Episode 7: MAiD

Transcript

This episode contains explicit discussion of medical abuse, suicide, and death. Please, take care of yourselves and each other.

> **Sarah Jama:**
> The last time I spoke in the senate about MAID, The arguments I posed, along with Naheed Dosani, Gabrielle Peters, and many others were that disabled people who were suffering because of systemic failures due to systemic ableism would be negatively impacted by this expansion.
>
> People who were living in abject poverty, or who were scared to enter our horrendous Long Term Care institutions, or who were on waitlists for treatments, or who couldn't see a reason for living because of a lack of accessible, affordable housing, would use this expanded MAiD as their only option.
>
> Elected officials you all gaslit us for months, stating that it was impossible for people to use MAiD in these ways, due to safeguards.

Hey, my name is Megan Linton and this is Invisible Institutions, a podcast about the ongoing institutionalization of people labelled with intellectual and developmental disabilities across Canada.

> **Sarah Jama**
> The right of an individual's needs should not supersede the harms faced by others. Thank you.

In 2016, the Canadian federal government passed legislation to allow access to physician assisted dying at the end of life. This is what is called **track 1 MAiD. And it** meant that people at the end of their lives would be able to access comfort care. In general, the disability community is very supportive of this! And it's **not** what we're talking about today.

Instead, we are talking about what is called **track 2 medical assistance in death**. This is **not** end of life care. **Track 2 changes** are specifically for people with disabilities **who are not** close to death, who are not at the end of their life. As a part of track 2 changes, people labelled with intellectual or developmental disabilities are technically eligible to access death. Recently, this was expanded even further to include people with mental illness.

These changes expand access to death at a time in Canada, where people with disabilities are rarely given access to LIFE.

At the top you heard Sarah Jama. She's the co-founder of the Disability Justice Network of Ontario, an organization working to create a just and accessible Ontario where people with disabilities are free to be. Sarah lays out the context of disabled life in Canada for the Special Joint Committee on Medical Assistance in Dying, and the impacts of the expansion of medical assistance in dying

> It's important to note that last week, the Canadian Human Rights Commission, in response to reports that disabled people are in fact, like we said earlier last year, using MAiD to escape systemic failures, they said: "Medical Assistance in Dying cannot be a default for Canada's failure to fulfill its human rights obligations."
>
> They said this because, this is what you have allowed, despite the warnings.

Sarah points to something important, something we've talked a lot about this season— the decision to maintain these institutions kills people labelled with intellectual and developmental disabilities. It's been 150 years, 150 years of disability confinement and institutionalization in Canada. So much of this century and a half can be characterized by institutional violence and death.

We don't know how many people these institutions have killed. But we do know it's a policy decision to maintain this system, to keep the institutions open.

> Across this country, disabled people are forced into Long Term Care facilities, where the conditions are so egregious and fraught with instances of physical, emotional, sexual abuse, lack of nutritionous food options, proper hygine practices. So much so that **we have normalized the death of 20,000 institutionalized disabled people from COVID-19**.

It's a policy decision to keep people with disabilities in chronic poverty and housing need.

> Across this country, social assistance rates further debilitate and harm disabled people by enforced poverty. Across this country, it can take years to access pain clinics, therapy, specialists, primary care practitioners and palliative care. And palliative care is so chronically underfunded that it's considered a privilege.

It is a decision to make institutions the default, to deny people with disabilities their fundamental rights.

> **How will you make amends for the lives that have been lost so far**, due to systemic coercion because of your decision to expand MAiD specifically for the disabled community?

> Due to your unwillingness to understand the adverse impacts of an expanded MAiD, more disabled people have died who would have been alive, since the last time I spoke to you.

This is the last episode of this season. And, **we need to have a hard conversation, a conversation about access to life, and death for labelled people subject to institutionalization.**

Through this season, we've uncovered the histories and the ongoing realities of institutions. That means we've talked a lot about violence, and death.

