeah, we sure have make sure everybody gets heard.
- 15:49:24 I wanna make sure that everything gets heard and has their question.
- 15:49:30 Disability. Justice is also anti-capitalist.
- 15:49:34 Ableism is one of the foundational pillars of capitalism.
- 15:49:39 Great comment.
- 15:49:41 I have a comment on how to mirror our situation with able-bodied people.
- 15:49:46 That's a great Hi, guys, I think it May be a question.
- 15:49:52 So we'll hang on to that for a bit. So we get through the comments.
- 15:49:56 How are we training psychologists and counselors to work with people with disabilities to find value in life?
- 15:50:02 Versus choosing. MAiD I have counseled a few people who have moved from MAiD to living?
- 15:50:09 I am a therapist with a disability and I'm mentored by a British disability rights activist.
- 15:50:16 Let's see how we do hold that one since that's a question.
- 15:50:18 There's another comment. It seems that gatekeeping resources towards the quote, difficult to think of unquote, and that quote too expensive, unquote toward death as a logical option.
- 15:50:32 When those gatekeepers then find themselves on the wrong side of these categories.
- 15:50:37 I wonder how their ideas would change great, great point.
- 15:50:44 Next one comment from Joe Masarelli, from Massachusetts.
- 15:50:50 Evaluation is real people with disabilities have had and do experience gross and grievous disregard of their rights.
- 15:50:58 In a autonomy by society. Having said this, made another death. Dealing policies use personal autonomy and choice-making as a major go-to argument. Whenever we defend the quote right of anyone to kill themselves, we enter the idiom of the enemy another great point.
- 15:51:18 For the panel. So we'll keep this question for later.
- 15:51:24 How are we training psychologists and counselors to work with people with disabilities, define value in life versus choosing? MAiD.

- 15:51:31 Oh, sorry! I've already been. Let's see.
- 15:51:34 Besides Ableism, do you recognize the toxic effects of disability, phobia?
- 15:51:40 Good new work, which is like homophobia, not disabled.
- 15:51:45 That is not yet disabled are prepared to kill those they are afraid of, or allow them to die.
- 15:51:52 Another excellent point.
- 15:51:57 Canada. Also brags about organ donation as a benefit of MAiD, hey, Paul?
- 15:52:03 I think that might be intrusive presentation.
- 15:52:07 Thank you for your comments. My master's thesis is looking at the institutionalizing, and perhaps the event of abolition, of long-term care.
- 15:52:17 So that is very helpful. I'm very glad to hear that that's my end.
- 15:52:21 One of my activist and research activities as well.
- 15:52:27 Here's a comment, dying with dignity.
- 15:52:31 Canada is focusing on making sure advanced requests are approved in Parliament, on or by June fifteenth this year, every since disability dying with dignity, Canada has collected recently.
- 15:52:44 It's being used on a yet unknown flurry of marketing.
- 15:52:49 To get advanced. Request approved. That's very good information.
- 15:52:54 Thank you for telling us that full disclosure. I am a Roman Catholic pro lifer.
- 15:53:00 The Canadian Association of made Assessors is not objected in that its members are pro-made.
- 15:53:07 To begin with, like my colleagues, sign off as the second MD.
- 15:53:12 Or nurse practitioner often without seeing or even speaking to the athletes as a pro-lifer, whose driving principle is that every life is valuable, worthy of respect and protection.
- 15:53:25 It seems to me we are not at all at odds with.
- 15:53:28 Disabled at this good see. Groups, excellent Conference.
- 15:53:34 Thank you very much.
- 15:53:38 One person comments is, then develop, decolonize great points, another one says, with 3 uploads, Eq.
- 15:53:49 Equals emotional intelligence also known as emotional, closing. Thank you for that point.

