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Joint Chairs:
The Honourable Marc GarneauThe Honourable Yonah Martin



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• (1830)

[English]

The Joint Chair (Hon. Marc Garneau (Notre-Dame-de-Grâce—Westmount, Lib.)): Good evening, and welcome to the meeting of the Special Joint Committee on Medical Assistance in Dying.

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

My name is Marc Garneau, and I am the House of Commons joint chair of this committee. I am joined by the Honourable Yonah Martin, the Senate's joint chair. We'll share our responsibilities this evening.

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.

I remind you that the Board of Economy requires that committee members adhere to health protocols, which are in effect until June 23. I know that you're very familiar with them. As joint chairs, Senator Martin and I will enforce these measures, and we thank you for your co-operation.

I would like to remind members and witnesses to keep your microphones muted unless you are recognized by name by one of the joint chairs. I remind you that all comments should be addressed through the joint chairs and that when speaking, please speak slowly and clearly. This is to help our interpreters. Interpretation in this video conference will work like it does for an in-person committee meeting. You have the choice at the bottom of your screen of the floor, English or French.

With that, I would like to welcome our witnesses for panel number one, who will discuss the issue of medical assistance in dying for mature minors in Canada.

We have two guests this evening. We are still trying to get the first one online, Myeengun Henry, indigenous knowledge keeper of the University of Waterloo.

Also, in person this evening, we have Ahona Mehdi, member and Just Recovery research lead of the Disability Justice Network of Ontario. Thank you to both of you for joining us.

We'll begin with opening remarks.

Ms. Mehdi, if you are ready, we will begin with you, and then we'll go to Mr. Henry afterwards.

In each case, you have five minutes, please.

The floor is yours.

Ms. Ahona Mehdi (Member and Just Recovery Research Lead, Disability Justice Network of Ontario): Hello, everyone. Thank you for having me.

My name is Ahona Mehdi. I'm 19 years old and I'm a member of the Disability Justice Network of Ontario's youth action council. I have multiple disabilities and, with respect to recent amendments to the Criminal Code, some of them would make me eligible for medical assistance in dying.

I'm here today because I'm extremely concerned and distraught, as a disabled youth, about the potential expansion of MAID to mature minors in this country.

Before I begin, I would like each senator and elected official here today to sit with this reality: Had MAID been offered to me just over a year ago when I was accessing treatments as a minor, I would not be here to testify before you today.

Elected officials, you continue to claim that safeguards will be in place for this expansion, that the assessment of MAID applications will be diligent and intentional, but how is this feasible? In Canada, disabled youth pay up to \$200 an hour for therapy, but you are looking to expand access to MAID for these youth and to make it cost-free.

I believe in the right to choose, but making MAID a default option for disabled children who have been failed by your systems equates to coercion, not choice. If this process is truly informed by disability rights and autonomous decision-making, why is it being undertaken during a global pandemic when health care professionals are more overworked than ever?

A recent survey by the Canadian Paediatric Surveillance Program shows us that Canadian health care professionals are steadily and increasingly being approached by parents of children, including infants too young to make an informed decision, regarding access to MAID. This is scary and it proves that these discussions are only amplifying suicide messaging. How has knowledge around access to MAID for mature minors been made so widely accessible when the government consistently and intentionally refuses to make home care, palliative care, assistive devices, gender affirming and culturally competent care, counselling and other resources accessible to disabled youth?

The potential of expanding track two of MAID to mature minors scares me as I think about my past experiences within the health care system. When I was 17, my loved ones admitted me to a hospital with hopes that I would receive support and care, but I was met with the opposite. My assigned psychiatrist told me that I needed to get over my anxiety if I wanted to be successful. He told me that if I ever had a suicidal thought, I should just shove it in a drawer and lock it away. As a teenager, I was placed in spaces where I was consistently harassed by other patients—adult male patients. Rather than having the issues I was experiencing in the hospital addressed and having a safer space created, I was consistently met with medication. This was done without taking the time to understand my situation, and I was often provided with treatments that worsened my conditions.

I fear for disabled youth like me and those who have it worse than I do, who could be offered MAID in place of treatment or care. In the same way institutions continue to use prescription drugs as bandaid solutions for complex concerns, expanding MAID would be truly reckless. Placing the onus to choose between life and death on individual disabled children while neglecting the realities of systemic ableism in this country is truly egregious.

You continue to claim you are censoring the right for disabled people to die with dignity, but death cannot be the default option for disabled youth who are struggling.

I am asking you to oppose this expansion and to fight for an alternative in which disabled youth are met with a government that wants us to live with dignity. I'm here asking you to pause, to slow down and to fight this expansion. I'm here because I refuse to let you discuss and question my right to live without me. I refuse to let you question the right for Black, indigenous, racialized disabled youth to live and be cared for, especially without making an intentional effort to create space for them.

You claim you want to end our suffering but you are only inflicting pain when you allow your fear of disability to inform your decision that those of us currently living with disabilities are disposable and unworthy of living.

Thank you.

• (1835)

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

I see now that Mr. Henry is with us.

Mr. Henry, I'm assuming you can hear me. We are now ready to hear your opening statement of five minutes. Go ahead, Mr. Henry.

Mr. Myeengun Henry: Good morning. Can you hear me okay?

The Joint Chair (Hon. Marc Garneau): We can.

Mr. Myeengun Henry: Thank you for allowing me to come and join you today.

I'm a former chief of the Chippewas of the Thames First Nation just outside of London, Ontario. I now work at the University of Waterloo. I'm the indigenous knowledge keeper. I'm also a traditional healer and I work in organizations where we do indigenous

healing practices for various people who are trying to find their way of healing.

Today was an interesting day. I took my faculty dean over to the Mohawk Institute in Brantford, Ontario, where we memorialized the survivors of that school and the ones who passed away at that school. Today's topic really resonated very well with me in terms of a person's life. I really think this committee needs to have an indigenous person's perspective to think about what we're going to do with the laws here in Canada. As I was at the residential school today, I knew very clearly that there is a deep-rooted history here that really needs to be looked at a bit more strongly in terms of life and the way indigenous people look at life in this world.

We also understand that there are times when people find a very complicated lifetime and some of the hardships they live through, but I think that in terms of how indigenous people look at life, it is really our Creator who we turn to at times like that. If we make laws that really look at this perspective, indigenous people have been through this already. We've been forced to leave this world, as you know from the children who have been lost and found at residential schools lately, in a form that was taken from them very similarly.

It's really hurtful to know that those children left this world without any type of opportunity in life. I know that survivors today are challenged, too, mentally, physically, emotionally and spiritually. I'm living through that right now with a father-in-law who doesn't want to live any more because of the residential school that he had to endure. In his later years, his mind just goes back to that era in time. What he has given to me is the fact that he still has worth. He still has an ability to share something that this country needs to hear about that experience. He's not going to allow himself to fall into suicidal thoughts, even though the pain he's feeling today has really hurt him so badly.

I think that with today's topic and what we're discussing we want to get involved in this conversation. Indigenous people throughout Canada have endured all these terrible things, but today, I think, when it comes to supporting people who can help themselves through alternative measures like indigenous healing practices... I've seen it happen already with some people who have gone to that point of wanting to leave this world, but now, in coming back to their culture and knowing there are ways that we are able to treat and work with these people, that thought of wanting to leave this world has subsided.

Throughout my healing practices that I've done with many people, it's very clear to me now that they need to have that extra ability to know their healing practices, and when they do that, because that was taken away from our people. For all those years, the residential schools didn't allow us to have our sweat lodges and our ceremonies, but because people now are able to practise these things again, they see an opportunity now, rather than trying to end their lives. It's not just for indigenous people, but for all people. If they find that peace that allows them to know that there is hope out there, then I think we can really look at this topic a little more strongly and have an opportunity once again to maybe revive in these people the hope that was lost.

I also know that there are times when people come to that point in life when it's inevitable and the pain they're feeling is probably at that point. I don't think medical professionals disagree that there are times when that is doable.

• (1840)

Until we get to that point, it has to come from the person. I think we can support that, and maybe make that decision a little bit later, rather than having somebody who has gone through this punishment in their own mind and wanting to just leave this world.

My message to you is, let's support this committee discussion. I don't know whether there are any indigenous people who have been invited to these meetings, and hearing that perspective. But for the years I have been doing healing work, I know we can help people, even at a point when they think there is no longer any hope for them. I have seen it happen so many times.

I'm here to reflect on that and to give us a chance to speak our mind. There's nobody else in this country who has been through what we have been through and the experiences we share. At a committee level like this, I think it's very important for you to hear this and for us to have these opportunities to share this knowledge that we have.

I hope we're able to continue on with this discussion with these very important elements that I think need to be addressed within this topic.

Canada is a great country, but we need to include the people who have been here since time immemorial on these topics. We have come through a hard time. Because of residential school, we're regaining those healthy ceremonies that we have always done. They were outlawed in this country for a long time. Now that we're regaining that, we're seeing people like my father-in-law being able to hold on a little longer, and then his knowledge gets passed on in his children and grandchildren.

I wanted to share that with you today.

• (1845)

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

Mr. Myeengun Henry: Thank you so much.

