



HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

44th PARLIAMENT, 1st SESSION

Special Joint Committee on Medical Assistance in Dying

EVIDENCE

NUMBER 010

PUBLIC PART ONLY - PARTIE PUBLIQUE SEULEMENT

Monday, May 30, 2022

Joint Chairs:
The Honourable Marc Garneau The Honourable Yonah Martin



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• (1940)

[English]

The Joint Chair (Hon. Yonah Martin, Senator, British Columbia, C): Good afternoon, and welcome to the meeting of the Special Joint Committee on Medical Assistance in Dying.

I'd like to begin by welcoming all the witnesses, as well as those watching this meeting on the web.

My name is Yonah Martin, and I'm the Senate joint chair of this committee. I'm joined by the Honourable Marc Garneau, the House of Commons joint chair.

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

The Board of Internal Economy requires that committees adhere to health protocols, which are in effect until June 23, 2022. As joint chairs, we will enforce these measures, and we thank you for your co-operation.

I'd like to remind members and witnesses to keep their microphones muted unless recognized by name by the joint chair. As a reminder, all comments should be addressed through the joint chair. When speaking, please speak slowly and clearly. Interpretation in this video conference will work like it does in an in-person committee meeting. You have the choice at the bottom of your screen of either the floor, English, or French.

With that, I'd like to welcome our witnesses. Thank you for your patience, as we went a bit over time in the first hour.

I'd like to introduce our witnesses. As an individual, we have Dr. Ramona Coelho, physician. From Disability Without Poverty, we have Michelle Hewitt, co-chair of the board of directors; and from Spinal Cord Injury Canada, we have Bill Adair, executive director.

Thank you to all for joining us.

We will begin with opening remarks by Dr. Coelho, followed by Ms. Hewitt and Dr. Adair.

Dr. Coelho, you have five minutes for your testimony.

Dr. Ramona Coelho (Physician, As an Individual): Thank you, Madam Chair.

My family medical practice cares for marginalized patients, including those living in poverty; refugees; men out of prison who are facing charges; the LGBTQ+ community; indigenous persons;

and those struggling with mental health, addictions, chronic pain and disabilities.

I have experienced childhood racism, bullying and sexual abuse, so I understand that the choice to die can easily be influenced by injustices that life has dealt us.

At prior committees I raised concerns that inequalities and circumstances, such as poverty, trauma, lack of timely access to medical care [*Technical difficulty—Editor*] can lead to MAID being raised as a treatment option to such a victim of discrimination.

I warned that many injuries and illnesses are accompanied by transient suicidality that ends with adaptation and support, but which on average takes two years. Then the overwhelming majority of persons after those two years rate their quality of life as the same as age-matched healthy individuals. Offering MAID in a period of known increased suicidality would lead to the premature deaths of those who would have recovered.

Now Bill C-7 is the law.

A man had a small stroke affecting his balance and swallowing. The patient was depressed and isolated due to a COVID-19 outbreak on his ward. The stroke neurologist anticipated the man would be able to eat normally and regain most of his balance. He declined all therapy, and psychiatry diagnosed him with an adjustment disorder, but they felt he would improve. However, he requested MAID. Neither of his MAID assessors had any experience in stroke rehabilitation and recovery.

In this acute phase while struggling with his mood and isolation with no therapy to gauge his final level of function, he received MAID. He had no terminal illness, but due to the fact that he was adapting to a slightly thickened diet and so was temporarily slightly undernourished, they considered him "track one" eligible, and he received MAID the following week. No safeguards were technically broken, and yet he died when acutely down, isolated and had not experienced living with maximal recovery from his stroke.

Mr. Ernest McNeill was a 71-year-old widower admitted to hospital for falls. During his admission, he contracted C. difficile, an infectious diarrheal illness. He was openly humiliated by staff for the smell of his room. He developed a new shortness of breath that was not comprehensively assessed. Without the patient requesting it, a hospital team member raised and recommended MAID to him.

The team said he had COPD, and it held a terminal prognosis. The MAID procedure was booked by the hospital team before he even had a second assessment, and within 48 hours of his first assessment he was dead. Post-mortem tests confirmed no significant COPD, and his family doctor also said he didn't have end-stage COPD, but no one had contacted her for collateral history.

MAID was raised with this patient. There is no safeguard in Bill C-7 that forbids raising MAID, and the related amendment was voted down by the Senate. CAMAP has a document called "Bringing Up Medical Assistance in Dying", and Susan MacDonald mentioned at this committee that MAID should be raised as part of the informed consent process. Was MAID raised because his admission was longer than expected as a result of his being a victim of ageism? Did he choose MAID because his acute care team made him feel horrible? His family believes so.

The "In Plain Sight" report by B.C. and the tragic story of Joyce Echaquan demand that we take these considerations seriously.

Finally, after a *CTV W5* story showed a gentleman's MAID provision, the immediate Monday afterwards, a patient let me know that the story was super appealing and that MAID would be good for her. My patient is in her early mid-life, has a recent spinal cord injury and hasn't had time to adjust, receive peer support or proper symptom control, nor reach maximal recovery, but she does now quality for track two MAID within 90 days. The legislation is built in a way that allows for her death before she has had a chance to experience maximal recovery. This case also shows how the government must consider current suicide research showing that messaging promoting suicide may lead to more people choosing it.

• (1945)

The MAID regime appears to be allowing a right to die with government assistance for certain groups. Inadequate safeguards suggest that this has been packaged and thinly veiled as a medical procedure. If this is not the case, I ask the government to reconsider its MAID regime.

Thank you.

The Joint Chair (Hon. Yonah Martin): Thank you, Dr. Coelho.

Next, we have Ms. Hewitt.

You have five minutes, Ms. Hewitt.

Ms. Michelle Hewitt (Co-Chair, Board of Directors, Disability Without Poverty): Thank you, Madam Chair.

I am a disabled woman with multiple sclerosis and live in Kelowna, B.C. At times, my disease has been aggressive and it's fairly advanced. I use a power wheelchair. I have severe fatigue and pain that is sometimes severe. However, I have a great quality of life.

Today, I represent Disability Without Poverty. Roughly two in 10 people living in Canada are disabled, but, among those who live in poverty, four in 10 are disabled. Disabled people are overrepresented. There are twice as many disabled people living in poverty than statistics alone would account for. Often, they live in abject poverty, as disability assistance payments are usually as low as half or two-thirds of the poverty line. We know disabled people have been

granted MAID because the intolerable suffering they face is caused by poverty, yet there are conditions they would consider acceptable to relieve that suffering.

Here are just two examples of people from B.C.

Sean had ALS and wanted to live at home. He managed to do so for a number of years. When the constant stress of finding the right care on his own became too much, his health authority offered to place him in long-term care four hours away from his 10-year-old son. Instead, Sean chose MAID. He described the funding decisions and institutional offerings advanced by the health authority as a death sentence.

Madeline has post-viral syndrome and has been living with it for 30 years. There are no Health Canada-approved treatments, but she found a combination of treatments that work for her, and they all require her to pay out-of-pocket. However, she has exhausted all options financially and is currently getting by, month to month, on GoFundMe payments. Madeline says that, when the money runs out, she'll have no option but to use MAID, which she has already qualified for. She says she has no wish to die, but she'll be facing an unbearable wall of pain with no quality of life.

No one in Canada should ever die because they live in poverty. Yet, for disabled people, we hasten that death. We provide a state-sanctioned procedure for those disabled people to die. For Sean and Madeline, we have remedies for their suffering that would have been acceptable to them. Sean and Madeline have been vocal in the media about their needs and the remedies for their suffering, but we heard nothing in response to this from the government. Either the government believes that disability accommodations set out in law do not need to be upheld or it does not take its role to oversee MAID safeguards seriously. Sean and Madeline's suffering came from a social condition, not their medical conditions.

I cannot believe that was ever the intention of MAID—sanctioning the deaths of disabled people because they live in poverty—yet we see it happening. I ask that you recognize the safeguards are failing and that you support disabled lives and the Canada disability benefit bill to ensure it lifts all disabled people out of poverty. Implement wide reform to our care systems to give disabled people the care they want. Until these conditions are met, MAID eligibility must be restricted to those who are approaching the end of their life, where their intolerable suffering is due to their medical condition, not the societal conditions under which they are forced to live.

I finish with Madeline's words: "I'm trying really hard not to freak out...but that I'm facing death for something that can be managed is bloody ridiculous, and it makes me so *angry*. I die when I run out of money."

Thank you.

• (1950)

The Joint Chair (Hon. Yonah Martin): Thank you very much, Ms. Hewitt.

Lastly, we have Mr. Adair.

You have the floor for five minutes.

Mr. Bill Adair (Executive Director, Spinal Cord Injury Canada): Thank you, Madam Chair.

I'm Bill Adair. I work for Spinal Cord Injury Canada, which was founded in 1945 by World War II veterans who came back home to a country that expected very little from them and who dismissed the idea that they would be shut away in convalescent homes.

Our founders fought in battles overseas and then back home to provide the proof that their lives are worth living. In fact, 13 of our founders received the Order of Canada because of what they did after the war. Apparently, 72 years later, people with spinal cord injuries still need to fight to prove that their lives are worth living. It's tiring fighting for existence, but here we are.

