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# Special Joint Committee on Medical Assistance in Dying

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Co-Chairs:  
The Honourable Marc GarneauThe Honourable Yonah Martin





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• (1945)

[English]

**The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)):** Good evening, everyone.

I am calling this meeting to order, hopefully before something else happens. I want to thank everyone who has been so patient this evening, waiting for this meeting to get going.

Welcome, everyone, to this meeting of the Special Joint Committee on Medical Assistance in Dying. I would like to begin by welcoming members of the committee, witnesses and those watching this meeting on the web.

I am the House of Commons joint chair of this committee, and I am joined by the Honourable Yonah Martin, the Senate's joint chair.

Today we continue our examination of the statutory review of the provisions of the Criminal Code relating to medical assistance in dying and their application.

As you know, we have certain sanitary measures in effect following the advice of the Board of Internal Economy, and I expect everyone to respect those rules this evening.

As a reminder, all comments should be addressed through the chair. If you have a point to make, you can use the “raise hand” feature. We provide translation in both official languages. You may choose the language of your choice.

The way we do things is to start off with the witnesses each giving a five-minute statement, after which we will proceed to a question period.

Tonight we have the pleasure of having, as individuals, Mr. Andrew Adams and Mr. Ghislain Leblond, former deputy minister. From the Disability Justice Network of Ontario, we have, in person this evening, Sarah Jama, executive director.

Welcome to all three of you. We look forward to hearing what you have to say. We will begin with opening remarks from Mr. Adams, followed by Mr. Leblond, followed by Ms. Jama.

Mr. Adams, the floor is yours. You have five minutes to make your initial presentation.

**Mr. Andrew Adams (As an Individual):** Thank you very much. It's a pleasure to be here.

I'm a person with a chronic illness and disabilities. I've had a condition that causes deep abdominal spasms, along with other terrible symptoms, for a very long time. I often experience intense,

long-lasting episodes that remind me of being poisoned. I sometimes say I have seasons of pain, as an episode can last for a few months at a time. I have lived in British Columbia all my life and feel very much shaped by open-minded west coast values. Therefore, I support access to choice.

As the law changed in Canada to more closely reflect the Carter decision, I decided to apply for an assisted-dying assessment. The new law, Bill C-7, made it legal for people like me, for whom death is not reasonably foreseeable, to have the possibility of MAID. Putting suffering at the core of the law shows great compassion and humanity. The ability of each of us to say, “Enough is enough”, when suffering becomes too much, is an essential liberty.

The dysfunction of my body has often felt like a prison. In applying for and being approved for MAID, I have taken responsibility for myself. I feel less worry, and a sense of overall relief permeates my days. I don't feel the need to use this choice right now, but I am very happy it is there. The steady worsening of my condition has reduced my capacity to function in my daily living activities and lowered the quality of my life.

No amount of mitigating these painful abdominal episodes has alleviated my predicament. I feel that I now have more of the tools needed to face the long-lasting difficulties ahead of me. I am enormously proud of my fellow citizens. Thank you for allowing this option to exist in Canada for people, like me, who suffer continuously in life.

I have had no say in deciding whether my body would trap me in intolerable suffering. I have coped with the cards I was dealt. Knowing I can access a safe and serene exit from my suffering is like reflecting upon some beautiful poetry. Suddenly, there's a rhyme and reason to my everyday. I feel a new sense of acceptance in dealing with my daily challenges—an added emotional benefit this medical care has provided me.

We all want to feel a sense of security in this world. MAID, as an option, has provided that sense of security to me. I feel the reduced stress and increased peace of mind have allowed me to better cope with my limitations. As a result, I tend to have an anxious attachment to this choice and I'm skeptical about calls to impose increased barriers. People with disabilities must not be treated as a monolith, but rather as individuals. The fear some individuals may have of MAID should have no negative impact on access to choice. I am my own person and do not want to be grouped together with others.

That said, when discussing protections for persons with disabilities, I have a few suggestions for policy improvements.

First, use some form of means testing that includes assessing whether the person has housing and supports from family or service agencies, etc., before approval is granted.

Second, allow voluntary self-exclusion for those who want to opt out of MAID. The individual could choose a fixed amount of time to have this exclusion in place and could renew it as needed or desired. I came about this idea because I know that, at casinos and similar establishments, people can have a self-exclusion and just don't have any access to that particular activity.

Third, quickly implement the Canada disability benefit to reduce poverty.

Overall, I hope to see continued balance between patient access and reasonable safeguards. That has to be maintained.

Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Mr. Adams, for that personal testimony.

We'll now go to our second witness.

[*Translation*]

Go ahead, Mr. Leblond. You have five minutes.

• (1950)

**Mr. Ghislain Leblond (Former Deputy Minister, As an Individual):** Thank you, Mr. Chair.

Good evening, everyone.