The Joint Chair (Hon. Marc Garneau): We will have a chance to ask you questions in the next hour. Thank you very much for those opening statements.

For your information, we had an indigenous witness in our last session, for example, and of course we have more sessions to go.

I will now hand it over to my co-chair, Senator Martin, for the first round of questions.

Thank you.

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

Thank you to our witnesses for your compelling testimony today.

We will begin this first round with Mr. Barrett, for five minutes.

Mr. Michael Barrett (Leeds—Grenville—Thousand Islands and Rideau Lakes, CPC): Thanks very much, Madam Chair.

Through you, I would like to thank both of our witnesses for appearing here today and sharing their perspective on this difficult topic.

I'm going to start with my first question for Chief Henry.

First of all, again, thank you, Chief, for bringing your experience and perspective to us.

The capacity that children have to make decisions, I think is really important, and I would like to get your perspective on that. We sometimes take it for granted. Other times, we are very protective of our children, based on their susceptibility to influence. I think about things like alcohol, tobacco, and lately vaping and narcotics, and the protections that we offer to youth. All advertising in the province of Quebec to youth is restricted.

I'm wondering what your perspective is of an offer of, or information provided to, youth, and specifically to indigenous youth, from a trusted person like a medical practitioner with respect to MAID while that youth is living with suffering.

Mr. Myeengun Henry: I think it would be beneficial to that youth if there were an indigenous healer or practitioner alongside with that medical perspective.

Now, we're seeing youth wanting to get back into the culture and doing these things. I think the benefits would be astronomical to have that child know there are, in their own culture, ways of dealing with these issues.

When I work with Dr. Conroy in Toronto—he's a lawyer and a doctor—and we bring the medical traditional healers in with them, the children who come into Anishnawbe Health in Toronto are a lot better off. At least they feel comfortable with the knowledge they are getting.

I really think it needs to be both of those in that scenario...to talk to these children. The trust is coming back to the indigenous knowledge keepers with our young children, and I think when there's a medical professional there, they have part of it. It's the research and knowledge that way, but there's a spiritual element for these children that the knowledge keeper would be able to provide.

• (1850)

Mr. Michael Barrett: Right.

Mr. Myeengun Henry: I think a best-case scenario would be having both of them together to work with them.

Mr. Michael Barrett: Thank you, sir.

We know that indigenous-specific racism is real in our health care system. I'm wondering if you have concerns or thoughts on MAID being offered to indigenous youth potentially on the basis of them being indigenous while they're living with suffering.

Mr. Myeengun Henry: Can you reframe that question for me?

Mr. Michael Barrett: Yes, sir. We've seen examples, even recently, of racism in our health system that has specifically targeted indigenous or first nations people. I'm wondering if you have concerns or thoughts on indigenous people potentially being targeted, for lack of a better word, with an offer of MAID in place of other health care options.

Mr. Myeengun Henry: Absolutely that concerns me, very much so, especially in the northern communities where they have only one doctor. Sometimes they have to fly them in or have them on Zoom. Sometimes what they're hearing.... It doesn't give the necessary knowledge to the child, or even to the people who are looking after that child to be able to help that child.

I do have concerns about health care with indigenous people throughout Canada. That's why I keep saying that we need to be participants in these conversations. That said, maybe we can help those communities who are feeling those racial issues happening within the medicare system here in Canada.

Mr. Michael Barrett: Thanks very much.

I'm not sure if I'll have time for a fulsome answer, but Ms. Mehdi, thank you again for sharing your time and your thoughts with us today. I was hoping you could expand on your concerns about discussions with youth living with disabilities being offered MAID, and how those offers might amplify thoughts of suicide.

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

Ms. Ahona Mehdi: Okay.

I think suicide messaging is a huge thing. When we're hearing it from our peers and from the media, it's huge, but I think it's going to be a lot more drastic when we're hearing it from the government, from the state specifically—an entity with so much power. I fear for youths, because we know that hearing suicide messaging and hearing about suicidal ideation is a trigger. It could lead to more suicidal ideation for youth.

The Joint Chair (Hon. Marc Garneau): I'm going to interrupt the meeting for a second.

There is a person at the back. I don't know his name. I told him to put on a mask. He has not.

Sir, please leave right away.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Mr. Chair, maybe you could put on a mask.

The Joint Chair (Hon. Marc Garneau): Do you know the rules? The rules are that the people at the table are allowed not to have a mask, providing they keep their distance, but everyone else is supposed to wear a mask.

Mr. Michael Cooper: So the staff member—

The Joint Chair (Hon. Marc Garneau): I'm not going to get into an argument with you, Mr. Cooper. Your colleague must leave.

Mr. Michael Cooper: Well, I think, Mr. Chair, you're being very unreasonable, and again—

The Joint Chair (Hon. Marc Garneau): I'm not going to sit here and argue with you.

Mr. Michael Cooper: —you're [*Inaudible—Editor*] typical Liberal [*Inaudible—Editor*]—

The Joint Chair (Hon. Marc Garneau): Your colleague needs to leave. Are you going to call on your colleague to—

Mr. Michael Cooper: I encourage him not to leave.

The Joint Chair (Hon. Yonah Martin): Does he have the option to put a mask on now?

The Joint Chair (Hon. Marc Garneau): Yes. He has the option of putting a mask on, which is what I asked him to do. He said no.

Mr. Michael Cooper: I would prefer that he stay.

A voice: We're all also disabled. I would really recommend that you put it on for our sake, if not for anyone else's.

Mr. Michael Cooper: Well, then, maybe all of us should put on a mask, if that's the case.

A voice: Fair enough. Put it on [*Inaudible—Editor*].

The Joint Chair (Hon. Marc Garneau): I'm happy to put on a mask as well, but your colleague needs to put on a mask. Those are the rules of the Board of Internal Economy. I'm not going to bend on that.

A voice: You're subject to different rules [*Inaudible—Editor*]. That's just the way it is. Put on your mask.

A voice: He doesn't have parliamentary privilege.

Mr. Michael Cooper: [*Inaudible—Editor*] better put on your mask.

Let the double standard be noted.

The Joint Chair (Hon. Marc Garneau): You bet I'll note what you have said tonight, Mr. Cooper. You're not following the rules of the Board of Internal Economy.

● (1855)

Mr. Michael Cooper: That's quite a double standard.

The Joint Chair (Hon. Marc Garneau): Please, let's carry on.

The Joint Chair (Hon. Yonah Martin): We next have Mr. Maloney for five minutes.

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

I will start by apologizing to our two witnesses for your having to see what just happened. We're here to talk about very serious issues, issues that are dearly important to both of you, and it's unfortunate, to put it mildly, that we're having this other discussion in your presence—or at all—but so be it.

Thank you, both of you, for being here. Your evidence was very powerful and compelling. I have a number of questions.

First, just so I am clear—and my question is for both witnesses—are you opposed to medically assisted dying in any circumstance or just in specific circumstances?

I'll start with you, Ms. Mehdi.

Ms. Ahona Mehdi: As I said, I do believe in the right to choose, but I don't think this is a choice when you are forced to pick between two egregious options, so when we are not funding things like home care—

Mr. James Maloney: Okay. I'll get into that, but my question is very simple.

So there are circumstances where you feel it's appropriate and acceptable?

Ms. Ahona Mehdi: Yes.

Mr. James Maloney: Thank you. I appreciate that.

Mr. Henry, what about you, sir? Do you feel the same or are you opposed to it generally?

Mr. Myeengun Henry: After witnessing some of our people, I'm not totally opposed to it when it comes down to that final decision, but it has to be at that extended decision. I'll leave it at that. There is a time when it's appropriate, yes.

Mr. James Maloney: That's very helpful, and thank you, because we're here to talk about safeguards and guardrails, however you want to characterize them. That's a good foundation for my questions.

Ms. Mehdi, I'll start with you. You're 19 now, you said?

Ms. Ahona Mehdi: Yes.

Mr. James Maloney: Okay. You indicated that if a year ago you had applied for MAID you would have qualified, you believe, but you were 18 a year ago? Is that right?

Ms. Ahona Mehdi: I was 17.

Mr. James Maloney: You were 17. Is it your view that there are circumstances where people under the age of 18—minors—can make decisions for themselves, be it for this or other medical circumstances?

Ms. Ahona Mehdi: I think to some degree, yes, but I also know that the development of the brain, especially the prefrontal cortex, which evaluates risk assessment—

Mr. James Maloney: I understand that there will be some medical circumstances where doctors deem it not appropriate because the person doesn't have the capacity, so my question to you is very simple: Do you believe, if medical opinion is there to support it, that it is okay for somebody under the age of 18 to make that decision on their own?

Ms. Ahona Mehdi: I think that if that were to be the case we'd need to slow down and evaluate and talk to more professionals about it.

Mr. James Maloney: With respect, though, Ma'am, it's a yes-or-no question. You're saying.... I agree that you need to slow it down in certain circumstances, but the question is very straightforward. There are circumstances where a person in that situation could make that decision, because at the end of the day what we're talking about is individual choice

Your view is that somebody under the age of 18 who does have the capacity, which is supported by medical professionals, should be allowed to make medical decisions on their own.