I have worked with our SCI federation for 33 of those 72 years. Our organizations across the country support people as they adjust, adapt and thrive while living with a spinal cord injury. I have fielded requests for support for half of my life. My experience as the past chief executive officer of Spinal Cord Injury Ontario and now as the executive director of Spinal Cord Injury Canada provides me with a distinct expertise to talk about MAID and its potential impact on people with spinal cord injuries.

I'm here to speak with you about two issues, which are the 90-day wait period and the lack of real choice for persons when they are offered MAID.

The 90-day wait period is arbitrary. There are very good reasons, especially related to people with spinal cord injuries, why this wait period should be longer. A recent study found that 50% of respondents with a spinal cord injury had suicidal ideation in the first two years post-injury. Another study found that after the first year post-injury, more than 70% of people rated their life equal to or better than their life pre-injury.

From my work, I know that it can take anywhere from several months to up to seven years or more for a person to mourn their loss and accept their new life. Rehabilitation, court battles, finding accessible housing and possible work retraining can take years. Sustaining a spinal cord injury is a huge life change. While laying in bed in acute care or in rehab, a person does not possibly have all the information needed to make a life or death decision. As you know, it takes time to think about all the options, listen to people's views, and understand what resources are available and what are not. A 90-day wait is not a safeguard for the 4,000 or more people with a new spinal cord injury in Canada each year.

Imagine the loss to our society if we allow our fellow citizens to make a impulsive, uninformed decisions during the early stages of rebuilding a life that is worth living. Which one of these people could have been our next Order of Canada recipient?

My second concern is that people do not have a real choice when they request MAID. When a person discusses MAID with a doctor, they should also be offered other choices such as home services, long-term care, basic living funds, suicide prevention, psychiatric services, and safe, accessible and affordable housing. These services are not offered or they're offered, but are not available because there's a wait list, they're too expensive or they're too far away. The person isn't really being offered a choice, are they? The person is in fact being denied a choice. It's MAID or nothing.

Many people with a disability suffer because of a lack of available services and being left to live in crushing poverty, not because of their disability. In turn, the lack of available services and a life in poverty kills hope and drives people to choose MAID to end their misery. This is not the Canada that any of us want.

Here's my list of proposed solutions: Extend the wait period if a person is not at the end of life. Implement the Canadian disability benefit now. Fund trained professionals from organizations to go into health care centres to provide peer support when someone requests MAID. Build accessible, affordable housing.

• (1955)

As parliamentarians, you have a responsibility to change this horrible situation and to prevent it. Please give my recommendations a sober second thought.

Thank you for listening and inviting me here.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Adair, and thank you to all of our witnesses.

We'll go into our first round of questions, and we'll begin with Mr. Cooper for five minutes.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Madam Co-Chair.

Dr. Coelho, can you elaborate a little more on the case of the first patient you cited, who suffered from a stroke and was granted medical assistance in dying under the Bill C-14 regime, despite not having a terminal diagnosis as required by law under Bill C-14?

Dr. Ramona Coelho: Mr. Cooper, just to clarify, it was actually more recent than that, but should have fallen under track two under the Bill C-7 regime.

This patient did not have any terminal comorbidities and was not dying from his stroke. As is normal custom when someone has a stroke and has difficulty swallowing, we progress their diet slowly to avoid aspiration—pneumonia and things like this—and he did not choke or aspirate before he died. The dietitian ordered a normal progression of meals. He was eating 1,300 calories a day, which is probably what I eat, and he ate his whole tray easily—every tray. And, it was temporary.

However, I guess this was beyond the scope of the MAID assessor's expertise, because he wasn't starving, but they decided that he wouldn't be able to survive on a diet as such, and therefore qualified him for track one so that he could die with no reflection period.

• (2000)

Mr. Michael Cooper: Thank you for that, Dr. Coelho.

Can you elaborate on the patient you were recently in contact with who watched the *W5* program, and as you said, has now found MAID appealing?

Dr. Ramona Coelho: This is my own patient, whom I love very much, and I asked her permission to tell her story today. She actually said, as did every single contact in every story I shared, that she is willing to talk to this committee. I've also emailed the chairs with other stories that I couldn't fit in here. They want to share their stories about what happened. She wants to tell you that she is very worried about the poverty she will be thrown into if she can't go back to work and that she'd rather die than live in poverty.

I'd be happy to be connected with the clerk, or whomever, to give you all of these stories. They are all recent stories, including the ones I already sent to Madam Chair and Mr. Chair.

Mr. Michael Cooper: How much time do I have, Madam Chair?

The Joint Chair (Hon. Yonah Martin): You have two and a half minutes.

Mr. Michael Cooper: Okay.

Dr. Coelho, can you elaborate on the second patient who chose MAID on the basis of an incorrect diagnosis?

To split the time, Mr. Adair, can you talk a bit about some of the phone calls your organization has received in regard to MAID from persons who suffer from spinal cord injuries?

Dr. Ramona Coelho: Okay. I will try to be very, very quick.

I have actually reviewed this medical chart and met with the family myself. The family relates that there was severe humiliation that he endured [*Technical difficulty—Editor*]

The Joint Chair (Hon. Yonah Martin): Dr. Coelho, your sound is affected at this time.

Dr. Ramona Coelho: Oh, sorry. Is something wrong?

The Joint Chair (Hon. Yonah Martin): Yes. Would you begin again? Your sound cut out. I think we're having some technical difficulty.

After that, we'll get Mr. Adair to respond as well.

Go ahead, Dr. Coelho.

Dr. Ramona Coelho: Basically, I talked to the family. I reviewed the medical chart myself. He was being humiliated by staff. They would leave the windows open, complain when they had to change him. He couldn't get in touch with his family that often. He would go hungry when they cleared his food trays. In this context, he developed shortness of breath that wasn't comprehensively assessed. He would become so confused that his oxygen, when it slipped off his face...they had to cancel his second assessment.

The second assessor told the family that she would have to go off the first assessment. So he received MAID in a very sloppy fashion, without proper diagnosis. As I said, the family doctor was never consulted and the diagnosis was not confirmed in hospital or through collateral history taking.

The Joint Chair (Hon. Yonah Martin): Mr. Adair.

Mr. Bill Adair: There are multiple calls that come in to our organizations across the country. I'm happy to speak about two of them.

I had a phone call several weeks ago from a colleague who was representing a woman who is 17 years old. She was in intensive care and had a high-level spinal cord injury. She wanted to access MAID. Since then, our organization has been able to connect with the family and help them see that there is life after this initial insult of paralysis, and she has turned away from that. We're grateful for that, but the fact that a 17-year-old woman, who has enormous potential to contribute to our country, is even considering MAID is very problematic.

The other is a woman in her mid-30s who contacted me. She has multiple disabilities and has been looking for housing that would support her independence and her ability to return to work after the onset of a second disability after having a spinal-cord injury. After 10 years, her words, to paraphrase, were "I'm ready to throw in the towel. I cannot take this anymore. I want to lift myself out of poverty. I want to get a job, but I can't find a place to live that will support my independence."

• (2005)

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

Next we have Mr. Maloney. You have the floor for five minutes.

Mr. James Maloney (Etobicoke—Lakeshore, Lib.): Thanks, Madam Joint Chair.

Thank you to all the witnesses for very compelling and helpful testimony. It was enlightening, too, I might add.

Dr. Coelho, I agree with what you just said. Nobody should ever have to.... The circumstances you described are appalling. I forget the language you used, but I agree with you. It sounds to me like, based on the facts that you presented, that this particular situation may have been more the result of poor quality care than the laws put in place, but that's just my interpretation.

My question really is.... I agree with you. Nobody's financial circumstances, because they're impoverished or have mental health issues or are disabled, should ever lead somebody to a situation where MAID is the option. Are there safeguards that can be put in place, in your opinion, that can protect against that?

I don't know if you've seen it or not, but there's an expert panel that released their findings last week, and they addressed some of these issues. I was looking for the specific recommendation while you were talking. I couldn't find it, but in there somewhere is the recommendation that there be a comprehensive process as part of the assessment to make sure that those aren't the circumstances giving rise to the request.

Is that possible, in your opinion?

Dr. Ramona Coelho: Thank you.

Thank you, Madam Chair, for the question.

First, to touch on what you were asking about that case with negligence, possible discrimination and a longer admission than they wanted or anticipated, I think it raises a really problematic issue. Abby Hoffman came to this committee and said that there are no cases, or hardly any cases, of non-compliance. It means that Health Canada is not able to capture the data correctly for safety and monitoring, and that really concerns me.

The second thing, about the expert panel—I reviewed the expert panel—is that it was actually for MAID for mental illness as a sole condition. The expert panel is very interesting. First of all, they never answered the question, “Can this be done for mental illness?”, considering that we have a lot of evidence that we have no prognosticators to know for sure if someone is irremediable—actually meeting the eligibility criteria for MAID—and if this is really a medical procedure.

Secondly, they offer 19 cautions. There are 19 things that they consider to be very dangerous—

Mr. James Maloney: Let me focus. Do you think there could be safeguards put in place to protect against the concerns you've raised? That's my real question.