My name is Ghislain Leblond, and I am 77 years old. I had the opportunity to spend most of my career in the public service, including as associate deputy minister in Ottawa and as deputy minister in Quebec City.

I had to retire at the age of 48 because I have a degenerative neuromuscular disease that paralyzes me. I have been in a wheelchair for 20 years, so you'll understand that tonight's discussion is of great interest to me.

I have also been a very active participant in the process that led to the adoption in Quebec of the Act respecting end-of-life care, including medical assistance in dying.

Given my situation, I am a potential candidate for MAID.

Thank you for having me.

[*English*]

Most importantly, I want to thank you for the work you're doing.

[*Translation*]

You are honouring your duty as members of Parliament and senators by tackling an issue as important as medical assistance in dying.

You're facing problems that aren't always easy to solve. Thank you for tackling the challenge.

[*English*]

You're a lucky bunch of people, because it's not given to everybody to have the opportunity to make decisions that will improve the lives of thousands of people, thousands of our fellow citizens, our fellow Canadians.

[*Translation*]

One of the things I'm interested in is the idea that people with physical disabilities need greater safeguards than the rest of the population. This is an idea that is floating around. I would like to talk to you about it in the discussion that will follow.

Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much for your testimony as an individual, Mr. Leblond.

I'll now give the floor to our third witness.

[*English*]

Ms. Sarah Jama, we go over to you for your opening statements. You have five minutes.

**Mrs. Sarah Jama (Executive Director, Disability Justice Network of Ontario):** Thank you.

The last time I spoke in front of the Senate about MAID, the arguments that I, along with Dr. Naheed Dosani, Gabrielle Peters and many others, posed were that disabled people who were suffering because of systemic failures due to systemic ableism would be negatively impacted by this expansion.

People who are living in abject poverty, who are scared to enter our horrendous long-term care institutions, who were on wait-lists for treatments or who couldn't see a reason for living because of the lack of accessible affordable housing would use this expanded MAID as their only option. I spoke about Chris Gladders the last time I was here, a man from Hamilton, Ontario, who used MAID because he was left sitting in his feces and urine for days at his long-term care home.

Elected officials, you gaslit us for months stating that it was impossible for people to use MAID in these ways due to safeguards. 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 folks I spoke about who were being systemically coerced into—

• (1955)

**The Joint Chair (Hon. Marc Garneau):** Ms. Jama, could you slow it down, please? The interpreters have to translate your remarks, so speak a bit more slowly.

**Ms. Sarah Jama:** Yes.

[Translation]

**Mr. Luc Thériault (Montcalm, BQ):** Mr. Chair, since you interrupted the witness, I'd like to take the opportunity to ask her to speak a little quieter, as well; otherwise we can't hear the simultaneous interpretation properly when we are in the room.

Thank you.

[English]

**The Joint Chair (Hon. Marc Garneau):** Could you speak at a slightly lower volume as well? The translation is going into some people's ears and they're hearing your English, because you're so close to them. You can speak more slowly and perhaps lower the volume a little bit.

Perhaps the technicians can lower...if there's anything they can do.

**Ms. Sarah Jama:** I'm a very loud person. I apologize.

**The Joint Chair (Hon. Marc Garneau):** No problem. It's a loud subject.

**Ms. Sarah Jama:** Can I start?

**The Joint Chair (Hon. Marc Garneau):** Yes, please.

**Ms. Sarah Jama:** 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's also the death of Denise, who explained that she applied for MAID essentially because of abject poverty. 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.

Due to your unwillingness to understand the adverse impacts of an expanded MAID, more disabled people have died since the last time I spoke to you, who would otherwise have been alive. Across this country, social assistance rates further debilitate and harm disabled people through enforced poverty. Across this country, it can take years to access pain clinics, therapy, specialists, primary care practitioners and palliative care. Palliative care is so chronically underfunded that it's considered a privilege.

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 and sexual abuse, and a lack of nutritious food options and proper hygiene practices. There is so much that we have normalized the death of 20,000 institutionalized disabled people from COVID-19. 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. What they are seeing as the response to their newfound impairments is the acceptance that to be disabled is a fate worse than death. That comes directly from this committee.

What have you done to respond to the growing disabled population who don't have dementia, the population who isn't sure what this new life of debility, ableism and, perhaps, unemployment means to them?

On the question of advance directives, we must acknowledge that people can and will often change their minds, even after consenting to MAID. It is ableist to assume that people would be 100% unwilling to live in bodies that are deemed as less functioning. True choice is the ability to change your mind. It is also worth noting that dementia is one disability that has been brought up often by this committee in this conversation on advance directives, and this disability impacts Black people disproportionately, yet this voice has been left out.