Ms. Ahona Mehdi: Well, what I'm going to say is that I don't know. I don't have that information—

Mr. James Maloney: Okay.

Ms. Ahona Mehdi: —but I think we also need to be putting.... We can't keep putting this topic of individual rights before the topic of collective responsibility.

Mr. James Maloney: Okay.

Let me digress for a second here. You mentioned palliative care, for example, and I assume you did so because there's a divergence of opinion in the palliative care field about MAID. Is that why you said it and that people should be entitled to services before they have access to MAID? Is that fair?

Ms. Ahona Mehdi: Yes, absolutely.

Mr. James Maloney: Okay.

All right, because we've had a number of witnesses, as I've said, and in the palliative field, for people who practise in that area, there is a conversion going on, and people are learning more about MAID. The conversion is based on situations where they are comfortable with the safeguards that have been put in place, but more importantly, they're doing it on the basis that their patients want it to happen, assuming those safeguards are in place. Do you think those circumstances are appropriate if those safeguards are in place?

Ms. Ahona Mehdi: Honestly, I don't think I can answer that.

Mr. James Maloney: Okay. Thank you.

This will probably be my last question. You said—and I don't want to misquote you—that this is “inflicting pain” on people with disabilities.

I am strongly of the view, as everybody is around this table, that nobody should be forced into any circumstance and that somebody who has a disability should not be at a disadvantage because of that. Can you clarify, perhaps, how you think this is disadvantageous to people who have disabilities? If the medical foundation is there and there's medical support for the decision, can you tell me how you bring those two things together?

• (1900)

Ms. Ahona Mehdi: I'm also speaking as a disabled youth who works with other disabled youths. Some of them are here today, behind me. I can say that all of us have experienced a great degree of pain listening to these conversations, because we know, through our lived experience, that we often have not had access to things like counselling, therapy, accessible housing, assistive devices—

Mr. James Maloney: I think we're all in agreement, in those circumstances. It's inappropriate—

Ms. Ahona Mehdi: Yes.

Mr. James Maloney: —but where the criteria have been satisfied, do you feel it would be appropriate?

Ms. Ahona Mehdi: No.

Mr. James Maloney: Okay, thank you.

[*Translation*]

The Joint Chair (Hon. Yonah Martin): We'll continue with Mr. Thériault for five minutes.

Mr. Thériault, you have the floor.

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

I'd like to thank the witnesses for sharing their experiences with us, because it's always interesting to hear people talk about their experiences, and these things are not the exclusive domain of the experts.

This question is for both witnesses.

You will agree with me that, in its most severe form, illness strikes at random. It doesn't discriminate based on gender, ethnicity or age. Why would it be unacceptable to give minor patients between the ages of 14 and 18, for example, the same thing we give to those who have reached the age of majority?

[*English*]

The Joint Chair (Hon. Yonah Martin): We'll have Mr. Henry first, then Ms. Mehdi.

Ms. Ahona Mehdi: As I was saying earlier, we know the prefrontal cortex, which evaluates risk assessment and decision-making, is not fully developed until well into the second decade of life, and sometimes into the third decade of life, so we can't expect youths to be making these decisions.

There's another thing: We can claim doctors will follow procedures that ensure these decisions are really intentional and the person who says they want to receive MAID is rational, but masking is a huge thing that disabled people use, especially disabled youth, in navigating health care systems that consistently show us they don't care about us and are not supporting us. We have—

[*Translation*]

Mr. Luc Thériault: Excuse me, but I don't have much time, and I don't want to get into a false debate. I will hear from Mr. Myeengun first, and then I'll make a brief comment.

Mr. Myeengun, I'd like you to be brief, please.

[*English*]

Mr. Myeengun Henry: I didn't have the translation headphones.

The Joint Chair (Hon. Yonah Martin): Mr. Henry, do you have headphones you can put on?

Mr. Myeengun Henry: They sent some, but [*Inaudible—Editor*].

The Joint Chair (Hon. Yonah Martin): You can click “English” at the bottom right-hand part of your screen to—

Mr. Myeengun Henry: Is that for interpretation?

The Joint Chair (Hon. Yonah Martin): Yes, it's for interpretation. Select “English”, please.

Monsieur Thériault, would you like to repeat your question to Mr. Henry.

[*Translation*]

Mr. Luc Thériault: Of course.

I will simplify my question. Under what circumstances do you believe medical assistance in dying should be allowed for minors?

[*English*]

Mr. Myeengun Henry: I can barely hear that.

The Joint Chair (Hon. Yonah Martin): In which cases do you believe MAID for mature minors could be authorized? That was the question.

Mr. Myeengun Henry: I think it has to go case by case. With the advice of a medical practitioner, somebody under 18 with a guardian, parent or someone like that would [*Technical difficulty—Editor*] make that decision. Every case is different, so we can't have a blanket statement saying yes or no on that. I think every case is going to take—

[*Translation*]

Mr. Luc Thériault: In clinical ethics, one must first and foremost—this is what they teach in medical school—use inductive reasoning for decisions made at the bedside. One can't apply an evaluation grid at the bedside, but must rather try to see what comes out, that is, listen to what the patient has to say, listen to the patient's wishes, and hear how the patient is suffering.

Wouldn't this approach, coupled with an assessment considering all the criteria, provide a safeguard and quite safely permit this practice?

• (1905)

[*English*]

Mr. Myeengun Henry: I believe they need to have their say, of course. That's telling you from their own perspective how they're feeling. It is very important that we hear that perspective. All of the medical information available, along with the information of the person, is very important. I would agree.

[*Translation*]

Mr. Luc Thériault: In the Netherlands, one of the two countries that administers medical assistance in dying to minors, the parents of 12- to 16-year-olds are always involved. Parents would have no veto power for 16- to 18-year-olds.

The parents must agree with the decision.

How do you feel about that? Do you really believe people would abuse that?

[English]

Mr. Myeengun Henry: Absolutely. I think that needs to have a lot of perspectives here. They know how their—

[Translation]

Mr. Luc Thériault: If parental consent is also required, what kind of abuses could occur?

[English]

Mr. Myeengun Henry: I'm sorry. Could you say that again?

[Translation]

Mr. Luc Thériault: If parental consent is also required, what kind of abuses could occur?

[English]

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

Mr. Myeengun Henry: I couldn't understand the question. I'm sorry.

The Joint Chair (Hon. Yonah Martin): Okay. Well, the time has lapsed here. I'm sorry about that.

Lastly, we'll go to Mr. MacGregor for five minutes.

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

Ms. Mahdi, welcome to the committee, and thank you for joining us today.

In my home province of B.C., when it comes to health care provision, a health care practitioner can get consent without a parent or guardian if they are sure that a child understands the need for the health care, what the health care involves and the benefits and risks of the health care. That's what allows children to make decisions on immunizations, and it's very important for teenagers and reproductive health care. Just to be clear, you do support that part.

That's very different from what we're talking about today.

What I've noticed in the way that this committee has conducted its hearings is that there is a difference between a person's medical condition and social condition. I understand that medical conditions and the choices about that are very personal, but a lot of witnesses have said that you can't adequately make that choice if you don't have the proper kinds of support open to you.

You talked about the fact that for many disabled youth, the cost of the care is a significant barrier. Can you expand a little bit on that, on how we, as a country, really have to pay attention to those social factors?

Ms. Ahona Mehdi: The first thing is that about one in four Canadians with disabilities are unable to afford things like assistive devices, home care and that sort of thing. They can't afford the necessary aids, prescriptions and that sort of thing. I think for minors particularly, this can also sometimes cause financial strain in the family, which minors are seeing. A lot of parents of children with

intellectual disabilities and that sort of thing are having to take time off work or not work, which results in the loss of income to take care of their disabled youth.

Something that comes in here is that disabled youth are seeing this financial strain and the struggle, and this impacts them. This might make them feel like a burden. Feeling like a burden is not a reason to die. We should be addressing why they feel like a burden and what can we do to make sure they don't feel like a burden.

Mr. Alistair MacGregor: To be clear, in this committee, at the end of our life as a committee, we're going to table a report with recommendations. It's not necessarily going to result in the law being changed. We're taking a deep dive into this to get a clear understanding of what people in Canada feel about this, from all sides of the spectrum, because there are some very strong feelings on both sides of these questions.

On the topic we are studying today, we have five major themes. One of them was protection of persons with disabilities, and now we're on to mature minors.

Can you talk to me on what we should be looking at, sort of as a minimum, to make sure that disabled youth have been represented adequately in this process?

• (1910)

Ms. Ahona Mehdi: I think that this process is moving extremely quickly.

I also want to talk about the fact that on June 2, Senator Wallin tabled a bill to expand MAID with respect to advanced directives. As a senator sitting on this committee, by doing this, I think she has put in question the integrity of this committee as well.

I also think that there haven't been a lot of people who have been consulted, especially disabled youth like me. To my knowledge, I'm the only disabled youth who has been called as a witness. I am very doubtful that enough disabled youth have been consulted on this, and that scares me. It's not okay to be making decisions about us and about our right to live or our right to die when we are not at the table, and we are not there.

Mr. Alistair MacGregor: Regarding the earlier theme of protection of persons with disabilities.... When you hear that our committee has been charged with looking into that, as a theme, what does it mean to you?