Dr. Ramona Coelho: If you heard me in Bill C-7, I proposed several safeguards, including never raising it with a patient, as they do in Australian legislation. People should be able, in their professional integrity, to decline things.

For scientific data, for example, with patients with disabilities, where we know the outcome takes years, there was an MP Green who tried to put forward an amendment to make sure that psychosocial issues were not the reason people were getting MAID. That was voted down.

I feel that the MAID regime is really dangerous.

Mr. James Maloney: Have you put these suggestions in writing and submitted them to the committee?

Dr. Ramona Coelho: I did send a brief on May 6, and it is still not up in the written testimony.

Mr. James Maloney: Is everything you've just said contained in there—all of these suggestions you're talking about?

Dr. Ramona Coelho: I can resend you my testimony on Bill C-7, if it's helpful, Madam Chair.

Mr. James Maloney: If you want to do that, that would be useful.

My question is then for everybody. I'm running out of time, and I apologize.

I recently attended a presentation at a palliative care facility. It was interesting to me, because they said that at the beginning when MAID first became the law in Canada, 12 out of 12 doctors at the facility were opposed to it. Six months later, six were accepting, and now all 12 are accepting it because that's what the patients wanted.

My question to all three of you is: Has there been any change in the thinking in the disability community over the last number of years?

I'll start with you, Mr. Adair.

• (2010)

The Joint Chair (Hon. Yonah Martin): There's less than a minute, so perhaps two of the witnesses could answer that, Mr. Maloney. We'll have Mr. Adair first.

Mr. Bill Adair: I don't know that there's been any growth in that area that I'm aware of. You'd have to ask others who have more information and expertise.

Mr. James Maloney: Ms. Hewitt, what about you?

Ms. Michelle Hewitt: I would also say that I don't have data to support it, but certainly anecdotally, people within the disability community are talking about MAID more often and seeing it as a response to societal conditions more than medical conditions. They feel that they're suffering and that there is a solution to it. They're not getting that solution; so, therefore, it's MAID.

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

Next we'll have Monsieur Thériault.

[*Translation*]

Mr. Thériault, you have the floor for five minutes.

Mr. Luc Thériault (Montcalm, BQ): Thank you, Madam Chair.

Thanks to the witnesses for their testimony, which will help us in our deliberations.

I'll go to you first, Mr. Adair.

I want to thank you because your association is important. It shocks the collective imagination when someone in his or her twenties suddenly suffers a spinal cord injury. It causes a radical change to that person's life.

The handicap is obviously a social one, but the disability is individual. Where there's an individual disability, whatever it may be, the social handicap must be made as insignificant as possible. It's a constant struggle, and you strive to make these disabilities less and less debilitating. However, I imagine it's still a shock.

You'd like to have stronger safeguards. I understand that. As a health professional, do you think the safeguard of avoiding any discussion of MAID with the patient immediately following the shock would be helpful to you and your patients?

[English]

Mr. Bill Adair: The best safeguard is to work with the family and with the person who has the new injury and connect them with families and individuals who have gone through this initial phase of terrifying shock in many ways, and have gotten through that and have rebuilt amazing lives. Many lives are, as I said before, stronger and more satisfying than they were before the injury.

Certainly not mentioning the option of MAID to people with new injuries would be preferable, and just not having it available until people have had an opportunity to test life and to find out the kind of dreams they can build and will be able to pursue in their new life.

[Translation]

Mr. Luc Thériault: Mr. Adair, don't you think it's good medical practice not to suggest that option following a traumatic shock of that scope?

I obviously agree with you that these people must be cared for in the best possible way and assisted in considering their life prospects and how they can contribute to society. I understand all that. As you said, the process you describe may extend over two, three, five or seven years.

Can you see how, in the minds of some people who have gone through that process for five or six years, medical assistance in dying might be the only possible option, despite all your good care?

• (2015)

[English]

Mr. Bill Adair: The first point is that I don't think MAID should be mentioned or offered to people when they are in acute care or even in rehabilitation after sustaining a spinal cord injury.

Do I think people, down the road after seven years or eight years...? It is, again, a situation where it's important to look at all the variables. It's a hypothetical situation. I can't say it would be a good thing or not.

I can say that I have not witnessed that. I have witnessed that after people turn the corner and rebuild their dreams and their lives, suicide is not something they turn back to, other than if they face multiple compounding problems in the social supports area. Housing is a major theme. The issues of affordable, accessible housing and living in poverty are crushers. They crush people's souls.

I think it's also important to say, sir, that I don't speak for everyone with a spinal cord injury. Each person is an individual who ultimately has a right to decide, if there is in fact informed choice and a real choice.

The Joint Chair (Hon. Yonah Martin): Thank you very much, Mr. Thériault.

Next, we have Mr. MacGregor.

You have the floor for five minutes.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Thank you very much, Madam Chair.

Ms. Hewitt, I'd like to start my questioning with you.

The mandate of our committee is actually quite broad. We were appointed to review the provisions of the Criminal Code relating to medical assistance in dying and their application, but we're also including things like mature minors, advance requests, mental illness, the state of palliative care in Canada and also the protection of Canadians with disabilities.

When you think of that last part—that the protection of Canadians with disabilities is part of our committee's mandate—what comes to mind for you with regard to that instruction to this committee from the House of Commons?

Ms. Michelle Hewitt: For me, that part of your mandate is why I asked to be a witness at this committee. I strongly believe that, as a nation, we're not protecting disabled people at the moment. I strongly believe that you cannot advance with the expansion of MAID until we've dealt with some of those issues.

For example, 7% of the people living in our long-term care facilities are younger disabled people who have no other option but to live there. I can tell you that they don't want to be there. Of course, the person I talked about, Sean, who passed away through MAID before Bill C-7, did not want to be there either, and he chose MAID over living in long-term care. That tells me that we are not protecting these people.

This is a real concern to me as someone with MS and someone who advocates for the MS Society, as well as Disability Without Poverty. We're not providing these basic societal conditions so that disabled people are able to have a choice about their futures. An institutional life somewhere that is designed for 85-year-olds with dementia when you're in your thirties or your forties—and, as Mr. Adair talked about, you're often in this rehab phase where your situation is new to you—is crushing. On top of that, you're going to be living in poverty.

Here in B.C., in our long-term care homes, the average amount of care a day is 3.28 hours. That's not per person, that's an average. If there's somebody in the facility who needs more time, such as that person with severe dementia who needs time, they are not getting those 3.28 hours. They're getting substantially less.

For people with MS, fatigue needs and so on... I know many people for whom the fear of long-term care would...they would prefer to choose to be eligible for MAID, and it seems that the eligibility is happening at the moment.

• (2020)

Mr. Alistair MacGregor: You made a great deal of separating intolerable suffering from a medical condition versus a person's social conditions. We don't want to speak with a broad brush for everyone. Everyone's different and it's a very subjective term.

For you, thinking about the safeguards at a bare minimum, what do you want to see in terms of protections, so that social conditions are not influencing a person and that they are looked after? They may still feel that their medical condition, despite all the supports they may have, is still leading them to a life of intolerable suffering.

What's the bare minimum that we need to be aiming for as a country?

Ms. Michelle Hewitt: Madeline, who I talked about, is a friend of mine. I know that you're in B.C. and Madeline is in B.C. She has treatment options that have worked for her, and they have now been removed because she can't afford to pay for them.

If there is a track record of treatment that works, the removal of that treatment cannot, therefore, lead to MAID. I believe that where the person is able to state what they need to have that intolerable suffering removed, those should be in place before they become eligible for MAID. If we cannot do that as a country, we must return to that original sense of MAID being towards the end of life for terminal conditions, and we have to fix those conditions for disabled people.

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

I'll now hand this over to my fellow chair for the round of questions by senators.

The Joint Chair (Hon. Marc Garneau, Senator, Notre-Dame-de-Grâce—Westmount, Lib.): Thank you, Senator.

[Translation]

We will now go to the round of questions from the senators.

Since some senators had to leave the meeting, the first three senators will have four minutes each.

We will begin with Senator Mégie.

Go ahead, Senator Mégie.

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

Thanks to the witnesses for providing us with this information.

My first question is for you, Dr. Coelho, and I would ask you to answer briefly.

When I practised medicine, one of my patients had multiple sclerosis. He suffered greatly and had only vestigial mobility in his fingers as he tried to bring his hand up to his mouth. He asked me to do nothing and to let him die if one day his heart stopped beating. One day his heart did stop and we reanimated him. He later told me that he was happy we had done so, that he was all there mentally and that he didn't want to die.

Do you have those kinds of patients?

If we were to transport that patient 20 years forward to the present, to 2022, would that kind of patient request medical assistance in dying?

I'd like you to paint a picture here, but briefly, because I also have a question for Ms. Hewitt.

[English]

Dr. Ramona Coelho: I will try my best, and thank you for the question.

Through Mr. Chair, I would say that I also did home care for people with severe mental health addictions, dementia and disabilities in Montreal before I relocated to London. Many, many times I've accompanied people through suffering—medical and psychosocial suffering—and they were able to overcome this and be super happy to be alive. Most of it required time. The CLSC system in Montreal was amazing when I was there. We had PSWs and a whole care team, and we were able to abate those death wishes.

[Translation]

Hon. Marie-Françoise Mégie: Thank you.