On the question of mature minors, we must remember that mental illness and suicidality are at an all-time high for youth across Canada, and they disproportionately impact disabled youth. It takes time to address, especially as a young person, a disabled life and research it. Until we are sure that have measures that prevent the implicit coercion of youth due to pressures such as bullying, shelter, poverty rates and a lack of access to resources, I recommend that you limit any conversation of MAID with children, especially in relation to track two.

Lastly, 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 last year—using MAID to escape systemic failures, said that 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.

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 to the disabled community?

The right of an individual's needs should not supersede the harms faced by others.

Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much, Ms. Jama.

That concludes the opening statements.

We'll now go to the question period, and I will hand it over to my co-chair, Senator Yonah Martin.

**The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)):** Thank you.

Thank you to all of the witnesses for your testimony.

We'll begin the first round with five minutes of questions and answers with Mr. Barrett.

• (2000)

**Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC):** Thank you, Madam Joint Chair.

Thank you to the witnesses for your testimony and for giving us your time and experience this evening.

My first question will be directed through the joint chair to you, Ms. Jama. You talked about having appeared before the committee and having personally spoken to senators and members.

Do you feel that disabled Canadians have been adequately consulted about MAID legislation?

**Ms. Sarah Jama:** Absolutely not. In this panel alone, of four representatives, two are from Dying With Dignity. Why am I the only representative from a disability-based org? Why is this the only day that we talk about disability rights when it impacts all of the sections that I have talked about. This shows that we are being left out on this committee and we have been left out systemically this entire time and throughout this process.

On top of that, the brief process of submitting only a thousand words leaves out disabled people who can't submit their thoughts in a written format, who don't have access to Internet or who would prefer to communicate using video. We asked this committee in writing what we could do to include other disabled people and we got no response.

This committee has shown no desire to reach out to disabled people, other than the people who are afraid of dying, but not people who are living with disabilities. It's a shame and it's been like that this entire time.

**Mr. Michael Barrett:** Thank you, Ma'am.

Again, I'd like to follow up on one of the comments you made in your opening remarks. You made the contention that the MAID framework is ableist in nature and I'd like to ask you why. Perhaps you can expand on that for me, please.

**Ms. Sarah Jama:** This is not a new understanding that has come from the disability community. Over 200 organizations this entire time have spoken about the fact that this is ableist. We expanded MAID specifically to people who are living with disabilities and who are seen as suffering. Many of us struggle day to day, but that doesn't mean that my needs should be met by simply being offered death. I'm terrified, as someone with mental health and physical disabilities, to enter a doctor's office. I'm terrified that I will be offered MAID as a form of treatment, when I already deal with suicidality.

You're not listening to those who are already living with disabilities. You're predominantly hearing from people who are afraid to be disabled in the future. Those two things are not the same. Disabled people have already died because of those decisions. We can't lose another single life of somebody who should have been fed or housed or offered therapy. It's not enough to say these things will come later because we already know that 200 people who were not terminally ill have died. Many were people whose needs were not being met elsewhere.

We can't allow other people to continue to die.

**Mr. Michael Barrett:** Thank you.

Again, through the joint chair to Ms. Jama, why do issues of race and poverty matter in this conversation, in your opinion?

**Ms. Sarah Jama:** Like I mentioned earlier, you guys spend a lot of time talking about dementia, but dementia disproportionately impacts Black and racialized people who are caregivers and who are staying at home supporting families. You've not heard from Black people living in that situation. Black people are less likely to send family members into long-term care institutions because of how volatile those are, with mistreatment and racism there, too.

Black people who are experiencing medical ableism and medical racism are already worried about being coerced into their treatment plan. For me, even the concept of rejecting surgeries was very difficult for me when I was a young person.

When you already feel that you're being treated differently or you're being othered because of your race—and we already know that a lot of data says that Black people are mistreated and treated differently when they enter a hospital—and you add that into the conversation around MAID, will Black people be pushed into accessing MAID versus other treatments that should be available? I think yes. I don't think we've done enough research to be sure that Black people won't be disproportionately affected.

Throughout COVID, Black people have been predominantly affected and have comorbidities, so we're not sure how this will impact the most marginalized in our communities, but the voices that you have been listening to are predominantly white. That scares me.

**Mr. Michael Barrett:** I have just a quick question, through you, Madam Joint Chair—

**The Joint Chair (Hon. Yonah Martin):** Yes, be very quick. You have about 20 seconds.

**Mr. Michael Barrett:** With respect to people being vulnerable to accessing MAID before having accessed other options, do you believe that is true as well for the disabled community as you've said it is true for racialized or Black Canadians?

• (2005)

**Ms. Sarah Jama:** I believe it to be the same for disabled people. I think that disabled people are often experiencing medical ableism. We've had many people online talk about doctors who don't listen to them or who don't provide proper supports. We've had people who are afraid to enter a long-term care systems because they fear mistreatment in long-term care, too. That's been documented.

Many people are more vulnerable, particularly if they're disabled, to accessing MAID versus other treatments.