- 15:53:57 Here's a one that's been upvoted 4 times.
- 15:54:00 I live in the US. The discussion around cost quote savings as an argument.
- 15:54:06 In my opinion, really unmasks the underlying valuation of life with a disability in my experience of advocacy with legislators on services for people with disabilities we are in constant needing to explain that what is viewed as savings is actually just the stolen cost frequently
- 15:54:25 imposing, more suffering and pain along the way. Thank you very much for that comment.
- 15:54:31 I'm just okay. Oh, that was good bye, Gregor.
- 15:54:37 I wasn't reading the chat to catch up with it.
- 15:54:40 Thank you very much. There's someone we've heard from before.
- 15:54:45 ARCH disability law and a consortium of others have launched a challenge with the UN.
- 15:54:51 Under the UN. Convention on the Rights of Persons, with Disabilities interested folks can watch this excellent webinar about how the expansion of MAiD only applies to disabled people in Canada.
- 15:55:04 A really important point, and then the person gives the how to reach this information that she's.
- 15:55:12 Referring to?
- 15:55:18 What we've got so.
- 15:55:20 That's a question.
- 15:55:26 Trying to run through all the comments.
- 15:55:31 Too many social workers divide folks into the keepers and the kept.
- 15:55:36 The do-gooders, and they've done grassroots.
- 15:55:39 Organizers align with the kept and done to seeking disability, justice, creative access, freedom, empowerment.
- 15:55:47 Thanks very much.
- 15:55:50 Another person writes, I happily use the research of Dr.
- 15:55:54 Hansen and Dr. Driedger. In my Social Work Classes.
- 15:55:57 I hear your point, Dr. ____. We'll pass that on to brother.
- 15:56:03 Sadly. I, Iceland claims to have wiped out in quotes Down Syndrome.
- 15:56:09 Where is the outcry? Very good point, and that's in the center.

15:56:15 There's a video on the subject so now I'm gonna go back to the top for a bit of slip, or Maybe we can last.

15:56:24 Can we go a little longer? That okay? With Sherry and Diane?

15:56:27 No, not financing. Okay. So how are we training psychologists and counselors to work with people with disabilities to find value in life versus cos in MAiD I counselled a few people who have moved from MAiD to living.

15:56:40 I'm a therapist with a disability, and I'm mentored by a British disability rights activist.

15:56:46 Anybody wanna answer that quickly, Diane? What comments?

15:56:48 Yeah, I think the answer is in the question. The ask her here was mentored by someone in the disability rights movement to see the value of digitalability and diversity around this building.

15:57:04 And I would encourage people with disabilities to join organizations of people with disabilities, whether those be arts, organizations, or organizations that are looking to change legislation, or even peer counseling groups where folks can talk about how life is the greatest you know the greatest support is

15:57:30 the person with disability. Who knows what it's like to live life with a disability, and I know for myself, I haven't always had a disability.

15:57:40 I started out as a non-disabled ally 40 years ago, and then 10 years into working as an ally.

15:57:47 I acquired disability, and the reason why I could see Hope see a live was because I had incredible mentors within the worldwide disability rights movement, who show how it's done, how we as humans can adapt we are creative.

15:58:11 And we can have good lives that are are worth a lot.

15:58:17 They are of value. People need to talk to other disabled people. It's great that you're counseling. As I disabled person.

15:58:26 Great I was still have a few things to go. How much to go over the street!

15:58:33 It's 2 min to the end of our webinar today. Today.

15:58:38 So some of the questions are administrative. Oh, the person you were just answering the question for.

15:58:44 Although I'll pass that on, and then and.

15:58:51 And what we send out after the webinar. So Maybe, Nancy, if you have any last a 1 min, wrap up, and then I'll wrap up the webinar.

15:58:59 I just think it's great to have this opportunity for the discussion.

15:59:04 And hopefully, this is the beginning and not the end. And just expect disability and understand the disabilities. Cool.

15:59:14 Right on. Thanks very much for that, Nancy.

15:59:21 So I this webinar far exceeded my hopes and expectations for organizing it.

15:59:31 We had such wonderful input from the audience, and lots of terrific discussion.

15:59:36 And there's still a few things to for us to include in our the report that we send out after the webinar.

15:59:47 Somebody was asking, Can you send us the And Transcript?

15:59:50 We're going, we'll think about that.

15:59:53 Thank you very much for the question, and we're going to send a report anyways.

16:00:00 So on your screen you'll see.

16:00:10 The contact and all the information needs for contacting the Canadian Sociological Association.

16:00:17 Thank you so much to the CSA. For sponsoring this webinar, and particularly to Sherry fox we're doing all the technical support.

16:00:25 And supporting us through it and helping me organize the webinar.

16:00:30 Thank you to our panelists. Nancy and Dianne who's had to skip out because he's got another meeting and thank you to all the audience members.

16:00:41 I'm thrilled that so many people attended, and so many people wrote comments.

16:00:46 And I hope, but, as Nancy says, we can start collaborating in some way and get some action going to circulating the material that you contributed, and the recording of the webinar and shoot those recording.