My next question is for Ms. Hewitt. Mr. Adair may answer it too, if he wishes.

I know you've seen the letter that 43 senators signed in January 2022 asking the federal government to promote Bill C-35. The purpose of that bill was to create the Canada disability benefit. Do you think that introducing a guaranteed basic income for persons with disabilities would be enough to prevent them from requesting medical assistance in dying?

• (2025)

[English]

Ms. Michelle Hewitt: Thank you so much for your question.

I think there are many things about the Canada disability benefit that are still unknown, such as eligibility and the amount. There are also things that relate to how much it actually costs, and where the poverty line would sit if you are somebody who is disabled. Research from other countries would say that the line is 40% more for the disabled than for those who don't have disabilities.

The poverty line is the poverty line. A common phrase that I know Mr. Adair has heard me use is that “it's not lollipops and rainbows; it's still the poverty line”. It's a start of where we need to get people to. Mr. Adair spoke of housing. When it comes to treatment, we need people to be able to function so that they can deal with their disability rather than dealing with the double whammy of their disability and abject poverty.

It's a start, but do I think that the Canada disability benefit alone will stop disabled people accessing MAID? My personal opinion is no, that it's one of a package of measures that we need to do as a country.

[Translation]

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

We will continue with Senator Kutcher.

Go ahead.

[English]

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

I have three short questions for Dr. Coelho, and then one slightly longer one for Michelle Hewitt.

Dr. Coelho, we have heard that many MAID providers are family physicians. I'm wondering if there is a consensus amongst family physicians that they all should inform patients about MAID even if their conscience precludes it.

Dr. Ramona Coelho: I'm so sorry Senator Kutcher; I don't know what you're talking about.

Hon. Stan Kutcher: What if a family physician feels that in their conscience they shouldn't tell a patient about MAID? Do all family physicians think that every family physician must, at all times, tell patients about MAID being available?

Dr. Ramona Coelho: I'm so sorry, I'm struggling. I don't know that there's any consensus on this issue. I am saying that Susan MacDonald and other people at the committee said that it should be part of informed consent, and I'm saying that's a very dangerous principle to apply when we know that there's discrimination in health care, like the B.C. report, "In Plain Sight", demonstrates.

Hon. Stan Kutcher: I appreciate that. That's what I was asking, whether there was consensus on that.

The second question, again, is on family physicians. Do they have consensus about MAID being provided to track one patients, as they currently are identified. Is there consensus amongst family physicians that they should be provided with it?

Dr. Ramona Coelho: Again, through you, Mr. Chair, Senator Kutcher, I don't actually know. I'm not an academic family physician; I'm a family physician who works, really, on the margins. I do connect with other family doctors who work in marginalized communities. We are all concerned about this. I have no idea, and I can't comment on the consensus of family doctors.

Hon. Stan Kutcher: Okay. So, you wouldn't know whether there's a consensus, or not a consensus, among family doctors about any aspect of the provision of MAID.

Dr. Ramona Coelho: I really wouldn't, so I can't answer the question. I'm sorry.

Hon. Stan Kutcher: Thank you very much. I appreciate your trying.

Michelle Hewitt, I think that everyone on this committee would agree that poverty and any other social or economic factors should not be the driver for MAID. The expert committee report noted that persons with a disability who request MAID should be offered housing and income assistance and other needed supports.

Would you agree that such safeguards should be provided to any person with disability who requests MAID?

Ms. Michelle Hewitt: I would say that housing and not having to live in poverty, as well as access to treatment, should be provided to all disabled people, whether they are approaching MAID or not. I believe that disabled lives are worth living, that we contribute to our society in so many ways, and at the moment there is a lot of

suffering in the disability community that isn't caused by our disabilities or impairments. It's caused by—

• (2030)

Hon. Stan Kutcher: I completely agree with you on that. However, our discussion is about MAID.

Ms. Michelle Hewitt: Right.

Hon. Stan Kutcher: The question is, if a person is disabled and doesn't have adequate housing and adequate social supports, as part of that MAID assessment, should those be offered to the person? That's the question.

Ms. Michelle Hewitt: Absolutely.

Hon. Stan Kutcher: How urgent would that be, in your opinion?

Ms. Michelle Hewitt: I would say that it's extremely urgent. A person who has got to the position of applying for MAID is already in crisis and would need a lot of support to put those complex pieces in place.

I would hope that's what we would be offering, that there would be a position, a person, a body, who would examine those complex pieces that go into those decisions.

I used the example of my friend Madeline. She knows exactly what she needs in order not to access MAID. She needs the treatment options that she can't afford and that work for her successfully.

Hon. Stan Kutcher: Right.

So if someone says, look, this is helpful to me and I need it, this should be considered, and every effort should be made to provide that to them.

Ms. Michelle Hewitt: Absolutely.

Hon. Stan Kutcher: Thank you very much.

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

[Translation]

Now it's Senator Dalphond's turn.

Senator Dalphond, you have four minutes.

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

[English]

My question will be for Ms. Hewitt.

You saw the task force report, and I'm sure you read it, as I did. The members of the group expressed consensus on the way the evaluation should be made, and they stressed the importance of socio-economic factors in the thinking process of the requester.

Am I to understand, from what you say, that this is not enough? If what they are proposing to make sure that the assessment rests on proper informed consent and not a short reaction to socio-economic difficulties is not enough, what kinds of other guidelines would you suggest we have to prevent people from requesting—not requesting, but receiving MAID? There's a distinction before requesting it and getting the assessors to agree that you're entitled to it.

Ms. Michelle Hewitt: I'm sorry, was that addressed to me? I think it was.

Hon. Pierre Dalphond: Yes. Sorry, I wasn't clear.

Ms. Michelle Hewitt: As I just mentioned, I think the role there has to not be just to examine those conditions leading someone to follow through with MAID, but the solutions have to be put in place. That's the piece that is missing, that the assessor sees there are these extraordinary needs that are causing this suffering.

We go to great lengths in this country to take care of all kinds of people in all kinds of ways. We had an incredible response when we started the pandemic. We found vaccines and we rolled them out and those sorts of things. We rose to the challenge. We are not rising to that challenge when it comes to people who are in such crisis that they are not only asking to access MAID, but they are following through and dying.

I can only refer you back to my friend Madeline and her desperate need for treatment.

Hon. Pierre Dalphond: Do you think, for example, as one of the safeguards is a 90-day period, if somebody's in crisis, time will maybe help to solve the crisis? The assessors must try to understand the real reason why the person is asking to have access to MAID and try to redirect that person to proper social assistance, if available.

• (2035)

Ms. Michelle Hewitt: My question would be back to you all. What if that proper assistance is not available, but it is still necessary to relieve that suffering?

I strongly urge you to say that we're better than this. We can find these solutions for these people. Accessing MAID for non-medical reasons—for suffering that can be alleviated by other conditions—is simply unacceptable. With those safeguards and in those 90 days, what are those assessors going to do? Who's going to take that responsibility?

Are you, as parliamentarians, going to stand up and say that you will fund those things that desperately need to happen? That's what we need.

Hon. Pierre Dalphond: Thank you.

[*Translation*]

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

[*English*]

We'll now go to Senator Martin for three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Co-Chair.

I want to thank the witnesses for your very compelling testimonies.

Mr. Adair, my father suffered from spinal cord injury. He showed us his incredible strength through the suffering he endured. Thank you for your important work.

My question is for Dr. Coelho.

I'm wondering if you could comment on the scope of MAID that's being looked at by our committee. Do you have any comments as a family physician and from the experience you bring?

Dr. Ramona Coelho: Thank you.

I've watched every hour of the AMAD committee thus far. Up until today, committee members have disputed the truthfulness of stories that have been shared by witnesses who have come forward and said that MAID professionals are beyond question.

Consistently, there has been talking on top of experts who have been warning about caution and even questioning their integrity. As well, some physicians on the committee have really failed to provide the expected medical expertise surrounding clinical epidemiology or correct guidance on how to approach this as a medical procedure.

The cases of concern that we've all mentioned signal that the MAID regime safeguards do not work to protect Canadians. These stories contradict the statements by Abby Hoffman in committee, which were that there are simply no problems with the MAID regime. They actually point to inadequate data collection. You can't make good decisions if you don't have data.

Committee members asking loaded questions with only one-word answers have tried to paint concerned witnesses as wanting Canadians to suffer through years of useless treatment, but actually the reality is that patients are waiting years for treatment and this wears people down.

Consider that Ellen Wiebe testified that if someone wanted MAID, because it took five years to access the service, she would consider that irremediable. Patients with unaddressed psychosocial suffering will, therefore, be given MAID by assessors like her.

Audrey Baylis said she'd rather die than live in a nursing home. That is actually a statement about the atrocious state of our underfunded long-term care centres.

Also, I keep hearing a recurring legal argument that withholding MAID from certain groups is discriminatory, but this is not how medicine works. In medicine, we have strict, medical standard-of-care safeguards, as well as required eligibility to meet criteria for a treatment. Persons with mental illness with or without disability, which is often exacerbated by psychosocial suffering, have a disease process that can predispose them to suicidality with no proof that their suffering is irremediable. We just don't have the evidence.