Travelling to Ontario's largest institutions, like the Rideau Regional Centre in Smiths Falls Ontario or wandering the thousands of unmarked graves at the Orillia. These deaths have been all come as a warning.

> **Alex reading Pierre Bertons:**
>
> **But Orillia's real problem is one of public neglect**. It is easier to appropriate funds for spectacular public projects such as highways and airports than for living space for tiny tots with clouded minds. Do not blame the present Department of Health for Orillia's condition. **Blame yourself**. Well, you have been told about Orillia.
>
> *You have been told, you have been shown.*

Driving through the flat plains to the Manitoba Developmental Centre. There, under the prairie sun I wept in the absence of headstones. **Every step, I grimaced as my feet connected with the ground, it's all a grave. I am walking on a grave.**

I laid down the wildflowers. I gripped the top of the memorial, right where the bird shit had accumulated. **What do we do with the weight of it all? Where do you put flowers down when it is all a grave?**

> *You have been told, you have been shown.*

We attend to these deaths together, in remembrance of all the people who have died in disability institutions in Canada.

> *(acoustic music) I met a man the other day, and this is what he had to say. He told me how things would have to change. Free the people, free their minds.*
>
> **We are having this vigil we are together to grieve our peers who died while living in Valley View.** This circle of people is our gift to our friends who hearts are with us right now. Forgive us because we do not like Valley View Center. Give us thank you for giving us a choice in life, that we can be here and help those that need our help and want our

> help. Thank you for all the people that gathered around around me and around the rest of us as we say goodbye to our loved ones.

Institutions kill people. And this is imperative to recognize, particularly in the context of death and access to life.

Like the more than 20,000 disabled people have died in institutions from COVID-19.

And that number doesn't count those who died from the conditions within the institutions— those who died to escape the institution. That number doesn't include Chris Gladders.

Chris Gladders was a 35-year-old disabled father. He was moved from hospital to Greycliffe Manor, a for-profit retirement home in Niagara Falls here they didn't have the equipment needed to care for him, the equipment needed to bathe him. Instead, he was isolated in his room, unable to shower, the room stained with feces and urine from rushed catheter changes.

But Chris didn't die from COVID. He died from the system that forces people with disabilities into institutions. Institutions that remove autonomy, and access to life. **His life ended from Medical Assistance in Dying, but I think it was the institution that killed him**.

Chris' death is not in isolation, it's among a pattern, among a history replete with the deadly tolls of institutions.

Here Jonathan Marchand was hospitalized with a severe case of pneumonia and given an emergency tracheotomy. During this, they offered him an uncomfortable life or a comfortable death,

> I am from Quebec, I am a senior network engineer in computer science, I am an activist and advocate for people with disabilities.
>
> I am appearing before you from what I consider my medical prison cell, a long-term care facility in Quebec.

He fought back. He fought back against this coercion. And here he is testifying in front of the senate.

> I oppose Bill C-7 because death with dignity doesn't exist without life with dignity.
>
> I am 44 years old, and just like Jean Truchon, I am forced to live here because there is no proper support to live in the community. In 2010, following a severe pneumonia I ended up in intensive care. I was given an emergency tracheotomy to help me breathe with the assistance of a ventilator.

Unable to speak, several doctors pressured me to accept euthenasia, comfort care as they called it, to end my life.

I never asked for this. I spent the next few weeks thinking and crying my eyes out. My life is really over? The thought had never crossed my mind—I was getting better. But losing control over my life, being completely dependent on others and becoming a burden to my loved ones was unbearable for me.

There are no support services to live outside of hospital. I had to choose between killing myself or living in hospital for the rest of my life. I was never offered the choice to continue my life at home with the required assistance.

I wasn't ready to abandon my partner, my family and my friends.

I signalled my refusal to be euthanized. I was prepared to do anything to get out of this medical hell. **But just like Jean Truchon, I was denied the home care support that I needed. I complained to the highest instances, i was told that it was a political issue.** As living in the community with the the necessary support is not a right in Canada. After 2.5 years in the hospital, I ended up in a long-term care facility. This place is a medical prison—you no longer have choice and control over your life—your love life is over, you can't live with a partner. Your private life? Forget it.