**The Joint Chair (Hon. Yonah Martin):** Thank you, Ms. Jama.

Next we'll have five minutes from Mr. Maloney.

**Mr. James Maloney (Etobicoke—Lakeshore, Lib.):** Thank you, Madam Joint Chair.

I want to thank all three witnesses not only for being here tonight, but for displaying the patience that you have. We're starting very late tonight. As Ms. Jama said, time is of the essence. We need to dedicate ourselves to the issue at hand. Sometimes that is delayed by procedural—I will use the word—nonsense in the House of Commons and tonight was an example of that. You have my apologies on behalf of the committee.

My first question is for Mr. Adams.

Thank you, sir, for being here tonight. You indicated that you had applied for MAID and that you'd been approved.

Is that correct, sir?

**Mr. Andrew Adams:** That is correct.

**Mr. James Maloney:** Did you apply for MAID after Bill C-14 was passed or did you apply only after C-7 came into force?

**Mr. Andrew Adams:** I had initially applied when C-14 had passed.

**Mr. James Maloney:** Thank you.

Lived experiences are important for all of us on this committee for the reasons we've heard. I'm wondering if you would be willing to sort of take us through the process you went through after C-14 and after C-7, so we have a better understanding of how it works.

Were you dealing with same group of medical practitioners on both occasions?

**Mr. Andrew Adams:** The first time I tried to apply for MAID, the process was shut down fairly quickly. Initially, I had been considering applying under the interim court ruling that was there before the actual C-14 bill was passed. As soon as it became clear that C-14 was going to limit eligibility, I was basically told that it's just not going to go forward. I sort of stopped trying after that for awhile.

Bill C-7 then passed and I reached out to my local health authority. Through that coordination centre, I was put in touch with a doctor and went through the 90 days. That was quite a lengthy assessment. The consultation with the third party—the specialist—was very thorough. I did more tests than I had ever done before. This specialist has dealt with me for a number of years, so they know me, know my condition and know what I've tried.

I went through all of the other measures in the law and was found eligible. I waited some time and then I eventually got a second approval as well.

One of the doctors was part of my initial exploration of C-14 and clearly had different conclusions for these two different bills.

**Mr. James Maloney:** Thank you. I'm assuming those were based on the law. Those were legal conclusions, not medical conclusions.

**Mr. Andrew Adams:** Can you rephrase the question?

**Mr. James Maloney:** By the *[Inaudible—Editor]* under the first legislation.

**Mr. Andrew Adams:** Essentially yes, I would say so. The full assessment didn't really happen on the first one. It was kind of just a meet and greet.

**Mr. James Maloney:** Do you feel you had a full hearing—if I can put it that way—and ample opportunity to discuss all of the implications and ramifications with your doctor and everybody who was involved in the decision-making process?

**Mr. Andrew Adams:** Yes, I do.

**Mr. James Maloney:** Tell me a little bit more about this idea of self-exclusion. Can you put a little bit more detail into that for me? What time frame would you be looking at? How would that work exactly?

**Mr. Andrew Adams:** I think it could be basically a form that a person brings to their doctor or to their health authority and chooses a set number years. I suppose you could put a cap on it if you wanted to. It could be maybe five years or so, up to a decade, depending on the needs of the individual and their level of comfort with MAID.

• (2010)

**Mr. James Maloney:** Thank you.

I've only got a few seconds left, so I'm going to turn to Mr. Leblond.

You said you have some ideas on safeguards. We don't have time for you to set them out tonight, but would you be good enough, sir, to send us some information in writing, if that's possible?

**Mr. Ghislain Leblond:** It would be my pleasure, but that would be very short because I do believe that you don't need extra safeguards for MAID for people who are physically disabled.

To believe that those people need extra safeguards means that because they are physically disabled, they are also, by definition, automatically intellectually disabled as well. That means you believe that because they have a physical impairment of some kind, they are not able to make decisions by themselves and for themselves.

*[Translation]*

**The Joint Chair (Hon. Yonah Martin):** Thank you, Mr. Leblond.

Mr. Thériault, you have five minutes.

**Mr. Luc Thériault:** Thank you, Madam Chair.

I want to continue the conversation with you, Mr. Leblond.

Ultimately, you would find it discriminatory if you weren't given access to MAID. That's what I understand, since you advocated for Quebec to pass the Act respecting end-of-life care, as you said earlier.

Have I understood you correctly?

**Mr. Ghislain Leblond:** Very well, yes.

As you say, it would be very discriminatory. If someone meets all the criteria established by the Supreme Court in Carter, I don't see why their request would be treated differently or a decision would be made differently because they have clubbed feet or are missing an arm. That would be discriminatory because it would put another barrier in the way of someone exercising their right to request MAID.