Thomas Insel, former head of the NIMH, wrote a book called *Healing*, in which he confirms the unknown prognosis of mental health disorders and outlines how prognosis does depend on community life, supports and productivity—purpose.

In light of this, the government providing death as an option while simultaneously failing in its duty to provide timely care, supports, enriching community life and livable income is actually quite shameful.

Mr. Luc Thériault reassured us that if the expert panel and special joint committee arrive at the conclusion, that mental illness should be excluded, we should be reassured it would be, but we know now that the expert panel didn't even weigh in on that important question.

The Quebec commission has decided that MAID for mental illness should be excluded.

Mr. Chair, thank you for inviting me. The work of this committee is so important. I ask you for an honest review because your MAID regime is very dangerous.

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

This concludes our first panel. On behalf of all the committee members, I want to thank Dr. Coelho, Ms. Michelle Hewitt and Mr. Bill Adair for giving their time this evening on this extremely important topic of the theme of people living with disabilities in the context of medical assistance in dying. Your testimony and your candour in answering our questions are very much appreciated.

We still have a long way to go. We hope you'll follow us as we move forward. Your testimony tonight is very much a part of it, so thank you very much.

With that, colleagues, we will suspend briefly in preparation for the next panel.

Mr. Clerk, tell me when the panellists are up and checked so we can get going and start right away. Thank you.

● (2035) _____ (Pause) _____

● (2040)

The Joint Chair (Hon. Marc Garneau): Welcome to our witnesses this evening. For the benefit of the committee, we have the following people with us. We have Jocelyne Landry, who is appearing as an individual. From the Quebec Intellectual Disability Society, we have Madame Amélie Duranleau, executive director.

[*Translation*]

She is accompanied by Samuel Ragot, who is a senior policy analyst and advocacy advisor.

[*English*]

We also have, from the Wabanaki Council on Disability, Mr. Conrad Saulis, executive director.

Thank you for joining us.

The way we do this starts with opening remarks. Each of you will be given five minutes to make an opening presentation and we'll follow that with questions.

With that, I would like to invite Ms. Landry to begin, followed by Ms. Duranleau and then Mr. Saulis.

Ms. Landry, you have the microphone for five minutes.

[*Translation*]

Ms. Jocelyne Landry (As an Individual): Thank you, Mr. Chair.

I won't need five minutes.

I come from a region in northern New Brunswick, more specifically from a tiny village called Balmoral. I live in Charlo, on the coast of the Bay of Chaleur. I'm here because my father requested medical assistance in dying two years ago. That's why I agreed to appear before you and to share my experience.

My father had convictions and the courage of those convictions. He was at the end of his life. He had cancer and was really suffering at the end. He had told us several years before then that he had made his decision. As a family, we of course respected that decision. I'm not happy about losing my father, but I'm happy that he had access to medical assistance in dying and that he was able to choose how he wanted to leave us.

That's my experience in a nutshell. Thank you.

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

[*English*]

Next, from the Quebec Intellectual Disability Society, we have Ms. Amélie Duranleau.

Ms. Duranleau, you have five minutes.

● (2045)

[*Translation*]

Ms. Amélie Duranleau (Executive Director, Quebec Intellectual Disability Society): Thank you very much.

Ladies and gentlemen, members of the Special Joint Committee on Medical Assistance in Dying, or MAiD, we would first like to thank you for the opportunity you have given the Quebec Intellectual Disability Society today.

We wish to make it clear that our organization is not opposed to medical assistance in dying for people nearing the end of their lives. Rather, we ask that adequate safeguards be put in place to ensure that no abuses occur. We believe that legislators must be cautious and consider the systemic forces that could threaten people with disabilities and specifically people with intellectual disabilities.

It should be noted here that intellectual disability, or disability in general, should never be a criterion for access to MAiD. With the necessary support and appropriate accommodations, people with intellectual disabilities can live fulfilling and rich lives. If people find themselves living with intolerable suffering related to their intellectual disability, it is because society does not include them, and they lack services.

The Society is also very concerned about the possibility of authorizing substituted consent for incapacitated persons at all stages of MAiD applications. This possibility had been raised by the Quebec National Assembly and, even if such a question is not under consideration today, it is important to discuss it.

On the one hand, the use of MAiD should always be tied to the validation of a free and informed consent from the person who will receive it; on the other hand, it may be difficult to assess this consent for incapacitated persons, especially those with a more severe intellectual disability. If these persons experience distress in relation to the death of someone close to them, it is generally more difficult for them to understand the permanent and irreversible nature of their own death. We therefore call on the legislator not to allow substituted consent for those who lack capacity to consent.

Regarding the legislator's desire to potentially allow the use of advance directives for access to MAiD, we would like to refocus the debate on the issue of the validity of consent in these situations. Asking a third party to consent to a procedure that leads to death through a substituted decision-making process is different from making advance requests to refuse certain procedures that may lead to natural death. In this light, opening the door to substituted consent, even for people who had previously consented, seems to us to be potentially dangerous and to fail to respect the spirit of the Carter decision which put the issue of consent at the heart of access to MAiD.

In our view, it is important to provide satisfactory alternatives for people with disabilities. This position has been advanced by the Canadian Human Rights Commission. Universal and high-quality public services, in sufficient quantity, must be provided to people who need them. Indeed, this is an obligation that Canada has towards people with disabilities under the Convention on the Rights of Persons with Disabilities. Thus, satisfactory alternatives are needed to provide a dignified life for people with disabilities and for the Canadian population in general.

As mentioned previously, we believe that MAiD should be a measure of last resort for people who are capable of giving free and informed consent and who, at the end of life, are living in unbearable suffering. We also distinguish between the issues of advance care directives and advance directives in relation to MAiD. The former allows for natural death, while the latter entails the use of an active procedure that ends life without clear and validated consent.

Furthermore, we believe that substituted consent should never be allowed for incapacitated persons, as they cannot provide free and informed consent. The Carter decision put the issue of consent at the heart of access to MAiD. It is important to respect this fundamental principle of health justice and ethics.

Finally, in the event that people with intellectual disabilities at the end of their lives make an application on their own, without any undue pressure, then we believe that they should be assessed like all other people, as long as their access to MAiD is not granted on the basis of disability.

● (2050)

However, it is important to have stronger safeguards in place to prevent ableism and the devaluation of the lives of people with disabilities.

Thank you.

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

[English]

We'll now go to Mr. Conrad Saulis.

Mr. Saulis, you have five minutes.

Mr. Conrad Saulis (Executive Director, Wabanaki Council on Disability): *Woli-Wolaqiwiw.* Good evening.

Woliwon, thank you for the opportunity to present to your committee this evening.

My name is Conrad Saulis. I am with the Wabanaki Council on Disability. We work to support indigenous persons with disabilities living on our traditional and ancestral Wabanaki lands. We work closely with a key partner, the Mawita'mk Society, an on-reserve group home providing services to persons with disabilities.

I want to acknowledge that I'm speaking to you this evening from and on the sacred, unceded, unsundered ancestral lands of the Algonquin nation.

I will right away that MAiD is not a readily welcomed concept or term for indigenous peoples of the Wabanaki lands. We have experienced far too much death in our families, communities and nations since first contact. Colonization has brought over 500 years of death, language and cultural knowledge loss, and loss of our ancestral lands for our nations and people. Believe me when I say that we are far beyond tired of losing things, including our identities as Wolastoqey, Mi'kmaq, Innu and Inuit, and our cherished family members.

We are tired of mourning the loss and deaths of our young people and of persons with disabilities. Both of these populations are amongst the most highly vulnerable peoples of this country and we believe that we must do everything we can to help them to continue to live their lives, find their identities and be meaningful people in our families, communities and our societies. Rather than finding ways of ending the lives of our young people and persons with disabilities, we would rather so much want to be finding the ways to extend their lives and to keep them in our families.

Our families have lost far too many children and youth during the residential and day schools era, which lasted for over 125 years. We have lost too many children and youth to child welfare agencies. What we want is to find ways to keep individuals, families and communities strong and to be embraced in our languages, in our cultures and in our traditional ancestral knowledge.

We want to establish the programs, services and supports that our youth and persons with disabilities need. They do not need to find a way to die; they need to find ways to re-establish their self worth to combat mental illness. We want them to be well. They want to be well. We want them to be well in their emotional, spiritual, physical and mental aspects. We want them to be well in the holistic views of our ancestors within the teachings of the medicine wheel. We want to see the world, Mother Earth and life that she sustains from the values of our ancestors through the Wabanaki world view of respecting all life.

We don't need or want to establish more ways for indigenous youth to die. There's enough death in our communities and families already. There are already enough existing threats.

There is so much systemic discrimination in the Canadian medical system. I remember, and we should all remember, Joyce Echaquan and the humiliation she experienced, which contributed to her unnecessary death in a hospital. Ms. Echaquan, sadly, is only one example of the indigenous people who have died due to systemic racism. There are many more in this country.

I reached out to indigenous youth last week on MAID. Their fear was immediate. Their fear of MAID lasted throughout our conversation. They spoke of mental wellness challenges, of youth suicides in their families and communities. They wanted to speak about how we can help our youth to be mentally well and speak the languages of their ancestors as a way to improve their self worth, value and identities. They spoke about how their youth group and conversations are part of their healing. Talking is healing. Being around people you trust and who care about you is healing.