A record is kept on your every move. You are now a property of the government. Now it is managers, civil servants, nurses and others who will decide how you will live. You are too independent for their taste? They will break you.

You have to submit to their rules. You have to be a good, kind, obedient, grateful little cripple. I gave up, and sank into depression. I was ashamed to live in this ghetto, without humanity and freedom life no longer has any meaning. I regretted having refused euthenasia, I simply wanted to live with my partner, work, and have a normal social life.

I wanted to die. I was Jean Truchon.

I discovered that about 70% of people with severe disabilities live in institutions in Quebec, the others that claim to live at home often find themselves isolated.

Many have committed suicide, or have accepted euthenasia to a avoid suffering my fate. My disability is not the cause of my suffering, but rather the lack of adequate support for my disability and the discimination i endure everyday.

Disability is not the cause of Jonathan's suffering, no. its a political decision to keep the 70% of people with severe disabilities in Quebec invisiblized. A political decision to keep people with disabilities institutionalized.

Catherine Frazee is a poet, activist, and nature lover, her titles include being an Officer of the Order of Canada and professor emerita at Toronto Metropolitan University. She testified at a Senate committee as well last year.

> Some say that the suffering of a disabling medical condition is unlike other suffering, somehow more cruel than the overwhelming pain of any healthy, non-disabled person who turns to premature death by suicide. There is no evidence to support this.
>
> **Some say that the suffering of disability defies all hope, as it did, they claim, for Jean Truchon. But the deprivations of institutional life that choked out his will to live were not an inevitable consequence of disability.** Did we learn nothing from Archie Rolland's harrowing struggle, and his final cri de coeur, before his assisted death? "It's not the ALS that's killing me," he said.
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> Some say that the suffering of disabling conditions falls in the domain of medicine, but the agonizing quest of Sean Tagert teaches us otherwise. L**et's not forget he called the bureaucratic denials of needed care "a death sentence" just days before his assisted death.**
>
> ***[etherally]*** *You have been told, you have been shown.*

Last year, Medical Assistance in Dying or MAiD was amended to include all disabled people, regardless of proximity to death. See before that, until 2021, the only people who could die through MAiD were people with a foreseeable death.

These changes are sometimes referred to by our guests as Bill C-7, that's what it was called before it became law. These changes through Bill C-7 are important in terms of the protections of disability rights. Here's Catherine again….

> Universality is the bedrock of our health care commitments. Why then does Bill C-7 depart so radically, dropping the threshold for MAiD (Medical Assistance in Dying) for one group known to bear the trauma of suicide at catastrophic rates, but not for others who suffer and die before their time.
>
> What is it about disability that makes this okay? Why such breathless confidence that Bill C-7 will bring no harm to disability communities? **Honestly, I do not know.**

(etherally) You have been told, you have been shown.

The catastrophic rates of suicide amongst the community of people with disabilities are perhaps most evident in institutions.

We're going to hear from a few people to discuss these crises.

> **Welcome everyone to the disability filibuster.**

> **Today we are tackling a very difficult discussion, a discussion that has been too often swept under the carpet in the conversation about MAiD, and that is what goes on inside the walls of institutions.**
>
> **We know that institutions like prisons are very dangerous places, and in the era of expanding and ever normalizing MAiD practice, we are going to talk today about what is happening and who are the casualties.**
>
> My name is Aisha Bensileman. I go by the pronouns they/them I organize here around prison and policing and deportations. I would like to start by acknowledging that i am speaking to you today from the unceded and the unsurrendered territories of the Anishinabe algonquin nation.

Aisha is part of the Jail Accountability and Information Line for incarcerated people at the Ottawa Carleton Detention Centre.