Why should these people, who already have a lot of difficulties in life, be subject to greater requirements than people with cancer who request medical assistance in dying? That would be completely discriminatory.

These people don't need to be protected. They are capable of defending themselves. If we respect their rights, if we respect them as human beings, they will be able to protect themselves. They do not need a good Samaritan to infantilize them or use them as pawns for other purposes. If their rights are respected, people with physical disabilities are able to make decisions by themselves and for themselves.

**Mr. Luc Thériault:** If the disability is individual, that is, specific to the individual, the disability is still social. It is essential that the person with any kind of disability be disabled as little as possible.

You mentioned earlier that people with physical disabilities are able to think and make decisions. An old philosopher, Paul Ricoeur, wrote a book in which he said that autonomy is not reduced to physical and social autonomy, for example the role one plays in society and the economic power one has. Autonomy in the full sense of the word is moral autonomy, that is, having the capacity to make practical judgments about oneself and to make free and informed decisions.

I imagine that you agree with Mr. Ricoeur's comments.

● (2015)

**Mr. Ghislain Leblond:** Yes, absolutely. It's the very essence of a human being. It's the very essence of humanity. You have to be able to exercise your autonomy in a way that respects society. You have to be able to fully assume your autonomy, during life and at the time of death; there is no greater demonstration of what it means to be human.

**Mr. Luc Thériault:** You said that you've been in a wheelchair for 20 years. I imagine that you aren't yet at the point of wanting to exercise your right to MAID. That said, you must have been relieved to know that this option was available to you before you reached your tolerance threshold.

**Mr. Ghislain Leblond:** Yes, absolutely. That's why I've been very active in advocating for it in Quebec.

I don't think anyone wants to have to resort to MAID. We're all afraid of dying, but what we're most afraid of is how we're going to die and what type of agony we're going to have to face.

Medical assistance in dying isn't an obligation, but a choice among others, and each person makes their own decision based on their situation and beliefs. Having a choice is a great moral relief for me, and also for my family. I've been in a wheelchair for 20 years; my family has been caring for a wheelchair user for

20 years. Knowing that MAID will be available, if I ever have to go there, gives me and my loved ones great moral relief.

**Mr. Luc Thériault:** Thank you, Mr. Leblond.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

[English]

Next we'll have Mr. MacGregor.

**Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP):** Thank you, Madam Co-Chair.

Ms. Jama, I think I'll start with you.

As you know, our committee was given a fairly broad mandate from the House to cover five areas. Only one of these is actually going to turn into law. We're studying the issue knowing that in March of next year mental illness as an underlying condition will come into effect in 2023, but the others are fairly broad.

When this committee got under way in April and we had our first couple of meetings, it felt right away like we were doing a fairly rushed job. The House initially gave us a deadline of June 23, and I think it very quickly dawned upon members of this committee that this was just going to be an impossible task. We've now extended it to October 17.

In terms of your testimony today, I remember that in our earlier conversation you were talking to me about the idea of pausing or slowing down. What I'd like you to tell us as a committee is why we should pause or slow down this conversation. Can you expand on that a little more? Could you suggest ways in which this committee could further engage with various members of the disability community over the remainder of the spring, the summer and the fall, just so we have as broad a cross-section of voices as possible?

● (2020)

**Ms. Sarah Jama:** Yes. A lot of us don't have the resources that the Dying With Dignity lobby—funded by Margaret Atwood and larger names—has, so by the time that I and many of us learned about the expansion of Bill C-7, we didn't make it to the third reading.

It was an unprecedented 18 months. That's how long it took all of you to make the decision to expand MAID.

I have named the names of people who died not because they wanted to end their lives, but because they had no other options around food, shelter and housing. I understand that the previous speaker did say that none of us want to use MAID and that everybody is afraid to die, but there have already been lives lost, on top of the fact that we know it's been documented and talked about by the Ontario Human Rights Commission that MAID was being offered in jails in place of probation.



We have a moral obligation to stop. Rather than reviewing the harms that have been caused, this committee has spent more time talking about potential expansion. You should have been using this time to look back, and to look at the mistakes and to look at what the rush has caused, especially in light of COVID, especially in light of the despair that a lot of disabled people are feeling around what it means to live as a disabled person right now, where we know that doorknobs were being removed from long-term care homes and where many people couldn't afford to eat. I have met disabled people living in tents who were housed there, who were talking about using MAID—in tents outside, in wheelchairs. This isn't okay.

It's not enough for those of us who want to feel some semblance of comfort to be making decisions for the rest of the people who are not in the room, because guess what? Nicole Gladu died naturally after setting the way for people to use MAID for no other option.

This committee has an obligation to slow down and to talk to more people—to talk to houseless people, to talk to racialized people, to talk to young people and youth—and to not succumb to the force that is the Dying With Dignity lobby, because it's not fair for the rest of us.