My mother spent her later life helping to heal Wolastoqey children by teaching them the Wolastoqey language in the school they attended. The school was a part of the provincial education system, located in the city, not on a reserve. She's passed into the spirit world now, but her legacy continues in the lives of those children she positively impacted through the language and cultural learning.

● (2055)

One of our regional partners stated:

All indigenous youth have specific lived experiences with intergenerational trauma stemming from displacement/forced relocations from ancestral lands, the Indian Act, Indian Residential School, the foster care system, etcetera. For these reasons, we know and have empirical evidence to show that Indigenous youth mental health is poorer compared to non-Indigenous youths' mental health.

Last week the Wabano Health Centre and the Ottawa Aboriginal Coalition released a new report focused on racism in the health care field titled "Share Your Story, Indigenous-Specific Racism in Health Care Across the Champlain Region."

Amongst the findings they presented in the report are these:

There were five stereotypes that emerged from the data: 1. Indigenous people are racially inferior; 2. Indigenous people are diseased, addicted, and mentally unwell; 3. Indigenous people are a burden; 4. Indigenous people are angry and aggressive; 5. Indigenous people are bad parents.

I recommend that you invite the Wabano Health Centre and the Ottawa Aboriginal Coalition to present to you as well.

Woliwon psi-te wen. Thank you, everyone.

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

I will now hand it over to my fellow chair, Senator Martin.

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

We'll begin with questions for a five-minute round. The first questioner will be MP Dominique Vien.

[*Translation*]

Mrs. Dominique Vien (Bellechasse—Les Etchemins—Lévis, CPC): Thank you very much, Madam Chair.

I want to thank our guests for agreeing to meet with us this evening despite the late hour.

Good evening, Ms. Duranleau, and thank you for being here.

The use of medical assistance in dying for persons living with an intellectual disability is obviously a concern, and, if my understanding is correct, you're opposed to it.

My knowledge in this field is limited, but I understand there's a gradation across the spectrum of intellectual disabilities. Is that in fact the case?

Ms. Amélie Duranleau: Yes, there is a gradation.

We're talking here about medical assistance in dying for persons who are incapable of making decisions regarding their health. I want to emphasize that they represent only a segment of persons with intellectual disabilities. I must emphasize that many persons with intellectual disabilities would be able to request MAID on their own because they're capable of making decisions concerning their own lives.

I'm going to yield the floor to my colleague, Mr. Ragot, so he can round out this part of the answer.

Mr. Samuel Ragot (Senior Policy Analyst and Advocacy Advisor, Quebec Intellectual Disability Society): Thank you.

Some people with mild intellectual disabilities are entirely capable of requesting medical assistance in dying for themselves. However, it's important that the decision be made without undue pressure, that the individual truly give free and informed consent, and that the request not be made for economic or social reasons. The request for MAID must truly be made in an end-of-life context in which the person is experiencing intolerable suffering consistent with the current criteria of the first component of Quebec's Act respecting end-of-life care.

Mrs. Dominique Vien: So, as I understand it, that's an essential condition for you.

Mr. Samuel Ragot: That's absolutely the case.

Mrs. Dominique Vien: What kind of abuses are you afraid of?

Mr. Samuel Ragot: That's an excellent question.

Sometimes, for example, we get calls from aging parents who have children with intellectual disabilities who are in their fifties. In some cases, the services offered are minimal, or even non-existent, and the parents wonder what will happen to their children once they themselves have died. Sometimes the parents tell us that they would decide to give their children access to medical assistance in dying if they could. It's tragic.

This raises some major issues. These are obviously tragic situations, and the solution probably isn't medical assistance in dying but rather a social response, to provide services, housing and financial security to those disabled individuals, as we mentioned earlier.

As I said, we're unfortunately hearing these things more and more frequently.

• (2100)

Mrs. Dominique Vien: Do you think that persons with intellectual disabilities who are aware of medical assistance in dying are so because they've inquired on their own or because someone has told them about it?

Mr. Samuel Ragot: That's a difficult question to answer without making unfair generalizations.

We've definitely read in the newspapers about people who are offered medical assistance in dying for lack of a better solution or for a lack of services. In light of those incidents, could we say that medical pressures may be brought to bear based on a certain undervaluation of the lives of people with disabilities? That must definitely occur. Can certain persons make valid and legitimate requests by exercising free and informed consent? That surely happens as well.

The greater concern is obviously undue pressure and the fact that MAID may be proposed by default or for lack of a better option.

Mrs. Dominique Vien: You talked about substituted consent. That refers to a situation in which someone makes decisions for a child with an intellectual disability, doesn't it?

Mr. Samuel Ragot: Absolutely.

Mrs. Dominique Vien: Are you telling us about this because parents tell you they'd choose that option if it were available?

Mr. Samuel Ragot: Absolutely.

[*English*]

The Joint Chair (Hon. Yonah Martin): Be very brief.

[*Translation*]

Mr. Samuel Ragot: That option has also been discussed in the National Assembly of Quebec, where it was rejected. Consequently, it wasn't included in the bill that was introduced last week.

Substituted consent has always been a relatively easy solution to apply to to prevent certain individuals from having genuine legal capacity. Rather than give those persons the tools with which to exercise their own rights, the system often grants substituted consent to parents, in particular, and families.

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

Mrs. Dominique Vien: Is my time up?

The Joint Chair (Hon. Yonah Martin): Yes.

[*English*]

Next, we will have Dr. Fry for five minutes.

Hon. Hedy Fry: Thank you very much, Chair.

Today, I guess I heard a lot of compelling evidence of both people who were disabled and people with intellectual disabilities. I think all of it makes a lot of sense. Obviously, if we had a system in which we could give everybody the support they needed, economically, psychologically and socially with support systems in place for them, and then people, having lived with that, still believe they would like access MAID with informed consent, I can see that happening.

I think you're absolutely right. I was appalled to hear some stories today about people who chose MAID purely because they were living in poverty and couldn't even afford treatments.

I could ask you what all three levels of government should do to give that kind of access, to create a system in which, when you look at all of the psychosocial supports that are needed, they are indeed there and are done. What would you suggest that all three levels of government do to create a seamless system, because provinces are responsible for thing A, and the federal government is not responsible for it, and of course we have a patchwork across the country. What would you suggest?

I'll ask Monsieur Ragot.

[*Translation*]

Mr. Samuel Ragot: Thank you for your question.

That's another question that's very hard to answer. As our colleagues in the Disability Without Poverty movement said, what's needed is money, a decent income, accessible high-quality public services and, of course, housing that's secure, accessible, of good quality and suited to the needs of persons with disabilities.

Transportation also has to be provided so people can get to work or to the place where their services are provided. We also need psychosocial services: social, psychological and psychotherapy services. There has to be a set of support services for persons with disabilities. It really takes a mosaic of services for people really to be well...

• (2105)

[*English*]

Hon. Hedy Fry: But it shouldn't be a patchwork, actually. I would suggest—

The Joint Chair (Hon. Yonah Martin): Dr. Fry, I apologize. There was a slight miscommunication and Mr. Arseneault will take the other half, if that's okay. I believe one of his witnesses is here this evening.

Thank you, Dr. Fry.

Monsieur Arseneault.

[Translation]

Mr. René Arseneault: Thank you, Madam Chair.

My first question is for Ms. Landry, I know it's late where you are, nearly 10 o'clock.

Some people who oppose medical assistance in dying tell us that inadequate palliative care could be driving the increased demand for MAID. According to the statistics, approximately 83% of people who've requested such assistance were already in palliative care, and approximately 15% had decided against palliative care and requested MAID directly.

Would you please describe your father's experience in that context?

Ms. Jocelyne Landry: That's exactly the situation my father was in. He was at the end of life, clearly. He was technically in palliative care, but he had been ill for years. He had had cancer for almost 20 years. He had always said that when there was no longer any quality of life and he was suffering too much, he would opt for medical assistance in dying, and that's exactly what he did. He waited until there was no longer any quality of life before making the request. Technically, he was receiving palliative care. He had been prescribed medication, including morphine, but he refused to take it. He wanted to remain lucid up until the final minute. And then, one day, he requested medical assistance in dying.

I was shocked to hear in the earlier presentation that people had been able to receive medical assistance in dying within 48 hours. In my father's case, it took two weeks after he made the request. The doctor and the medical team regularly checked with him about his request right up until the final minute, over a period of two weeks.

So the process wasn't exactly rapid. By rapid I mean that it wasn't within the 48 hours mentioned in the example we were given earlier about how things are apparently done elsewhere.

Mr. René Arseneault: Thank you very much, Ms. Landry.

My next question is for Mr. Conrad Saulis.

I agree with and understand what you were saying about the fact that suicide in your community is not an option and that the emphasis is on resilience, healing and hope. I would like to see all communities in Canada, no matter where they may be, give the same message to their young people.

Last week we heard from expert witnesses who told us that they could distinguish between someone with suicidality who is requesting MAID, from a person who is making the same request, but who does not have suicidal tendencies.

A few of my colleagues were reassured by these comments.

What's your view of psychiatrists who tell us that they can make this distinction?