> We have to remember that we live in in a settler colony under a regime that perpetuates like genocide and -that in itself is something that should not be acceptable to anybody walking on this land. It all comes back to apartheid regimes that are just killing off people and killing off the land you know.
>
> there is an increase of folks who are living with disabilities who are incarcerated these things they are statistics but we know them from lived experience that this is what it is that's how the state deals with disability. When i walk in the neighborhood around me, when i do time inside in jail who comes to jail? It'is our disabled kin, who are getting targeted by the police in different areas you know either at encampments or shelters or around areas where there is poor people and they push them through the revolving door of the prison uh of the prison you know and that's what happens you get out there is literally no support for you you go back in prison **the jail destroys your life.**

In many instances, prisons confine people labelled with intellectual or developmental disabilities who are living in housing insecurity, who are forced into homeless encampments. And in other instances, labelled people are incarcerated because there is no other place for them to go.

> I was just talking a disabled comrade who was like fighting very like hard inside you know against all the violence that he faced at the hand of the the prison system like for example not bringing him to appointments that he needs to for his health care staff the guards not willing to push his wheelchair..

And, this experience of incarceration is particularly damaging for labelled people. Because prisons, like long-term care institutions and hospitals, are sensory hell—fluorescent lighting, strong smells, constant noise. This can cause sensory overload in a lot of people, particularly those with developmental disabilities.

As a result, they are often responded to with solitary confinement, sometimes called administrative segregation. In solitary confinement, you are locked in a cell with no window. All alone, just a fluorescent light and a toilet, maybe.

And despite agreements to keep people with psychiatric and intellectual disabilities out of solitary confinement, **provinces keep failing people**. Solitary confinement has been condemned as torture,-as it causes increased risk of self-harm and suicidality

This happened to Joe, an adult with a developmental disability living in Ontario. Joe was being pushed between shelter and hospital, hospital back to shelter, and then back to the hospital again, where he was arrested and incarcerated. While he was incarcerated he struggled to gain access to developmental services and instead was placed in solitary confinement

Cause many people with disabilities, like Joe, many people with disabilities often experience layers of oppression that makes their experience of incarceration even more damaging. Among these layers is the disproportionate incarceration of Indigenous people labelled with developmental disabilities.

> After that, folks were literally getting killed by the state and that's what happens because in prison, it creates death and a lot of folks take take their lives you know take their lives when things get too much and when they can you know just like live you know when i don't know they just folks take their life a lot of times, **you know in prisons and uh there is no natural there is no natural death behind bars any death behind bars is not a natural death so like no one is** gonna come tell us that uh our kin who are dying in jail for various reasons because of the structural neglect from the health care systems.
>
> Because everything is linked like those like those austerity measures they affect people who are also um incarcerated you know what i mean like more so there's like the in the community there's no continuity of care between community and in prison you know like folks who come in with medication does stuff like get suspended or gets like um get suspended like the doctor just like suspends your medication that you have been taking for a long time you know what i mean so um yeah like uh they are dead like **jails are dead traps uh for our kin and they're being killed in there and we can't just stay on the sideline and do nothing um but unfortunately like we're not able to**
>
> to do much because this continues to happen and on a regular basis and it must stop because **we cannot treat each other based on ableist ways because it's not going to work for all of us.**
>
> *You have been told, you have been shown.*

There's no natural death behind bars. Consistently, institutions push **people with disabilities towards death towards suicide**. Whether that be through solitary confinement, or denying medical care or coercing people towards medically assistance in dying.

This coercion in death is the subject of recent research by Peter Driftmier and Jessica Shaw at the University of Calgary. Their research looks at the specific experience of Medical Assistance in Dying (MAiD) in Canadian Prisons. It demonstrates the challenges and dangers of expanding medical assistance in death, because of that very reason— prisons kill people.