**Mr. Alistair MacGregor:** I want to expand on the minister's mandate letter. She has been tasked with a review of access to federal disability programs. In the previous Parliament, the government introduced Bill C-35, which was going to set up a federal disability benefit. It was introduced on June 21. The government knew that an unnecessary election was coming, so I think that was introduced for show.

We are well into the 44th Parliament. We still have no sight of a federal disability benefit bill coming forward.

In the 45 seconds I have, could you expand on what the landscape is like out there? When we look at federal disability supports, what does the Parliament of Canada really have to tackle to address that issue, because that's a big part of this conversation?

**Ms. Sarah Jama:** Disabled people should not be legislated into poverty in every single province. That's what's happening. People can't afford to eat or pay rent.

There are also our health care issues. Why does it take up to two years to access a pain clinic in Ontario? Why are there so many wait-lists? You're making it impossible for us to choose to live, especially those of us who are aging into our disability. It's getting harder and harder, not because we can't do it ourselves, but because there are no resources available and not enough funding in our health care systems. We simply can't afford it.

As much as we're talking about the federal disability benefit, we also need to be talking about our health care systems and their failures. This committee has an obligation to look into that, because it's all connected. If you're going to allow people to kill themselves, look into why they are doing that, and look into our health care systems.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

I will turn it over to Mr. Garneau, for questions from senators.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Chair.

We will start with senators and three minute rounds.

[*Translation*]

I'll now give the floor to Senator Mégie.

**Hon. Marie-Françoise Mégie (Senator, Quebec (Rougemont), ISG):** Thank you, Mr. Chair.

My question is for Ms. Jama.

I believe I understood from what you said that, when people are in a situation of poverty, for example when they are poorly housed, the first proposal that will be made to them is to receive medical assistance in dying.

I know these people need care. The decision to receive MAID should be made by the person themselves; it shouldn't be imposed on them.

Have you heard any stories of people having MAID imposed on them?

[*English*]

**Ms. Sarah Jama:** Yes, there have been stories in the media. There were two cases, and I talked about them in my testimony.

One of them was a woman named Denise who was looking for affordable housing. Her friends were fundraising for her, and it still wasn't enough. Her only option was to use MAID, because where she was living was causing her disability to flare up so badly, and she also couldn't afford to eat.

When I talk about systemic coercion, I'm not saying somebody's holding a gun to your head. I'm saying that the systems are working together to provide no other options for people to choose life, and we're allowing that to happen as elected officials. It is still coercion whether or not someone explicitly told you to do it. We are voting on situations that don't allow housing supports but allow death as an option first.

• (2025)

[*Translation*]

**Hon. Marie-Françoise Mégie:** As you've heard, other people with intolerable pain or disabilities are comfortable with the idea that they will be able to request medical assistance in dying when they need it. I don't get the impression that these people are feeling pressure or that they will be forced to request MAID when there is no more medicine to give them.

I'm having a bit of trouble following this idea, but maybe it's true that when you are poorly housed, you may be inclined to request MAID.

What do you think?

[English]

**Ms. Sarah Jama:** When you have lived without, it's not hard to imagine that people wouldn't want...It's getting harder and harder to live. These cases were all over the Toronto Star. People were saying, "I have really tried hard to survive, but MAID is my only way out, and I wish it wasn't. I wish I had housing, because I would have stayed on this earth." That's a coerced choice. It's a choice made, because there was no other option available, so it's not really a choice.

We have seen in this country where forced sterilization was a thing against disabled people, including institutionalization, and the idea that many of us don't want to send our families to long-term care homes, but it's our only option, because we can't afford anything else. All these things are examples of coercion.

While it may be hard for specific committee members to imagine why someone would make that choice, it's because maybe you have not been without food, shelter, housing, or had to live in these situations. I have, so I have come all the way here to tell you that it's true.

**The Joint Chair (Hon. Marc Garneau):** Thank you.

Senator Kutcher.

**Hon. Stan Kutcher (Senator, Nova Scotia, ISG):** Thank you very much, Mr. Chair.

I have two questions. The first one is for Ms. Jama. In MAID assessment, the assessors, as we have heard already, pay very careful attention to the treatments people have had and treatments that are suggested as possible.

Many providers have suggested that this kind of assessment should also include addressing structural inequalities—for example, the need for housing or income assistance—and that those should be integrated into every single MAID assessment so that they don't coerce people where they shouldn't be coerced. Would you suggest or consider that this thing should essentially be a part of any MAID assessment to make sure people aren't being coerced?

**Ms. Sarah Jama:** Absolutely.

At the same time, I think about the case in B.C., in which a woman accessed MAID under the 90 days and is being investigated by the RCMP. She was given MAID and she didn't access treatment for her mental health disabilities. That's being investigated.