Ms. Ahona Mehdi: I'm sorry, I didn't have my headset on. Could you repeat the question?

Mr. Alistair MacGregor: The previous theme we looked at was the protection of persons with disabilities. When you look at that as a guiding theme for this committee, what does it mean to you?

Ms. Ahona Mehdi: I think that's important, but I'm not really seeing it in action.

We also need to be considering the many social determinants of health being neglected, right now. We need to be talking about the lack of housing, especially for racialized, Black, and indigenous disabled youth. We need to be talking about the disproportionate levels of poverty and housing precarity, and the fact that indigenous peoples experience suicidality and die by suicide at a disproportionate rate. Indigenous youth are being disproportionately targeted by this bill, as well.

I think those things are really being neglected, right now. I don't know if I see the protection of people with disabilities in this.

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

I'll now hand this over to my co-chair for a round of questions from the senators.

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

You raised a point, Ms. Mehdi. Just for your information, this is the first night we've looked at the issue of mature minors, so you're the kick-off to this.

We'll now go to the senators. These are three-minute rounds.

[*Translation*]

We'll start with Senator Mégie.

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

My three questions are for Ms. Mehdi.

If I understood correctly, when you were young, about 17 years old, you were very ill and you say you were eligible for medical assistance in dying. Why do you say you were eligible for medical assistance in dying? Who told you you were eligible for MAID?

Even if, as you say, you were eligible for medical assistance in dying, did you know that you would have had to undergo two assessments to see if you really met the eligibility criteria for MAID? Were you aware of that?

As a minor, do you feel that you would be free to refuse medical assistance in dying?

[*English*]

Ms. Ahona Mehdi: To my understanding, I think you asked why I would be eligible. I don't think that's something that's necessary for me to disclose here. I don't think it's necessary for me to disclose my disabilities, particularly to all of you here today.

You also asked a question about whether I would have been able to say no, had a doctor offered me medical assistance in dying. I was in the hospital because I was in crisis. I was at my worst. At that point in time, perhaps I would not have said no, because I was suicidal and in crisis. However, I'm telling you that a lot of youths could be put in the situation. If you think about it, had I been offered it at the time, I would not be here today.

[*Translation*]

Hon. Marie-Françoise Mégie: You know that it wasn't up to you to decide if you were eligible for medical assistance in dying. It would have taken an assessment by a physician or other health care

professional to confirm whether or not you were eligible for medical assistance in dying. Were you aware of that assessment?

When a person is in crisis, it's not the time to assess their eligibility for medical assistance in dying. This is made very clear in the reports.

[*English*]

Ms. Ahona Mehdi: Yes, I was aware of this fact. I was aware they would have to consult with me, but I also have multiple disabilities. I don't think they would have seen the thing about me being in crisis.

I also mentioned earlier that disabled people, growing up in health care systems and having to navigate these systems, we're often able to mask our issues. We're often able to present ourselves as needing one thing when actually, internally, we are feeling another thing.

Yes, I am aware of this process, but I'm scared and I also don't know.... You say these processes are in place, but how can we ensure this? Many of you may have seen headlines about a registered nurse who murdered eight long-term care home residents in Ontario in 2019. No one would have known about this had they not disclosed it to a psychiatrist. How would you be able to guarantee this would not happen again?

I understand it's a different circumstance, but there is absolutely no way to guarantee this will not happen.

• (1915)

[*Translation*]

Hon. Marie-Françoise Mégie: Ms. Mehdi, I will stop you there because those are not MAID cases. The case you're talking about involving the nurse is not medical assistance in dying. It's a criminal case, and that's something else. Do you understand?

What I want you to understand is that you don't need to be afraid, because an assessment will be done by health care professionals, and you can trust in them. They can determine who is eligible for medical assistance in dying. That's kind of what I wanted to say.

Do you feel that you were capable at 17 of expressing your opinion voluntarily and thoughtfully, feeling no pressure?

[*English*]

Ms. Ahona Mehdi: Yes, so what I'm saying is that I believe, I understand, that those cases were not medical assistance in dying, but we know that medical racism exists, and we know that medical ableism exists. There is no way to guarantee that these medical professionals—right?—would not engage in these acts of coercion, knowing that these things exist, and I'm saying that as a 17-year-old I have a lot less power than those people in positions of power, so I would be in a very vulnerable situation.

[*Translation*]

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

Senator Kutcher, you have the floor.

[*English*]

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

There are two questions and they're for both witnesses.

Thank you very much for being with us today.

MAID for mature minors is currently available in some countries. Do you know for what circumstances or conditions it has been provided in those countries? Can you share with us in what circumstances and conditions people have received MAID for mature minors in the countries where it's been provided?

The Joint Chair (Hon. Marc Garneau): Do you want to start, Ms. Mehdi?

Ms. Ahona Mehdi: I don't know particularly, but I would assume around terminal illness, chronic illness....

Hon. Stanley Kutcher: I'm sorry?

Ms. Ahona Mehdi: I don't know particularly, but I'm wondering if it's around maybe chronic illness or terminal illness.

Hon. Stanley Kutcher: Okay. So you don't know?

Ms. Ahona Mehdi: No, I don't know.

The Joint Chair (Hon. Marc Garneau): Mr. Henry, do you want to answer that question?

Mr. Myeengun Henry: I'm not aware of it either, unfortunately.

Hon. Stanley Kutcher: Thank you for that and for your honesty.

The second question is again for both of you.

Have either of you spoken to a young person who is terminally ill and experiencing intolerable suffering and who wanted to be assessed for MAID? Have you spoken to a person—a kid, a young person, a mature minor—who was in that circumstance?

Ms. Ahona Mehdi: Yes.

Hon. Stanley Kutcher: What was the situation?

Ms. Ahona Mehdi: I don't think that it's appropriate for me to disclose. It's very personal information.

Hon. Stanley Kutcher: It's hard to evaluate that.

Sir, what about you?

Mr. Myeengun Henry: I have, and it was very interesting, this conversation I had with her. We actually did a naming ceremony for her.

Hon. Stanley Kutcher: Right....

Mr. Myeengun Henry: She was considering this, but after we did our ceremony, a lot of her thought process changed, because it wasn't as bad as she felt. We were in that same situation where, as I think I said earlier, when they did have the right people there to assist them, it helped them along tremendously. That's why I said that the ceremonies are really important.

When this young lady was considering that strongly, we, along with the medical professionals at the time.... I guess things changed for her and she didn't have that thought of MAID after the ceremo-

ny. I can't tell you how exactly, but she did change her thoughts on it.

• (1920)

Hon. Stanley Kutcher: Well, thank you very much for that. I think that's a very important point that you made. What I heard was that you said that you and the medical professionals worked with her to have these ceremonies and that you tried to meet that person's needs and, as a result of the intervention, that person changed their mind.

I thank you very much for sharing with the committee how important those kinds of conversations are in meeting the person's needs. Thank you very much for that.

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

Next is Senator Dalphond.

[*Translation*]

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

[*English*]

I will ask Ms. Mehdi a question, if she wants to answer.

I'm not sure I understand your position. Are you opposed to anybody who is 18 and below having access to MAID? You say that even in the mid-20s the brain is not yet properly formed, but you accept that 18 is okay even if the brain is not properly formed...?

Ms. Ahona Mehdi: I also don't believe that past bills moved slowly enough. I don't think enough people were consulted.

I think that's a great point you're bringing up. It can't be right, at 18, that you are able to evaluate whether or not you want to die. I think there needs to be more of an evaluation around all ages, for all disabilities. It's not like a hard cut-off, that it's just under 18.

I think for everybody with a disability, there needs to be more information, and there needs to be more work and more space to consult with these people.

Hon. Pierre Dalphond: You're right that the choice has to be an informed consent, and it has to come from the patient, not from the doctors. It has to be based on the situation as assessed by the person first, and then assessed by two independent persons, and maybe even more people.

You said that it's difficult to put a line somewhere. If you have somebody who is 17 years old, suffering from cancer, in terrible pain and suffering, and he or she is asking for access to MAID, you will deny that? For example, in some provinces, like in Quebec, at 14 years and over, they can decide to consent or not to medical treatment. That person could refuse to get another treatment and decide that they want to end their suffering. Will you deny them in such a case? Or, do you think there should be no hard line in such a case, so that we could say yes after properly assessing the situation?

Ms. Ahona Mehdi: Could I ask what your specific question is again?

Hon. Pierre Dalphond: You have a case of somebody who is 17 years old, who has terminal cancer with no chance of being cured, but having six months to live. That person is asking to put an end to the suffering and to receive MAID. Would you deny that in such a case? Or, according to you, it should be based on that person's request and an assessment of his or her situation, and then in such a case, even if the person is 17 years old, he or she should be provided MAID.

Ms. Ahona Mehdi: Again, as I mentioned earlier, I do believe in the right to choose.

What I want to come back to is that we're talking a lot about individual rights, which are important, but I'm coming from a perspective that we need to also be censoring collective responsibility, right? We need to be censoring, is it suffering that actually cannot end, despite social circumstances or external circumstances that don't have to do with the functioning of their body or with their physical disability, or whatever disability it is they have.