Their research goes through a few different stories of medical assistance in death behind bars. Among these stories was the story of **Matthew who spoke about a doctor he saw after he was diagnosed with cancer..**:

> "you've been here a long time, you've been a drug addict for a long time." He said, "you don't have much of a future," he says, "tell you what: why don't you just let nature take its course? And I'll keep you happy, I'll keep you comfortable"… He said "I'll keep you comfortable." I said, "what, you want me to give in on this?" (from Driftmier & Shaw, 2020)

I think about the innumerous suicides at institutions that we've have talked about through this season. David Weremy, shares a bit more about this:

> **Megan! One boy hung himself**
> One boy hung himself at MDC, where was that?
>
> In the kitchen.
>
> **That room had to be locked at all times. But somebody forgot to lock the door that day.**
> That room had to be locked at all time, but somebody forgot to lock the door and a boy hung himself

There's no natural death behind bars.

> **Joyce Gibbins, she climbed up the water tower and threw herself off of it, 150 ft.**
> Joyce Gibbins, she climbed up the water tower and threw herself off of it, 150 ft and many many people who were at MDC watched

These deaths in institutions are often labelled suicides. But I don't think Joyce or Chris died by suicide. No, it was the institution that killed them.

> *You have been told, you have been shown.*

An important piece about the changes to Medical Assistance in Dying Legislation, is that our current state of affairs is systematically failing people with disabilities.

And COVID-19 aggravated this reality, with a backlog of more than 700,000 surgeries, extended waitlists for home care, affordable and accessible housing with more than 100,00 people labelled with intellectual or developmental disability in acute housing need.

> Across this country, there have been a REPORTED 3.4 million COVID cases, we are seeing a mass debilitation of the most marginalized Canadians, responding only with greater access to death.
>
> The low estimate is **300,000 Canadians** who are suffering from long COVID, who are now newcomers to the disabled community, and raised by an ableist society. **And what they're seeing as the response to their newfound impairments is the acceptance that to be disabled is a fate worse than death, that comes exactly from this committee**.
>
> What have you done to respond to the growing disabled population who don't have dementia? The population who aren't sure what this new life of debility, rampant ableism and perhaps unemployment means to them?

Addressing the causes of these forms of suffering have been promised across government's for fifty years. The first report that came out about disability in the 1980s shows just how slow it's been. The report was called *Obstacles.* It outlined the hundreds of obstacles of disabled life in Canada, and presented tangible short-term and long-term solutions.

At the time, People First of Vancouver testified to the committee:

> "We wish to live the same as the other person and expect to have to do our part for society. Why should we have to keep proving that we have a place in society when the normal person knows they have. **We are all here for one reason or another; does this not mean that we should be treated as equals?** But are we now? I think not, for we are laughed at, made fun of, or worse—we are pitied for pity's sake and this is not what we want. We want to do our part to help society as a whole."

We are all here for one reason or another. Shouldn't we be equals? The government promised to attend to this. They promised:

> Many disabled adults, now institutionalized, would prefer to live independently, if they could be assured of community support. This support would involve special education, training and counselling needed to learn how to function independently. It would also cover attendant care, and assistance in securing housing and transportation

> **Long-Term:** The Department should now begin developing standards for long-term institutional care, with special emphasis on the following problems:
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> • **Legal Access:** At the present time, some individuals have no access to legal assistance. In many cases, disabled persons are not directly informed of the legal services that can be made available to them.
> • **Privacy:** Some institutions provide individuals with almost no privacy, and few provisions are made to protect personal property.
> • **Activities:** In most homes for special care, there are no activities whatsoever to keep disabled persons occupied during daytime hours.
> **Refusal:** Few disabled persons are aware of their rights within an institution. Institutions do not inform a person about his or her right to refuse a treatment.

And that was 40 YEARS ago. Just one item of the extremely lengthy itemized lists. I went through them, every item and it makes my head explode. So many things that would make people with disabilities life better, and there are so many detailed, tangible plans. But nothing, nothing at all.

Nowhere in the forty years of disability policy has there been a request for the **expansion of death**. It's always been about access to life, and they always take it.

> ***[etherally]*** *You have been told, you have been shown.*

But once there was a single request for expanded access to death, the government summoned their urgency. Urgency that we have never seen in the 40 years we have been requesting, fighting for life. So what's with the urgency?

A big part of this urgency is that Liberal politicians are very invested in expanding Medical Assistance in Dying Legislation.