So while we can keep saying that we're going to add safeguards, if we lose one life, that's enough for us to pause and evaluate why that happened. I am somebody with mental health issues myself. I have been in treatments over and over again. They're difficult to sustain when you're also trying to continue to live. Sometimes I get so overwhelmed and I'm like I don't want to be here. That changes maybe after the 90-day period, but it's hard.

I just mean that we need to have more options available, because it took me a year to get into proper therapy. And even then, I could have decided to do something else.

So, one, we're losing people because they're—

**Hon. Stan Kutcher:** I'm sorry but I have a question for someone else.

**Ms. Sarah Jama:** Okay.

**Hon. Stan Kutcher:** I think you answered that question very well. Thank you so much.

I have a question for our first witness, Mr. Adams.

You've done a MAID assessment but you have not yet chosen to move towards MAID. You said something that I didn't quite catch about reduced stress and improved state of mind. Did you mean that you were getting actual relief from intolerable suffering simply by having gone through that process and having that option? I couldn't quite understand that.

● (2030)

**Mr. Andrew Adams:** Yes. I'm trying to explain that the knowledge that I am assessed and approved has changed the way I experience my condition psychologically. I feel just intense relief. As a result, I have more strength to endure my episodes.

**Hon. Stan Kutcher:** Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much.

[Translation]

Go ahead, Senator Dalphond.

**Hon. Pierre Dalphond (Senator, Quebec (De Lorimier), PSG):** Thank you, Mr. Chair.

[English]

Thank you to our panellists. I think this is very important, and your testimony is very important.

[Translation]

My question is for Mr. Leblond.

As you have heard, the dilemma we always face is that some groups may be disadvantaged by the system. This makes the options available to them less attractive than the ones you've experienced. You're an educated man. You were deputy minister in Quebec City and associate deputy minister in Ottawa.

What do you say to people who say that no one with a disability should have access to medical assistance in dying, in order to protect those who cannot give consent that seems as valid as yours?

**Mr. Ghislain Leblond:** I don't see the connection between being physically disabled and being able to think. It's as if physical and intellectual disabilities were perceived in the same way. That's the equivalent of what was said during debates on whether women, simply because they were women, were smart enough to vote. Here we are with the same kind of arguments in 2022, saying that people with physical difficulties are unable to make decisions for themselves.

It is undeniable that we have immense problems socially, economically and in the health care system. MAID cannot make up for all these problems. It's not a panacea or a generic remedy. I understand that people have a hard time accepting this idea, but it shouldn't prevent those who meet the criteria set out by the Supreme Court from using it.

**Hon. Pierre Dalphond:** Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator Dalphond.

[English]

Senator Wallin.

**Hon. Pamela Wallin (Senator, Saskatchewan, CSG):** Thank you, Co-Chair.

I think many people seeking MAID are less able than they once were. Some may be disabled or have become disabled, and some may be contemplating suicide reluctantly because they don't have the option of MAID. I think we have to be very careful in our discussions here that we do some fact-checking. I think it's risky that we accuse MAID providers, licensed medical professionals in this country, of coercing people into MAID, of imposing MAID on people, of making offers of MAID in exchange for freedom. These are matters of law, the courts have ruled on this and the governments have responded by writing very carefully crafted legislation, so I want us to be very cautious in that.

I want to go to Mr. Adams, if I could, because you have been through that process, both attempting to do so under Bill C-14 and then again under Bill C-7. You said that you thought it was an intense process. Give us a couple of examples. Do you think you could have walked in and said, I have nowhere to live, or I'm part of a minority group, please give me MAID, and they would have responded?

• (2035)

**Mr. Andrew Adams:** I certainly wouldn't think to say those words. I think that would be totally divorced from my reasoning for going forward with the assessment for MAID. And I am an indigenous person, so some of the conversations tonight at this meeting, I feel, were talking about me without me, and I find that a little bit frustrating.

To get back to your question, no, definitely not. I found it very personal in a sense, in that I felt that I was really sharing things with the assessor that perhaps I hadn't told anyone before, things like indignities that had occurred as a result of my symptoms that I haven't even told my parents. These are very sensitive conversations that I had, and I felt heard. For the first time probably in my life, I felt that I was seen, and I can't really give you in proper words the gravity of what I experienced in that assessment. What it meant for me was enormous. I'm sorry to emote here, but it's hard not to. It's profound, that's all I can say.

**Hon. Pamela Wallin:** But that experience was thorough. You couldn't have walked in and said, "Look, I'm having a bad day".

**Mr. Andrew Adams:** It was extremely thorough, yes.

**Hon. Pamela Wallin:** Okay, I'm going to leave it at that. Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you, Senator.

Senator Martin, you have the floor.

**The Joint Chair (Hon. Yonah Martin):** Thank you to all of the witnesses for your very compelling testimonies.

I have two questions for Ms. Jama.