Hon. Pierre Dalphond: The question is simple. For somebody who has cancer, is in the terminal stage, has maybe a maximum of six months and is in terrible suffering, can that person have access, according to you, to MAID?

Ms. Ahona Mehdi: I don't think I would be able to decide that. I don't think it's appropriate for me to say.

Hon. Pierre Dalphond: So you would refuse the medical aid if the person was asking for it?

Ms. Ahona Mehdi: I don't know.

Hon. Pierre Dalphond: Thank you.

[*Translation*]

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

[*English*]

We'll go to Senator Wallin.

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

I have a follow-up question for Ms. Mehdi.

I understand that you support choice, and you support the right not to choose as well—to not opt for this. I think everybody is generally in agreement on that.

I want to come to this other point, where you argued that people are not emotionally or intellectually fully developed until about their mid-twenties.

When you first encountered this issue, you were 17, and now you're 19, you said.

• (1925)

Ms. Ahona Mehdi: Yes.

Hon. Pamela Wallin: Okay.

You have obviously very strong opinions on this. Are you arguing that now, at 19, that you in fact are fully emotionally and intellectually developed and therefore able to make this decision?

Ms. Ahona Mehdi: I am not arguing that.

Hon. Pamela Wallin: Sorry?

Ms. Ahona Mehdi: If I were to have to decide whether or not I should access MAID right now, you're asking me whether or not I would be capable of doing that.

Hon. Pamela Wallin: Yes.

Ms. Ahona Mehdi: No, I don't believe so.

Hon. Pamela Wallin: Okay. Thank you very much.

That's the end of my questions.

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

We'll now go to Senator Martin.

The Joint Chair (Hon. Yonah Martin): Thank you to both of our witnesses. I think your voices are very important at this table. You're very courageous.

My one question is regarding MAID being available to minors. Do you believe that there should be parental consent, and why or why not?

Ms. Ahona Mehdi: I think parental consent is also extremely tricky. In my field of work, I have seen multiple parents of young children with chronic disabilities who have coerced or forced them to undergo treatments they did not want to undergo. I worry that this could be similar when it comes to MAID. I worry that parents who are scared of their children's disabilities and don't understand them would be able to do the same thing with regard to MAID.

I also know that parents have a lot of influence in how children feel within themselves too.

The Joint Chair (Hon. Yonah Martin): Those are very good points.

Chief Henry, I was hoping to ask you about the consultation process. We've heard from officials, and we feel that not enough consultation has been done with indigenous, Métis and Inuit peoples.

Are you having these conversations with members of your community? Would you share with us whether there has been adequate consultation? What are your community members saying?

Mr. Myeengun Henry: I have been speaking to our members and the indigenous community at large, and it's a very tough situation. We have such a history of these types of scenarios. I would guess we wouldn't have everybody agreeing.

When we go back to our history and think about how we dealt with these issues throughout our spiritual journeys, that's where we align. We let the Creator decide that. It's a tough situation. Every single case has its own scenario.

However, when I speak... You have to realize that we're just coming out of the residential schools and we're still facing the barriers of those. I think what they saw at those schools still has a bearing on people's thinking right now.

They know that the medical support they have is, hopefully, the best that they can have, along with their community helping them with these types of decisions. It also resonates with other members of our community when these decisions are made when they get into these scenarios.

It's a big story, and it requires a lot of [*Inaudible—Editor*] thought—

The Joint Chair (Hon. Yonah Martin): In terms of government consultations, there hasn't been very much.

Mr. Myeengun Henry: No, not at the government level.

The Joint Chair (Hon. Yonah Martin): It's important to note that we need to do that kind of consultation regarding MAID and all of the groups that would be impacted.

Mr. Myeengun Henry: I've seen very little, so thank you for that question.

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

The Joint Chair (Hon. Marc Garneau): Thank you very much. That brings our panel to an end.

I would like to thank both Ms. Mehdi and Mr. Henry for being here tonight, appearing, providing opening comments and answering all of our questions on this very important subject, which we initiated tonight. We very much appreciate your input on this. It will help the committee as it deliberates on this matter.

With that—

Mr. Myeengun Henry: Can I say one more thing before I go?

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

Mr. Myeengun Henry: I want to think about the children who are going through this. In my line of work, I offer a really quick thought or a prayer with them for all of those people who are going through this. I give all the strength for the medical people and for the children, families and communities who are going through these difficult situations.

I wanted to share that with you these evening. Thank you for allowing me to share what I know with you.

• (1930)

The Joint Chair (Hon. Marc Garneau): Thank you, Mr. Henry. That was very lovely. We much appreciate it.

With that, colleagues, we're going to suspend very briefly as we prepare for the second panel.

• (1930)

(Pause)

• (1930)

The Joint Chair (Hon. Yonah Martin): I call the meeting back to order. We will resume.

I'd like to take a few moments to remind our new witnesses who have joined us to please wait until I recognize them by name before speaking. I remind you that all comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly. Interpretation for this video conference will work like it does for an in-person committee meeting. You have the choice at

the bottom of your screen of the floor, English or French. When you are not speaking, please keep your microphone on mute.

With that, I'd like to welcome our two panellists. As an individual, we have Ms. Constance MacIntosh, professor. From the College of Physicians and Surgeons of Saskatchewan, we have Mr. Bryan Salte, who is a lawyer. Thank you, both, for joining us this evening to lend us your expertise and insights.

We will begin with opening remarks by Ms. MacIntosh, followed by Mr. Salte. If it is Dr. MacIntosh, I apologize. You will each have five minutes for your opening remarks.

Go ahead, Dr. MacIntosh.

Professor Constance MacIntosh (Professor of Law, As an Individual): It is professor, not doctor.

Thank you, Chair and committee members, for inviting me to join you this evening. My name is Constance MacIntosh. I'm a full professor of law at the Schulich School of Law. I served as the director of Dalhousie's Health Law Institute for six years.

By way of background on the issue at hand, I was on the organizing committee for four international conferences on end-of-life clinical practice, empirical evidence, law and policy. Among other focuses, I've published on law and policy concerning minors and health care decision-making for very young minors—children and neonates—as well as adolescents and mature minors.

I have two recommendations from my perspective as a legal scholar. The first is that the Criminal Code should be amended to remove the reference to an age requirement. In my view, that is unconstitutional. If the committee concludes that an age needs to be included, to ensure public confidence I would recommend placing it at 12, because that's in line with the psychological evidence about capacity development, where it's just so unlikely that a child younger than that could be found to have decisional capacity to make that sort of decision. That sort of age bar would be constitutional.

Further, I recommend developing regulations, or introducing another amendment to the code itself, that codify or potentially enhance the existing process for assessing decisional capacity of youth were they to seek to access MAID. I think this is required as a matter of public transparency, because the public doesn't know about the concept of the "mature minor", and also for public confidence. I think we need to be very clear, if we take this step, about how the potential vulnerability of youth is recognized and assessed.

I have five reasons for these recommendations that I'll slide through.

First, the MAID regime is based in the actual decisional capacity of each individual. Given that foundation, it makes no sense to disregard the actual decisional capacity of people just because of their age.

Second, the MAID regime's approach to consent and capacity should be consistent with Canadian clinical practice and law on health care decision-making by minors. Those are crafted to assess the situation of each individual and their potential vulnerability. As I'm sure you know, being under the age of 18 is not an absolute bar to minors making their own decisions about medical procedures, including decisions to withdraw or withhold life-sustaining treatment.

The regimes vary in their details across the provinces, but at their heart they all turn on the maturity of the youth and, in particular, whether the individual understands and appreciates the nature and consequences of a decision, and of course any possible alternatives, and their consent is freely given. In assessing that, experts look to factors like maturity, life experience and the youth's psychiatric, emotional and psychological state. A team of experts decides if the minor truly possesses the required maturity to make whatever the medical service decision in question is.

Third, as I've already alerted you to, I believe the MAID regime will be found unconstitutional if it maintains an age-based bar, because this is inconsistent with the evidence on how capacity develops with age and with experience. Because this absolute age bar bans youth who do in fact possess capacity, and because it bars them from accessing MAID and they don't need the protection of a ban, it's going to be found overbroad. Because the age of 18 doesn't signal anything in terms of maturity and development—it's arbitrary and not a magic birthday—this law, I believe, will be found unconstitutional if it's challenged.

- (1935)

The vulnerability of youth does require a different approach from what's taken with older people. Other safeguards are required. I believe that many are already built in to how health care providers approach adolescents who seek to make decisions about medical services. Effectively, as the seriousness of the health treatment decision escalates, so too does the scrutiny which is used when assessing capacity, voluntariness, and understanding. It may be, once again in the interest of public confidence and transparency, that additional safeguards are required for mature minors, such as the requirement of parental consultation.

Finally, I note that all the Canadian expert panels that had a mandate to specifically make recommendations endorsed a capacity-based approach, and rejected an age-based approach.

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

Next, we have Bryan Salte from the College of Physicians and Surgeons of Saskatchewan.

- (1940)

Mr. Bryan Salte (Legal Counsel, College of Physicians and Surgeons of Saskatchewan): Thank you.

I certainly want to echo the comments of Professor MacIntosh in almost everything that she has said.