[English]

Mr. Conrad Saulis: The measures are of cultural differences. First nations, Métis and Inuit cultures are vastly different from mainstream society—European society. We live in your society. We live under your terms and conditions. We'd love to be living under our terms and conditions. Being assessed by the standards, values

and morals of the European societies that came over here and established the governments in place does not provide the kind of cultural support or knowledge required to determine when an indigenous person might be considering, or acting on thoughts of, suicide.

• (2110)

Mr. René Arseneault: Sorry to interrupt, Mr. Saulis. Time goes by so fast here.

If you had one recommendation for a safeguard—only one—what would it be?

Mr. Conrad Saulis: Regarding safeguards, I would say there definitely need to be regulatory requirements for people involved in the medical field who are providing this advice to individuals. They would need to seek out supportive advice from elders, knowledge-keepers and family members. That would be a legal requirement for those medical people.

The Joint Chair (Hon. Yonah Martin): Thank you, Mr. Saulis, and Mr. Arseneault.

Next we'll go to Mr. MacGregor, followed by Mr. Thériault.

Go ahead, Mr. Thériault.

[Translation]

Mr. Luc Thériault: Thank you, Madam Chair.

My questions are for the representatives of the Quebec Intellectual Disability Society.

In one of its recommendations to us, the Association québécoise pour le droit de mourir dans la dignité stated the following:

To temporarily maintain a complete prohibition on eligibility for medical assistance in dying for persons with a serious intellectual disability unless there is absolute certainty about the person's decision making capacity.

I was reading the brief that you submitted to the Select Committee on the Evolution of the Act respecting end-of-life care, in July 2021, and noted that it could also apply to your second recommendation, which was, in all instances to prohibit proxy decisions on behalf of people with an intellectual disability who are deemed unable to consent. So far, I would imagine, you might find that reassuring.

You also made other interesting recommendations which I believe are consistent with best practices and reflect what appears to currently apply in medical practice. You also said that it was essential to “require that persons with an intellectual disability be unable to apply for medical assistance in dying unless they are at the end of life”. I think that borders on the grey area between capacity and incapacity, in which case I would like to know how one determines decision making capacity

Ms. Duranleau or Mr. Ragot, can you provide an example of a case that would fall into this grey area?

Ms. Amélie Duranleau: Mr. Ragot will answer your question.

Mr. Samuel Ragot: That's a difficult question to answer.

The research would appear to show that people with an intellectual disability understand the death of people around them. That's pretty clear. They can deal with and live with such situations. What is less obvious is whether they are capable of understanding the irreversible aspect of their own death. That's when we find ourselves in a grey area that is very difficult to sort out, as you've just said.

In Quebec, the difference between medical consent and legal consent, in terms of signing a contract, for example, is established by means of tests to determine their understanding of the medical procedures at issue. To my knowledge, there is no perfect tool to determine whether a person is capable of understanding their decision to request medical assistance in dying. It really depends on the severity of the intellectual disability.

Mr. Luc Thériault: You require that a physician with relevant skills and expertise in intellectual disability participate in the assessment of the request. I would imagine that the corollary of what you just explained. I think that goes without saying.

You also raised all the issues surrounding socioeconomic inequality. I further believe that the assessors would clearly have to take all of that into account. That's also something that was noted in the expert report on mental health.

Not only that, but you said that all applications for medical assistance in dying should require a mandatory comprehensive statement from the health professional. I'm not sure what you're thinking of specifically, given that there are reports already. There is a Quebec commission that examines every medical procedure.

Do you think that something more is required? I would imagine that it's not anything too complicated. What form might it take?

• (2115)

Mr. Samuel Ragot: There was the Vulnerable Persons Standard, which had been put forward in connection with the first medical assistance in dying bill. The standard suggested measures that would analyze the social determinants of health and other determinants of people's vulnerability, and requested that more exhaustive reports be prepared. This would make it possible to document the real reasons why people were requesting medical assistance in dying, which might have been less obvious on the surface. That's also what underlies our advocacy role, because we know that there are many social determinants of health and vulnerability that act as major motivating factors for some people who are requesting medical assistance in dying.

Mr. Luc Thériault: Your seventh recommendation is "to require that discussions on medical assistance in dying be initiated only by patients". Your eighth recommendation is to "consult the immediate family when assessing a medical assistance in dying application" for cases involving an intellectual disability. I believe that these are measures that should be part of medical practice. Do you get the impression that the assessors or providers would not be receptive to that?

It seems to me that the medical community would be altogether prepared to talk with the families. It goes without saying.

[English]

The Joint Chair (Hon. Yonah Martin): Be very brief, please.

[Translation]

Mr. Samuel Ragot: Absolutely. I agree.

I think it's mainly about avoiding applications being made as a result of pressure from medical staff or elsewhere, and which could result from a certain form of ableism towards these people. It's a matter of protecting them against having their lives undervalued, and being placed under undue pressure.

[English]

The Joint Chair (Hon. Yonah Martin): Mr. MacGregor, you have five minutes.

Mr. Alistair MacGregor: Thank you very much, Madam Chair.

Mr. Saulis, I'd like to start with you and thank you for appearing before our committee and offering an important indigenous perspective on this conversation we're having.

You very correctly outlined the disparities that exist and the intergenerational trauma that is still there. I know I see it in communities where I live, among the Halkomelem-speaking people, the Coast Salish and the Nuu-chah-nulth nations.

I've gotten to know many elders in my time as a member of Parliament, and the hurt is there; it's just below the surface.

When you look at the calls to action that were released so many years ago, and particularly the health calls to action, calls to action 18 to 24, do we need to frame this conversation about medical assistance in dying with that frame in mind, the fact that so many of these calls to action, particularly on health outcomes and the supports and services that are available for first nations, Inuit and Métis across Canada are still so substandard? Can you expand on that, please?

Mr. Conrad Saulis: I think the calls to action are an excellent blueprint for moving forward together with indigenous peoples. I think there is always a need for continuing dialogue between jurisdictions, federal and provincial, and indigenous nations, whether they be first nations, Métis, or Inuit. Dialogue and conversations are what's needed.

The health calls to action, absolutely, are definitely things to utilize and to be benchmarks as we move forward. I think there needs to be a lot of caution and concern, though, with regard to moving forward with anything that speaks to or is about medical assistance in dying and indigenous peoples.

Sam's comments were about social indicators being things that can be misleading, because indigenous people have such a vastly different quality of life, substandard quality of life. When you talk about indigenous persons with disabilities and indigenous youth, like I said in my presentation, we're talking about the most vulnerable people in Canadian society.

At the same time, of course, we always have to take into consideration missing and murdered indigenous women and the outcomes of that. I think the calls to action can be one thing, but there's a lot more. There are probably things even going back to the Royal Commission on Aboriginal Peoples, to be very honest with you. Dust that off and look it over. We live in today's society as well, so the people who are in the know, so to speak, always have to be included and involved.

• (2120)

Mr. Alistair MacGregor: You mentioned the murdered and missing indigenous women. It was remiss of me to not mention the calls for justice that are in that report, as well, which have some important overlap.

Madam Co-Chair, I'm pretty close to the end of my time, so I'll thank Mr. Saulis for his intervention and cede the rest of my time.

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

Again, thank you to our witnesses.

I'll turn this back to our co-chair for a round of questions from senators.

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

[*Translation*]

Like the last time, the first three senators will have four minutes. We'll begin with Senator Mégie.

You have the floor for four minutes, Senator.

Hon. Marie-Françoise Mégie: Thank you, Mr. Chair.

Thank you to the witnesses.

My questions could be for all the witnesses, but one or two of them might be able to answer.

Normally, a doctor or any other health professional could explain the various treatment options to a patient, whether for palliative care or intensive care. However, the anecdotal evidence reported not only by the media, but also by witnesses, gives me the impression that these people requested MAID or were forced to request it.

How do you, as someone with a disability, feel about this?

Do you have the impression that no matter where you go, you'll be pressured to apply for MAID, when you're the person who should be deciding?

Is that something you're concerned about?

I'm not sure who might want to answer my questions.

The Joint Chair (Hon. Marc Garneau): Perhaps we could begin with the representatives of the Quebec Intellectual Disability Society.

Please go ahead.

Mr. Samuel Ragot: While that's a very difficult question to answer, I would nevertheless say that ableism is insidious. It's not openly displayed, or explicitly referred to, very often. It's something that shows in attitudes, social judgments and obstacles that

people come up against in society. It can sometimes occur in the medical field, of course.

It bears repeating that the services available are inadequate. As we have been able to see, there's a shortage of staff in hospitals. Our health services are in a terrible state, particularly after the pandemic. This can indirectly result in resorting to MAID rather than providing services. That's something we often hear on the ground.

Hon. Marie-Françoise Mégie: If you were offered this option, you could refuse it, couldn't you?

Mr. Samuel Ragot: If another option were available, then yes, but very often that's not the case.

Hon. Marie-Françoise Mégie: Would another witness like to answer my questions?

Perhaps Ms. Landry could give us her thoughts on the matter.

• (2125)

Ms. Jocelyne Landry: Thank you for your question.

In my father's case, no one offered him this option. It really was a personal initiative. He requested MAID. As I mentioned earlier, the process ended up taking much longer than we've been talking about here. The people were very professional. They also spoke to him about it, questioned his initiative and returned repeatedly to ask the same questions again to make sure that's really what he wanted. They also wanted to make sure that he had not been pressured by anyone.