Consider this: non-disabled people give the quality of life for people with disabilities as lower than we do. Sarah brough up a woman's desire to die with a champagne glass in her hand.

> You implied that the rights of people like Nicole Gladu, who testified that she wanted the choice to die with a champagne glass in her hand, was more important than the need to protect the folks that I spoke about who were being systematically coerced into using MAiD due to government failures.
>
> (Ms. Jama can you slow it down, the interpreters have to translate, so just speak a little bit slower)
>
> You implied that race and poverty had very little to do with freedom and choice. Nicole Gladu has since died naturally, not using MAiD, yet her testimony allowed for the death of Sophia, who shared in death that "The government sees me as expendable trash, a complainer, useless and a pain in the ass,".

there are a few more different easons…

I think that one of the reasons the government is invested in MAiD as a solution to the rapidly expanding population of people with disabilities both COVID and expansive long COVID cases, and the increasingly aging population.

It's cheaper for people with disabilities to be dead, than to help them when they are alive.

> And the death of Denise, who explained she “applied for MAiD essentially...because of abject poverty”. And these are two, among many others who used it only because the government funded access to death over their ability to have food, shelter, and a sustained life.

Here’s Natalia Hicks, Director of Community Justice and Health Equity at inclusion Canada. And she is going to give us a bit more context of medical assistance in dying legislation.

> So, Jean Truchon was institutionalized when he was bringing this case forward and he talked a lot to the court about how, how he, he was suffering and in the, the Truchon decision, there's a whole section of the decision that outlines what a typical day looked like for Mr. Truchon.
>
> So Jean Truchon was suffering in an institution and he showed up in court and said, “I'm suffering so badly that I think I'd like to die”.
>
> > “They come to give me my pills at 8:00 a.m. I eat breakfast around 9:00 a.m. I am given 15 minutes to digest. After that, I try to catch someone as they are going down the hall to lower the head of my bed and my feet too. After that, they roll me onto my side because it’s more comfortable for me and there’s less pain. Now it’s 11:00 a.m. They get me up, get me dressed, and put me in my armchair. At noon, they feed me. That’s my life, my poor, poor life.”
>
> And our court systems, we're like, you know what? You've got a point there. You should ~~be~~, be able to die because of your suffering. And I've heard it said, from within the disability rights community**, that really Jean Truchon should have been the Canary in the Coal Mine. We should have dropped everything and thought we need like, we're in crisis here, we need to do things differently.**

Jean Truchon should have been the canary in a coal mine. It should have been a moment for Canadian society to come together and recognize the persistence of institutions for people with disabilities. To recognize the violence of institutions.

Afterall, this is a person trying to **die because they are trapped.**

Trapped in an institution that kept him away from community, that reduced him to a point of efficiency, a practicality that robbed him of his humanity.

> And so for Jean Truchon to show up in court and outline the nature of his suffering, like that should have been alarming to us.

> But I think we, we didn't stop and pause and see this as a systemic issue, just like to put his suffering in context. And I think it's kind of alarming that this is a system wide issue where people with disabilities are being.. they're still being tucked away and institutionalized and their suffering still goes unseen.

And instead of a lifeline, a call to action, a reckoning, we killed him.

The invisibility of institutions is a really important piece of this. **People are protected from witnessing the violence of institutionalization, they are protected from the suffering**. They are protected because institutions are designed for hiding.

And Jean Truchon was suffering. He saw no life outside the institution. No future for him, him a person with a disability who requires support, just like all of us.

When Jean Truchon died in 2020, he said it was his freedom to choose.

But here's the thing, I think he should have been given the freedom of choice a long time ago. He should have been able to choose where he lives, to choose what time he wakes up, to choose what time and what he eats, to choose who is providing him care.

Why didn't we give him those options? Why didn't we give him those choices? instead, we gave him only two options: to choose between the institution or death. And I get why he chose death.

Catherine Frazee, troubles this idea of choice. She asks is this freedom?