By way of my background, I've been a lawyer for the College of Physicians and Surgeons of Saskatchewan for the past 23 years. I have responsibility for policy development, among other things. I was also part of the expert panel that presented the report from the Council of Canadian Academies on mature minors. It was quite a

remarkable experience, because it gathered together a group of people who had divergent backgrounds in medicine, ethics, law and other backgrounds. The report is the consolidation of the wisdom of all of those people sitting around the table and talking about all of those things. Finally, I took part in developing the draft policy for the Federation of Medical Regulatory Authorities of Canada, as well as the actual policy of our college as it relates to medical assistance in dying. That is my background.

The first point that I'd like to make is that the Supreme Court of Canada in *A.C. v. Manitoba* recognized that the decisional capacity of an adolescent is not dependent upon age and that adolescents who have decisional capacity are entitled to make their own health care decisions. That includes circumstances in which the result of those decisions may cause death.

The second point I would make is that many of the individuals who access medical assistance in dying are individuals of quite advanced age, some of whom have somewhat diminished capacity, but still have the capacity to make their decisions. The result, I would suggest, is that it is quite anomalous that individuals of an advanced age and with somewhat diminished capacity are entitled to access medical assistance in dying—provided, as I say, that they do have the capacity to make those health care decisions—yet that is denied to individuals under the age of 18 who may well have more decisional capacity than some of the individuals who are currently accessing MAID.

The next point that I would make comes from the discussions and the information that was gathered by the Council of Canadian Academies group, of which I was a part. There is often a great deal of concern that adolescents tend not to be as concerned about the outcome of their decisions, that they are risk-taking and that their prefrontal lobes are not fully developed. Consequently, their capacity for executive functioning is somewhat diminished as compared with individuals who are somewhat older. The evidence of that is fairly compelling.

However, the evidence that has been gathered with respect to individuals who have life-threatening illnesses, and who have dealt with that for a considerable period of time, demonstrates that they are fully aware of the consequences of their health condition. They are very informed about their condition and are very thoughtful about the decisions they make.

Therefore, if medical assistance in dying for adolescents is to be allowed, and they have decision-making capacity, it means you will not be dealing with those individuals who are thoughtless, who are risk-taking and who are doing all of those things. Rather, you'll be dealing with individuals who have a quite sophisticated understanding of their health condition and are capable of sophisticated thought on how that health condition may progress.

A concept that was new to me at the discussion with the Council of Canadian Academies was the issue of relational economy. All of us are embedded in our relationships with our families and with others. The way of looking at the patient autonomy is not necessarily to look at it exclusively as individuals, but also with a recognition that decisions are made in the context of the relationships with those who are around the patient, namely, families. In the case of adolescents, that will very often be parents, or it may be other caregivers.

I suggest a couple of things. One is that the discussion around medical assistance in dying and whether it should be available to mature minors should not focus on whether it should be allowed, but rather that there should be additional safeguards for individuals who are required to undergo additional safeguards that are not required of adults. There are two things that might potentially be considered by Parliament in order to implement that.

• (1945)

The first is, again, the recognition of relational autonomy, a recognition that a decision to access medical assistance in dying affects those around you, whether you're an adult or an adolescent. It may be worth considering that parents at least be involved in the decision and are aware of the decisions being made. However, I suggest this does not require consent. One of the recognitions in the report from the Council of Canadian Academies is that, if parents are required to consent to the death of their child, they may feel very reluctant to be involved in the consent and may feel very guilty and unwilling to provide consent. That could deprive an adolescent of their full capacity and ability to end their intolerable suffering.

The second thing you might want to consider is what Parliament has done with respect to individuals whose death is not reasonably foreseeable. The requirement is that there be the involvement of somebody with expertise in the health condition, if the individuals doing the assessment do not have expertise in that health condition. Something similar to that might be considered when it comes to the potential of extending this to mature minors.

One concern identified is the availability of these kinds of services. It's somewhat inconsistent across Canada. For example, the requirement of a psychiatric consultation is probably relatively easily met in downtown Toronto. In rural Canada, I think, it is much less easily met.

Those are my opening comments. I'm looking forward to the opportunity to have a discussion with the members of this panel.

Thank you so much.

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

Thank you to both of our witnesses.

We'll move into our first round of questions.

We'll begin with Madame Dominique Vien.

[*Translation*]

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

Thank you, Mr. Salte and Professor Macintosh, for being available this evening to answer our questions.

My first question is for Professor Macintosh.

In the case of mature minors, you argued that a different approach was needed and that other safeguards should be considered. Could you quickly paint a picture of what should be considered as new safeguards?

[*English*]

Prof. Constance MacIntosh: Let me start by saying that I think the approach developed by clinicians working with minors seeking to make decisions about medical treatment—things like withdrawing or not undergoing life-sustaining treatment—is a pretty robust system in each province in their assessment of the capacity of a minor in this situation.

That said, if I were designing my dream measures, I'd want to be certain there is an express requirement that palliative care options are fully explored and understood. I'd like to see a higher level of detail present in the identification of guidelines developed by different medical and palliative care associations when it comes to assisting youth making decisions, and that those be more publicly available and can be publicly scrutinized.

That would be my starting point.

I would like to see teams involved. I would like to see pediatric—

[*Translation*]

Mrs. Dominique Vien: I have very little time, Professor Macintosh, but you could send your thoughts on these safeguards to the committee in writing. I would appreciate it.

I have a second question for you. You spoke of a duty to consult with parents. If the parents were to disagree, what would take precedence at that point? Would it be what the teenager, the mature minor chooses, or what the parents choose?

[*English*]

Prof. Constance MacIntosh: I think that's going to turn on what the health care team has concluded with regard to the decisional capacity of the youth.

Decisions like this are made collectively by families. My co-presenter, Mr. Salte, mentioned the concept of relational autonomy. Decisions like withdrawing treatment or not having life-sustaining treatment are made slowly and carefully in conversation.

I would not require parental consent. I think that is unnecessary, but I would—

• (1950)

[*Translation*]

Mrs. Dominique Vien: Thank you very much, Professor Macintosh.

My question is for both witnesses.

Do you feel that the Canadian public is now ready to accept that mature minors may be eligible for medical assistance in dying? Do you feel they are?

[English]

Mr. Bryan Salte: To the extent that there is evidence out there, it is older evidence in the report of the Council of Canadian Academies. The population appears to be quite split in terms of what their perspective was a few years ago.

What I think I can say is that over time, MAID as a general concept—ignoring whether they're mature minors or otherwise—has been much more broadly accepted, and the increasing acceptability of medical assistance in dying is part of what the public believes. I have not seen any recent polls in the past several years that have addressed what the population of Canada thinks about the potential of opening this up to medical assistance in dying for mature minors.

To the extent that I've seen information, it accepts that mature minors have a right to make health care decisions, including in situations that may result in their death. It may well flow that there is not a great deal of concern, providing that the safeguards are in place and other things are there that would provide assurance that these decisions are informed decisions.

Thank you.

The Joint Chair (Hon. Yonah Martin): Thank you. That's five minutes.

Professor MacIntosh, the time has run out for this round.

[Translation]

Mrs. Dominique Vien: Thank you very much.

[English]

The Joint Chair (Hon. Yonah Martin): Next we will have Monsieur Arseneault. You will have the floor for five minutes.

[Translation]

Mr. René Arseneault (Madawaska—Restigouche, Lib.): Thank you, Madam Chair.

My questions are for both of our witnesses, whom I thank for being here.

I'd like to start by saying that all of us on this joint committee are honoured to be here, but we have a very heavy weight on our shoulders. We have to discuss the issue of mature minors.

Professor MacIntosh, you tell us that no matter what happens, it could become unconstitutional to deny mature minors medical assistance in dying.

I'd like us to look back at *A.C. v. Manitoba*, a decision rendered in 2009. It involved a young female minor who refused medical treatment. According to the Supreme Court of Canada, she had the right to refuse medical treatment against her will. In *Carter v. Canada*, it's quite the opposite: they're asking for medical assistance in dying. They want MAID and they want the Criminal Code amended to allow it to happen.

On the one hand, in *A.C. v. Manitoba*, the court rules that a person has the right to refuse medical treatment. That's self-evident and understandable. On the other hand, in the *Carter* case, they want medical assistance in dying.

How do you think the courts could make refusing medical assistance in dying for mature minors unconstitutional?

[English]

Prof. Constance MacIntosh: The Supreme Court of Canada rejected the distinction of not giving treatment versus giving a medical service in *Carter*. They found that was a false dichotomy in *Carter*, which I think is a complete answer to the question.

I would note that the reasoning in *Carter* turned very much on the reasoning in the *A.C.* decision. I don't think that's a live issue.

[Translation]

Mr. René Arseneault: Thank you very much.

Mr. Salte, I'd like to know how you feel about this.

[English]

Mr. Bryan Salte: I completely agree with Professor MacIntosh's comments. *Carter* is based upon the idea that it is unconstitutional to deny people who are suffering intolerably the right to have a suitable end to their life that's done in a compassionate way. There's nothing in *Carter* that would say you only have that right if you're over the age of 18 and you don't have that right if you're under the age of 18.