They always showed respect. They made sure that it was really what he wanted. Needless to say, his medical record left little doubt. He was suffering and no longer had any quality of life. Dad was a bon vivant. He never talked about dying until he was really at the end of his tether. He was suffering, and clearly at the end of life. He might have lived for a few more months.

Hon. Marie-Françoise Mégie: Thank you.

Do I have a few seconds left, Mr. Chair?

The Joint Chair (Hon. Marc Garneau): There isn't really any time left, Senator, unless all you're looking for is a short reply.

Hon. Marie-Françoise Mégie: Yes.

I don't want to be told that it's just wishful thinking, but if the government were to do everything possible and adopt proactive measures to do away with all the obstacles and systemic inequalities, do you think that people who are already being treated unfairly in terms of access to healthcare would experience the same unequal treatment in terms of access to MAID?

The Joint Chair (Hon. Marc Garneau): To whom are you addressing this question?

Hon. Marie-Françoise Mégie: To Ms. Duranleau or Mr. Ragot.

Mr. Samuel Ragot: Could you repeat the question?

To be honest, I'm not at all sure that I understood it.

Hon. Marie-Françoise Mégie: I'll give you a shorter version of it.

Given all the systemic inequalities faced by certain groups, then just as these groups have more trouble gaining access to care and services, how come they have easier access to MAID?

Mr. Samuel Ragot: It's because the measure is not expensive and it's easy to organize and offer it to people. It's a straightforward measure that requires less systemic effort. It requires less effort in terms of bias and requires less money from the government. It's just easier. Some people, and I'm not saying that it's our position, have use the term "eugenics". That's a term to be used with extreme caution, but it's something to think about.

The Joint Chair (Hon. Marc Garneau): Thank you very much.
[English]

Senator Kutcher, it's over to you.

Hon. Stan Kutcher: Thank you very much, Mr. Chair.

I want to thank all the witnesses.

My questions are for Ms. Landry. I have two questions, but before I ask them, I want to note our appreciation for your coming and talking about a very personal and difficult topic, having lived experience with MAID. We really appreciate your coming and talking about a real experience, not hypothetical experience. Thank you so much.

The first question is what difference did it make to you and your family that your father could make a decision to choose MAID as an end-of-life action?

[Translation]

Ms. Jocelyne Landry: My father was among that generation of men who took control of their lives, built their nest, started a family and made decisions throughout their lives. It was important for him, and for us, to be able to make informed choices and decisions. And this decision was something he had thought about. You might say that he decided to put an end to his suffering just as, when he was growing up on the farm, an injured horse or dog would be put out of its suffering.

Making a decision like that was important for my Dad. He didn't want to suffer any more. He had already suffered enough.

I am happy and proud to live in a country that gave my father that option. He didn't have to travel to Switzerland or anywhere else to have access to it.

• (2130)

[English]

Hon. Stan Kutcher: The other question is whether you could please share with us how you and your family prepared for your father's death by knowing when it would be. Could you consider how different it might have been for you and your family if he had died without any preparation?

Ms. Jocelyne Landry: It's a very interesting question.

It was during COVID. It was two years ago. We were in lockdown at the time.

[Translation]

It would be easier for me to continue in French, if that's all right.

Because it was in the early days of the COVID-19 pandemic, we kept the house as long as we could. He was of course receiving palliative care at the time, through the outpatient service from the hospital that would come and provide services at home when required. But Dad wanted to die at the hospital, not at home, probably because he would have found it difficult if Mom were to die at home. He therefore insisted that he be taken to the hospital. Once in the hospital, though, he couldn't have any visitors. Mom was also over 80 years old. So I found it unacceptable for her to be supporting Dad without any other help from the family. So I contacted the province's Office of the Chief Medical Officer of Health for permission to have at least one of the children providing support. We received permission. I was there the day before Dad left us, and my brother was there the day he left.

The preparatory process was gradual. For a number of years, Dad had been telling us that once he no longer had any quality of life and wanted to put an end to his suffering, he would request medical assistance in dying. He came to that decision quite a long time beforehand. He had spoken to his doctor, but that's not who performed the procedure. The Restigouche medical team in charge of the procedure was very conscientious and did their work highly professionally. Not only that, but for Dad, the wait was a little too long. He would have liked to go to the hospital and for it to be done within a few hours or days. But it took a lot longer. Towards the end, he was saying that waiting to die was taking too long. He nevertheless joked with us right up to the final minute, but he was ready, and we said goodbye to him.

When I drove him to the hospital with Mom, we were crying, of course, but I respected his decision and it was important for us to tell him so. We understood his suffering and respected his choice. I think that it was important for him as well as for us.

For my mother, the experience was different. When her father had died, she was with him, and he died a peaceful, natural death. She always used to say that her father's death was like a candle burning out. For my father, however, the emotional experience was different. He was her spouse, they were the same age, and they had shared 60 years together.

It was therefore more distressing and difficult for her, because the process took a lot longer than she had expected. After the drugs had been injected, it took about 20 minutes for his heart to stop beating. But even though she found it distressing and hard, she respected his decision.

Up to that point, my mother had always said that when she was ill near the end of life, she would opt for that solution. However, after her experience with my father, she didn't want her children to have to go through it again.

• (2135)

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

Over to you, Senator Dalphond.

Hon. Pierre Dalphond: Thank you, Mr. Chair.

I'd like to thank all the witnesses for their testimony, and we are grateful to them for having been here.

[English]

My question is for Mr. Conrad Saulis.

Mr. Saulis, I'm happy to see you back. We met two years ago when we were discussing the previous situation of the bill.

I assume you have read the report from the task force. One of the task force's recommendations is to make sure there is consultation with first nations, Inuit and Métis peoples to make the MAID system incorporate indigenous perspectives and other factors relevant to their communities. The report also notes that, to date, engagement with indigenous peoples in Canada concerning MAID has yet to occur. I understand you will be in agreement with the task force's recommendation to engage in conversations with first nations about making systems that will be culturally sensitive and that relate to the spiritual values of the first nations.

Mr. Conrad Saulis: Thank you very much for the question.

When we're talking about medical assistance in dying.... It's such a foreign concept in the first nations world, in my experience growing up on the reserve, and in all the work I've done and continue to do. As I said in a previous answer, conversations are always required and necessary for governments, as well as medical service providers, to understand the values, morals and perspectives. We look at the world through the teachings of the medicine wheel—the emotional, the spiritual, the physical and the mental. Those are very real to us. Those were almost lost to us. Conversations are always going to be necessary. Even after conversations are had, more conversations are still going to be needed, so whatever dialogue...whomever....

I know there are many first nations and indigenous people involved in the medical field, as both practitioners and analysts. I mentioned Joyce Echaquan a while ago—what she went through and the medical experience she had. Sadly, it's not any different for many of us who go from our first nation community—called a reserve—to the local hospital in town. We just know it's not a welcoming environment. How do you trust that? How do you trust an environment where you're looked down upon? The findings of the Wabano health centre here in Ottawa, as well as the Ottawa Aboriginal Coalition, are the opinions and findings of people they spoke with, and who responded to interviews and questions. Look at those conclusions. I really hope you hear from the Wabano health clinic and Ottawa Aboriginal Coalition. I'm sure they would have a lot of thoughtful and meaningful things to say based on their experiences.

• (2140)

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

Senator Martin, you have three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you to all of our witnesses.

I'll end with a quick question for Mr. Saulis to give him an opportunity to tell us what the federal government can do to care for indigenous youth instead of offering MAID.

We're discussing what would happen with mature minors. You said you spoke to youth before this, and I think your voice is very important this evening. What can the federal government do?

Mr. Conrad Saulis: I believe there is such a vacuum of youth programming and support for indigenous youth. One of the groups we're working with is an indigenous group based out of Cape Breton, Unama'ki, in Nova Scotia. They struggle and are challenged to find any kind of funding to support them to be able to have the conversations they want to have.

That's definitely one of those things. The federal government needs to have a much stronger and better program directed towards indigenous youth so that they, themselves, can come together; they, themselves, can be their own leaders; and they, themselves, can identify the things they want to talk about.

I know that invariably they're going to want to talk about language and culture and being able to connect with elders and traditional knowledge keepers and land-based learning and things like that, but they're also very serious people. I think that if those kinds of resources are provided to indigenous youth, as well as safeguards within whatever legislation and whatever policies that are in the regulations attached to the legislation.... Safeguards are needed to protect the indigenous youth of these lands.

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

[Translation]

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

We've come to the end of the meeting. I'd like to thank the witnesses who were with us this evening.

Ms. Jocelyne Landry, I'd like to thank you for your highly personal testimony about your father.

I would also like to thank the representatives of the Quebec Intellectual Disability Society. And I'd like to thank you, Ms. Duranleau and Mr. Ragot, for your testimony and for answering our questions.

[English]

Finally, Mr. Conrad Saulis, thank you very much for coming this evening and providing us with the indigenous perspective on this very important subject. We very much appreciate it.

With that, this brings us to the end of this evening's committee meeting.

We will be meeting next Monday at 6:30. Thank you.

We are adjourned.

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