Dr. Heidi Janz has written about Canada's MAID regime saying, "When a government starts making laws based on the premise that some lives are not worth living, it is setting out on an extremely dangerous path".

Ms. Jama, do you believe that the current MAID framework communicates to people with disabilities that their lives are less valuable than those of able-bodied Canadians?

**Ms. Sarah Jama:** Yes, I have maintained, like many other disabled people throughout this entire conversation, that I am pro-choice in life and in death, but when you have a situation where it's been documented that disabled people are choosing to use MAID because they have no other options available....

Again, I talked about Chris Gladders, who was sitting in his feces and urine for days and then chose to use MAID because of an understaffed, under-cared-for, long-term care situation. He didn't have another option. Yes, this idea that we're going to allow only disabled people and not the rest of the population to use MAID as a way out because of other conditions that they can't control.

I want everybody to have the comfort of using MAID when they want to, but I'm also thinking of all the people who have died. It's been documented. It's in the news. I think you all should look it up. It was in the Toronto Star in the last couple of weeks. I want these people to have their choice, but I don't want more people to die if their needs could have been taken care of elsewhere.

My comfort in having MAID as an option is not more important than someone else's life.

**The Joint Chair (Hon. Yonah Martin):** What can be done to improve the MAID regime to protect Canadians with disabilities from premature deaths? What recommendations do you have?

**Ms. Sarah Jama:** Like I said earlier, I recommend that this committee move slowly. We're moving really quickly to talk about further potential expansions versus looking back on all of the missteps and potential cases that I'm talking about, which you guys seem to not know about, where people have died when they shouldn't have.

In our jail systems there were situations where MAID was being offered in place of parole to the point where the Canadian Human Rights Commission last week put out a statement against this.

What I'm saying is that we need to slow down. My recommendation is that we take our time and take it seriously.

**The Joint Chair (Hon. Yonah Martin):** Thank you.

**The Joint Chair (Hon. Marc Garneau):** Thank you very much.

To all of the witnesses, a very big thank you for coming on this evening and for, first of all, putting up with the long delay, and, secondly, for your powerful testimony.

I also want you to know that this is the first session on the theme of disability. We will be talking about this subject as we go forward. There are other sessions planned.

Thank you very much again for your presence this evening.

For the committee members, we have an option here that we can choose to exercise. It requires unanimity. That option is to continue with this session. I'm going to be asking everyone around the table. Bear in mind that there are people who have been waiting for upwards of two hours to provide testimony this evening. I will be looking for a show of hands for those who wish to continue. I need unanimous consent if we're to continue with this meeting. I'm asking for unanimous consent. I want a vote right now.

Those who want to continue the meeting?

**An hon. member:** What are we voting on?

**The Joint Chair (Hon. Marc Garneau):** We have three hours protected this evening.

• (2040)

**Mr. Michael Barrett:** At what time would the committee break to vote?

**Mr. Michael Cooper (St. Albert—Edmonton, CPC):** I need to go into the chamber to vote.

**The Joint Chair (Hon. Marc Garneau):** If you decide that you're not going to support unanimous consent, you're going to have to raise your hand and say, "No, I don't support".

**Mr. Michael Barrett:** I have a point of order, Chair.

**The Joint Chair (Hon. Marc Garneau):** I beg your pardon, that is the rule.

**Mr. Michael Barrett:** I challenge the chair. We have a right as members to vote, sir.

**The Joint Chair (Hon. Marc Garneau):** Please, don't interrupt me when I'm speaking, okay?

The rule says that we can seek unanimous consent. If it isn't given, then we break, and everybody goes to vote.

**Mr. Michael Barrett:** It isn't given.

**The Joint Chair (Hon. Marc Garneau):** All right. It's very clear. I'm afraid that we're not going to be able to continue this meeting for the rest of this evening. The meeting for the rest of this evening is cancelled. We're going to have to pick it up at a later time. We cannot ask people to stay on—

**Mr. Michael Barrett:** We could break for five minutes, vote, and come back.

**Mr. Michael Cooper:** It's such a sham.

**The Joint Chair (Hon. Marc Garneau):** Go ahead, Mr. Anandasangaree.

**Mr. Gary Anandasangaree (Scarborough—Rouge Park, Lib.):** Mr. Chair, in the interest of moving along with the agenda, may I ask that at least one member of each party remain so that we can have an informal discussion on what the rest of the study is going to look like? I know we had set aside an hour. Notwithstanding that people may need to go, I'm asking if one member could stay back. I think we can hammer this out in the next 20 minutes.

**The Joint Chair (Hon. Marc Garneau):** I don't share your view on that, because there are two motions and there are probably other things that people will want to talk about.

Given the fact that we do not have unanimous consent to continue with the second hour, I apologize to those who have been waiting for two hours to provide testimony, many of whom, as we can see, are people from the disability group.

However, unfortunately, that is the situation.

This meeting is adjourned.







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