Again, I don't think that it is completely essential for this analysis to look at the difference between an active ending of life and a denial of treatment, which has the effect of ending life. However, to the extent that it is relevant, the trial court in *Carter* completely rejected that as a false dichotomy, and said that the dichotomy does not exist, essentially. It's the same issue. People are being given the right to make decisions that will result in the termination of their life.

Thank you.

● (1955)

[Translation]

Mr. René Arseneault: Thank you very much. That answers my question.

My next question is also for both witnesses.

In your opinion, additional safeguards could be established with respect to mature minors. Both witnesses seem to agree that parents should be consulted. There is a difference between consulting parents and getting their permission. How do you see that playing out?

I believe you've already been asked this question, but I'd like to come back to it. What would happen if the parents refused to give their permission?

Mr. Salte alluded to the fact that, because they are broken-hearted, parents might refuse to allow their minor child to decide to die for medical reasons and due to intolerable suffering.

I'd like to know what you think. Should parents be consulted or is their permission required?

I'd like Professor MacIntosh to answer the question first.

[English]

Prof. Constance MacIntosh: Thank you.

In my view, if the health care treatment team has determined that the youth has decisional capacity, is psychologically, emotionally and psychiatrically stable, understands the decision at hand and understands the consequences and the irreversibility, then I think that it is an affront to their dignity, to their basic charter rights, for their parents to be able to overrule that decision and so to make the outcome turn on the consent of the parents. That's why I think it's very important to involve the parents as part of that decision-making circle all the way along and, ideally, there would be a consensus that was reached.

[Translation]

Mr. René Arseneault: Thank you.

Mr. Salte, do you have anything to add?

[English]

Mr. Bryan Salte: Yes, and again, I concur with what Professor MacIntosh has to say.

The point I was trying to make and obviously made poorly is that if you have a requirement of consent, it has some unintended consequences that may be problematic, in that in fact now you are involving the parents in being required to agree to the termination of their child's life in a situation in which their child is suffering intolerably.

That is part of the reason why I do not agree with the idea of a requirement of consent—rather, consultation and involvement in the decision-making process. But assuming that the child is decisionally capable which is, of course, the whole basis of the mature minor doctrine, then the ultimate decision is that of the child, but only to be reached after there has been discussion with the parents and discussion with those around in order to assist in a joint decision-making.

All of the evidence around decision-making at end of life for young people suggests that almost always the decisions are reached jointly, so it would be, I expect—

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

Mr. Bryan Salte: —a very rare situation in which parents would say “absolutely not” if there has been that discussion.

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

[Translation]

Mr. René Arseneault: I'd like to thank the two witnesses.

Thank you, Madam Chair.

[English]

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

Next we'll have Monsieur Thériault for five minutes.

[Translation]

Mr. Luc Thériault: Thank you, Madam Chair.

I'd like to stay on the same topic.

Professor MacIntosh, in response to my colleague Mrs. Vien, you spoke of the need for additional safeguards.

Personally, what I understand is that it's not a matter of adding criteria or requirements on both tracks, but rather ensuring that there are guidelines for the regulatory bodies in Quebec, the provinces and the territories that properly frame the practice so that more adequate assessments can be done.

You're not talking about including this in the Criminal Code. You're not asking lawmakers to add more criteria for the two safeguards.

[English]

Prof. Constance MacIntosh: I'm open to additional criteria among the safeguards, so that would be part of the code, potentially, if we were to add factors—

• (2000)

[Translation]

Mr. Luc Thériault: What would those criteria be?

[English]

Prof. Constance MacIntosh: Consultation with parents I think is a very important one, and just in general I would like to see a regularization of how we approach the decisions of mature minors across the country and get some consistency across the provinces. The only thing that I would be really pushing on in terms of the code itself is bringing in parental consultation.

[Translation]

Mr. Luc Thériault: What do you think, Mr. Salte?

[English]

Mr. Bryan Salte: Thank you so much.

I am a regulator. I've worked with professional regulation for a long time. One role of professional regulation is to ensure that professional standards are upheld. One concern I would have, if this was incorporated in some form of regulation or statute, is that it is then difficult to change and it really may be quite rigid in terms of how it is addressed. I would support the minimum level of safeguards incorporated into the legislation. Consultation is one that I think we—both of your speakers—agree on.

In terms of any additional requirements, I think you can rely upon the regulators across Canada to provide guidance, which I think we have done. When we provide that guidance to our members, we say what we expect of them if they are to be involved in medical assistance in dying.

Thank you.

[Translation]

Mr. Luc Thériault: On the issue of parental consultation, we have very little evidence. Few people can come and testify about what they do in such cases, because it's not allowed here. Only two countries allow the practice.

Based on what both of you are telling us, unlike the Netherlands, if we were to move forward in Canada, it would not be a matter of defining an age where parents would have veto power, for example, when the child is age 12 to 16, and taking away that right when the child is age 16 to 18. It's simply a matter of establishing decisional capacity. Would that be the case even between the ages of 12 and 16?

[English]

The Joint Chair (Hon. Yonah Martin): Professor MacIntosh.

Prof. Constance MacIntosh: The younger a person is, the less likely it is that they will have decisional capacity. When I suggested 12 as a potential threshold, I raised that because that is where the psychological evidence rests as being really the minimum possible for a person to have the level of discernment necessary. However, I have a great deal of faith in our health care assessment teams to determine whether a person is freely making a choice and if they truly understand it or not, so I'm comfortable with there not being an age limit here.

The Joint Chair (Hon. Yonah Martin): We're near five minutes. Monsieur Thériault, I apologize, but we have run out of time.

We will continue with Mr. MacGregor.

[Translation]

Mr. Luc Thériault: I would have liked to hear Mr. Salte's opinion on this.

[English]

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

Mr. Bryan Salte: Just very quickly, decisional capacity is very much based upon the nature of the decision to be made. What we're talking about here is a very significant decision resulting in death, so the decisional capacity that will be required for medical assistance in dying will be very significantly different from the capacity to be treated for a sprained ankle.

I have great confidence in the medical profession's ability and their recognition of that as a concept and the seriousness with which it would take this. I can't imagine any physician being involved in this process unless they were fully satisfied that the young person fully understood the implications of their decision.

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

We'll have Mr. MacGregor next for five minutes.

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

Thank you to both the witnesses for joining our committee today and for helping us on this journey.

Both of you have mentioned the fact that MAID should be based on decisional capacity. I know in my home province of British Columbia—and I'm sure this is echoed across many different provinces—in the health care interests of a child, an assessor has to determine whether the child understands the need for the health care, what that health care involves and what the benefits and risks are, and I think that a MAID regime, according to both of you, would be based on the same basic principles.

For many children, especially those who are living with disabilities or who have chronic and incurable conditions, you may have examples of how two children have the same medical conditions that may make them eligible for MAID, but they have had completely different experiences with the medical system. One has had the privilege of being born into a wealthy family or a well-to-do family and has had access to all kinds of services, while the other may have come from a broken home, lived in poor socio-economic conditions and never had access to any of those kinds of treatments. What we've been hearing at this committee is very real fear from those in many segments of society who feel that if you have not had those choices to obtain that kind of medical intervention, it's not really a choice at the end.

Maybe, Professor MacIntosh, I'll start with you. What can we do to address that perception out there and the inequities that exist in the levels of care in two completely different circumstances when both people are coming to the place where they're making that very big decision?

• (2005)

Prof. Constance MacIntosh: I would certainly hope that if a physician or a care team was approached by an individual who was living with a disability in the sort of situation of poverty and exclusion that you've been describing, the physician would realize that situational aspect and hopefully support getting them to a better place and getting those supports in place that should be there. I can't imagine a physician agreeing that the individual met the criteria for MAID in those circumstances.

Mr. Alistair MacGregor: Mr. Salte, do you have anything to add? It is a recurring theme that we hear.

Mr. Bryan Salte: And the same recurring theme, I suggest, was the subject of discussions with respect to adults, because I've been involved in those discussions for quite some time. Not that it's a perfect answer, but all of the evidence suggests that the people currently accessing medical assistance in dying are, in fact, the well educated, the socio-economically advantaged, not disadvantaged, and the concerns about the disadvantaged inappropriately accessing medical assistance in dying are simply not there.

It is true that what is intolerable suffering will be to some extent dependent upon the environment in which one lives, and the people who do these assessments are sometimes astonished at the individuals who by almost all of the objective criteria would be thought to be suffering intolerably, and they say, "No, I really don't want to do that," whereas you have others who will find intolerable suffering in lesser physical discomfort, pain, etc.

While it is a reality and it is a concern, I guess the other concern I would have is if, based upon that theoretical concern that this might happen sometime to somebody, you say no mature minor is able to access medical assistance in dying because someone may someday be disadvantaged, that is a very unfortunate outcome. Requiring those individuals to continue to suffer intolerably until they reach 18 is not the appropriate approach.

Mr. Alistair MacGregor: I guess my closing comment is that I'm trying to determine how much a person's decisional capacity is influenced by their life events and whether a medical assessor can properly take those into account. I guess that's the big question we're grappling with.

I appreciate both of you intervening today and assisting our committee in this.

Thank you.

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

I'll turn this back to our joint chair Mr. Garneau.