> Some will fall back on the mantra of choice. They say that not everyone wants to live *that way*. But not everyone wants to live with the indignities of poverty either. No one wants to live under threat of racial or gendered or colonial violence. No one wants to live hungry, incarcerated, abject, or alone.
>
> Madam Chair, will our lawmakers carve out other shortcuts to assisted death for those who do live in such conditions, or will you rise to the defence of human rights? If the latter I respectfully urge that you start with us, for our equality is right now on the line. Thank you.

Choice, that's what we call it.

in an ongoing pandemic, we see abundantly that people with disabilities are deemed disposable. This is what Henry Giroux calls disposability politics. Which he defines is:

> "A politics in which the unproductive (the poor, weak and racially marginalized) are considered useless and therefore expendable; a politics in which entire populations are considered disposable, are consider unnecessary burdens on state coffers, and consigned to fend for themselves."

Disposability politics are most evident in crises. They are most evident when the death toll is counted

Here's Natalia Hicks again.

> I was introduced to like disability related discrimination in the healthcare system by looking at triage protocols from the SARS pandemic. So COVID hadn't hit yet. And I was learning that people with physical and intellectual disabilities would have been deprioritized for care during SARS.
>
> And then lo and behold, we're in the middle of, of this debate and like timing wise. Bill C-7 was tabled, I think in February, like at the end of February and the world shut down in March.
>
> So timeline wise, this was happening very much at the same time and much like what happened during the SARS pandemic. **We did see from different provinces across Canada, that again, people with physical and intellectual disabilities would have been deprioritized for ventilators, for life saving care for life support during the pandemic**. At the same time, we're actively seeing people with disabilities, like be deprioritized, factually deprioritized. There's also legislation that's passing that would make it okay for people to die if they're not approaching their natural death, but only if they have a disability or disabling medical condition. So there, I think there is a really clear connection there to like when looking to how we value people with disabilities and Canadian society.

Bill C-7 is enshrined in law, making an entire population deemed disposable

But we see this in other policies too. Like when we fail to protect congregate facilities during COVID-19, forcing people with disabilities into poverty, or pushing people with disabilities towards death.

People with disabilities are fighting back, refusing lifetimes in long-term care, fighting for futures filled with care and justice.

I think it's about time we make an irresistible disabled future. Here's Jonathan Marchand again:

> For ten years now I have been fighting to get out of here and retain my freedom. And a path for community living for everyone, because living in the community is a human right.
>
> As a last resort, I occupied space in a cage, in front of the national assembly in Quebec to protest my incarceration and community living solutions. **Why is it so hard to be seen and heard when we want to live? Suicide prevention is offered to people without disabilities, but I deserve assisted suicide. I have been told before that if I am not satisfied with what you are being offered, why not accept euthenasia?**

Alongside Jonathan Marchand, Sarah Jama, and Catherine Frazee, there are a lot of people fighting there are rich histories of disability dissent and disability resistance. People with disabilities have always been resisting institutionalization, no matter the cost.

I met Tyson in 2018, when he sat in a prison cell in Old Market Square, a popular tourist destination in WInnipeg. Tyson was there in protest, demonstrating how the provinces' care system locked him out of his own life.

> My name is Tyson Sylvester, I am 22. I put myself in a jail cell to show that the disability system and the way it is working right now is a jail cell.

> **Finally I would just like to add free our people exclamation point exclamation point exclamation point.**

Here's Natalia again,

> they made the discrimination. So, so tangible for the community. So concerns that otherwise might have been like someday in the future, this might happen, or people like some day discrimination or some day disability might be the reason that determines whether or not a person is eligible to die. They were, they used to be super hypothetical concerns. And then bill C seven was tabled.
>
> "And it was so obvious that it was discriminatory legislation and the community rallied in a really like beautiful and powerful way. So there was like a grassroots up swell of activists who were, were fighting back against the legislation. And there was much unity across like disability rights organizations in Canada. And then as kind of, as the debate unraveled, and as we looked at medical assistance and dying through, through different lenses and highlighted different facets of marginalization, even like groups and organizations outside the disability, like the traditional disability space started to get engaged. And to recognize that while this legislation might have go od intentions and might be responding to legitimate concerns that like this isn't the way forward.
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> And yeah, so, so people with disabilities themselves were speaking out, self advocates were speaking out organizations, representing people with disabilities were speaking out. There were lawyers and doctors speaking out on this issue. And then there were advocacy from, I wanna say from far off lands, but that were, that were, that were focused on, on different aspects of marginalization that kind of got involved in this too.
>
> So the allies were tuned in and it was, you might not have seen it from the outside because the, the pro assisted dying lobby is so loud that you might not have seen it. But seeing like from where I sat, it was actually like a really moving, coming together across

> the community. So definitely it definitely showed me what the disability rights community is capable of in 2020 and 2021.

Among the ground swell of disability activists was the Disability Filibuster.

> **Welcome everyone to Canada's spectacular uprising of disability resistance, to the proposition which now is entrenched in law. That disability somehow is an exception to the rule of equal dignity and equal rights.**

The disability filibuster is a place for people with disabilities who believe that we are entitled to live good lives. The disability filibuster began in 2021, in response to the efforts to amend legislation, it ran a live, continuous broadcast for almost 60 hours.

They explain their origin as:

> "A bold and perhaps unprecedented coalition of disability rights defenders and our allies had come together in opposition to this Bill, but we were being sidelined, stonewalled, patronized and betrayed at every turn."

The disability filibuster struggles, celebrate disability cultures and together do the hard work that solidarity and survival demand.

Here's Catherine again.

> If you are a filibuster newcomer, welcome aboard. I think all that you need to know about us for starters is that this is a crip space. **It is a space in which our unruly bodies and minds and our pain, our rage, our trauma, our art, our humour and our fierce pride and love for each other**. All of this is part of the package, and all of it is respected and embraced.
>
> This is a space for learning, reparations, for creativity and for mutual care. This is for building solidarity across every axis of oppression. And, it is a space at this time in Canadian history where we come together in defiant objection to the expansion of laws that authorize the killing of disabled people, and claim it to be a reasonable and compassionate response to our suffering.

The filibuster comes together in defiance, resistance, and joy. This coming together is how we keep going. How we build movements that celebrate the joys, wonders and diversity of disability.

A lot of people ask me how I deal with all these thick, devastating stories. Researching and living amongst institutions, institutionalization and the label of intellectual/developmental disabilities is hard, often soul crushing.

We've done a lot of counting bodies, tallying the wreckage that government refuses to even acknowledge, and exposing the realities of institutionalization that make it so difficult.

I think the only way to keep going is to organize, and to help each other. It's to find people who care about injustice and are willing to make a difference.

Maybe this means for you, talking to friends and family about institutions, or disability justice. Maybe it means helping a neighbour pick up groceries, or organizing your building to get an elevator!

There's a lot of fundraisers out there to support people who are struggling with access to what they need to survive. Donate! share them! Help them!

Because we all need to do a bit more dreaming. Dreaming of futures without institutions. Dreaming of the amazing possibilities of life when we look outside the institutions and into abundance of our communites.

I'm Megan Linton, thanks for joining me for this season of Invisible Institutions.

Please follow us on instagram, twitter, and stay tuned for the release of our newsletter the Institutional Remains, with extra bonus content!

I am so grateful for the work of Helena Krobath, sound designer and co-conspirator. Thank you to People First of Canada and Inclusion Canada's Joint task force on deinstitutionalization for their advisement, patience, and financial support.

We are an incredibly proud member of the Harbinger Media Network, and grateful for the support of the many wonderful shows over there. Check them out!

Invisible institutions was created by me, Megan Linton. With support and advisement from People First of Canada and Inclusion Canada's Joint Taskforce on Deinstitutionalization. Audio Recording by Megan Linton. Audio and sound design by the amazing Helena Krobath. And theme music by Bara Hladik, Bara's book is out now, you should order a copy.

And don't worry, we'll be back. Stay Safe.