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

We'll go to the senators for their round.

[*Translation*]

Senator Mégie, you have the floor.

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

My question is for Professor Macintosh.

In 2016, you published an article entitled “Carter, Medical Aid In Dying, and Mature Minors”. In the article, you outlined the jurisdictions where minors are included in MAID regimes. You demonstrated how little empirical evidence existed at that time regarding minors' requests.

Today in 2022, have you found further evidence and managed to gather any other information on minors' requests for MAID?

• (2010)

[*English*]

Prof. Constance MacIntosh: Do you mean in Canada, or in jurisdictions where youth are able to access MAID?

[*Translation*]

Hon. Marie-Françoise Mégie: I'm talking about other jurisdictions, because it's not allowed in Canada yet.

[*English*]

Prof. Constance MacIntosh: It's not yet allowed.

There was a recent publication by the Canadian Paediatric Society, which was a survey of pediatricians with regard to whether or not people had been approached for requests or queries about MAID in the last few years. There were a number of requests or queries that had been made here in Canada. I think it might have been 17 that were documented. I can get you that information later with some specificity.

In the jurisdictions where it's legal, in Belgium and in the Netherlands, the numbers are still very low.

[*Translation*]

Hon. Marie-Françoise Mégie: Thank you.

I have a short question for Mr. Salte.

What is the real definition of “mature minor”?

[*English*]

Mr. Bryan Salte: “Mature minor” means somebody who has decisional capacity with respect to the specific decision they're being asked to make. They need to be in a position to be able to understand the risks and benefits of the decision they are being asked to make, fully understand the implications of the decision, and be able to make an informed decision, understanding all of the implications of that decision. That is what I would understand to be the mature minor.

“Decisional capacity” is the other term that people prefer to “mature minor”. Thank you.

[*Translation*]

Hon. Marie-Françoise Mégie: Thank you.

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

[*English*]

Senator Kutcher.

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

Thank you to the witnesses for being here with us.

I have three questions, and I would like it if each of you could weigh in on them. They shouldn't be long answers.

First, would MAID be provided to a young person experiencing a crisis? Second, how common is unresolvable disagreement between parents and child when it comes to decisions about MAID? Third, there are countries in which MAID is provided to mature minors. Are there any lessons that Canada could learn from these experiences, things that we should avoid or things that we should apply?

The Joint Chair (Hon. Marc Garneau): Perhaps, Professor MacIntosh, you could start.

Prof. Constance MacIntosh: A young person in crisis would not be eligible for MAID anymore than they would be eligible for any other decision, for example, to deny life-sustaining treatment. The individual's emotional state is taken into account when assessing whether, in that instance with that decision, the minor is able to fully appreciate the decision they've been asked to make and its consequences. So that's a clear no for me.

On the question of how common are unresolved disputes with regard to MAID, I have no information on that question.

As to lessons from other countries, some of the practices we see are review boards. For any instances in which MAID is to be performed on a minor, or an adult as I recall, there is a report that is filed with a central body that will review everything. That's one of the safeguards.

I think that we actually picked up a lot from what other countries' practices were when we created our MAID regime a few years ago.

I'll pass the mike.

Mr. Bryan Salte: Thank you so much.

I'll answer the second question first, because I don't think there's any evidence as it specifically relates to medical assistance in dying. However, there is good evidence as it relates to many other life-challenging decisions. The number of significant disagreements between parents and children is small, not so small necessarily in some of the issues that relate to, for example, abortion, where there are very strong ethical or religious viewpoints that may differ between the two. In terms of health care, not a large number of individuals have reported those kinds of strong disagreements. Of course, because MAID is not illegal in Canada, that really has not been an issue with respect to medical assistance in dying for mature minors.

With respect to the lessons from other jurisdictions, certainly Belgium and Netherlands are more restrictive in what would qualify than what I would support if it were my decision to make. I also think that it's problematic for boards to become involved unless absolutely necessary in these kinds of situations. Consequently, the better approach, again, is to rely upon the judgment of the medical professionals who are required to make these decisions following the guidance of the regulatory bodies and the expectations for establishing informed consent with respect to the entirety of the practices they engage in, which may include medical assistance in dying.

With regard to somebody in crisis, if it is a temporary situation that may pass, I completely agree that the state of mind during that period of time, which is likely to be different later, would not qualify somebody for medical assistance in dying. If, indeed, that is a concern, one of the things that one could possibly look to is the cooling off period, or the period of time that's required between the first request and when medical assistance in dying might be administered, as is the case for individuals who do not have a reasonably foreseeable death under the current legislation.

● (2015)

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

[Translation]

Senator Dalphond, you have the floor.

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

I have two questions I'm going to ask right off the bat.

Here's my first question...

Would the access to MAID for mature minors that you're proposing apply both when death is foreseeable and when it isn't? Access to MAID when death isn't foreseeable was added to Bill C-7.

Here's my second question...

Aren't the additional safeguards you are proposing essentially just variants of the usual safeguards in place for all cases of medical assistance in dying? I mean proper assessment of the person's capacity to consent, and the need to ensure that they are requesting MAID freely and voluntarily and that they are capable of making the request.

For example, it could be a 70-year-old widow who lives alone, and has been abandoned by family or other loved ones.

Don't the same criteria always apply? Basically, it's about determining if the person really still has the decisional capacity based on their situation.

[English]

Mr. Bryan Salte: Certainly, the requirement of consultation with family members is not part of the current regime. If I were eligible for medical assistance in dying, and I chose not to inform any members of my family, I am perfectly entitled to choose not to do that. Now, whether the physicians involved are prepared to provide medical assistance in dying in those circumstances is a different issue, because, of course, no physician is compelled to provide medical assistance in dying even if the individual is technically capable of meeting the criteria.

Therefore, I think that additional criteria is important. The thing Professor MacIntosh has been speaking about to some extent, which is something worth considering, is whether there are additional safeguards that are necessary in order to have a degree of confidence, and, potentially, whether the public has a degree of confidence that this really is the decision of the individual, fully informed with a full understanding of the implications of the process that was involved in order to do that.

While I don't personally support that, because I think the medical profession will deal with that appropriately, I can understand there may be an appetite in the public to see something like that occur.

Hon. Pierre Dalphond: Would that be true for both tracks, namely, that which is foreseeable and that which is not foreseeable?

Mr. Bryan Salte: I feel most strongly about those situations in which death is reasonably foreseeable. I think there are some interesting constitutional arguments, because of course with adults the decision in Quebec required that medical assistance in dying must be made available whether death is or is not reasonably foreseeable.

I think a decision to only allow medical assistance in dying for adolescents who have a reasonably foreseeable death would be constitutionally very questionable as a political decision. As something that might be supported more broadly, it would probably be easier to achieve support for individuals whose death is reasonably foreseeable.

But constitutionally—

● (2020)

Hon. Pierre Dalphond: I would maybe ask Professor MacIntosh just to complete this for a few seconds.

Prof. Constance MacIntosh: I don't think I have much to add there.

For me, the heart of the suggestion about safeguards is about public transparency and public confidence, that they understand the process that's being undertaken to ensure that vulnerabilities are identified and addressed when it comes to youth.

Hon. Pierre Dalphond: Thank you.

The Joint Chair (Hon. Marc Garneau): Senator Wallin.

Hon. Pamela Wallin: Thank you very much, Chair.

I'd just like to hear from Dr. MacIntosh, just in response to what Mr. Salte said, that he has some reservations about review boards and the complications that might come with them, as opposed to relying on the judgment of the assessors and the medical professionals who are hands on in a particular situation.

Prof. Constance MacIntosh: I don't suggest review boards as being in an intermediary position necessarily, because I don't think they can move quickly enough. I don't think they can get in there in that 10-day period and determine if they think the request has been properly considered.

I would personally want to see some sort of a collective body receiving information about every instance where MAID has been given to a minor so that we understand what is happening in that practice, and that there is that other level of scrutiny.

I know that creates paperwork, and that's not exactly a favoured thing, but I would have more confidence in the system, and I think others would as well, if we understood—

Hon. Pamela Wallin: It is a kind of post facto review to establish practices and review outcomes.

Prof. Constance MacIntosh: That's right.

Hon. Pamela Wallin: Yes, that's helpful.

Mr. Salte, I was interested in your phrase, to go with “decisional capacity” versus “mature minors”, because it seems to be clearer just using those words, as Senator Mégie said, as definitions for these things.

Are there other situations where “decisional capacity” as a concept is recognized and used regularly with legal weight?

Mr. Bryan Salte: Certainly the discussion around the Council of Canadian Academies table was that “decisional capacity” is a much better term than “mature minors” because “mature minors”, as a legal term, is understood by lawyers and judges, but is not so clearly understood by members of the public. “Decisional capacity” better describes what it is that you're actually looking for.

I understand from that discussion that among medical professionals they do not use “mature minor” usually. What they'll refer to is individuals with “decisional capacity”, and that's true whether the individual is 14 or 94. The same issue applies.

Hon. Pamela Wallin: Do you see that concept used in your experience as a lawyer, versus someone dealing almost strictly with the medical side of legal issues or the medical field? Are there other places where that idea is recognized and accepted?

Mr. Bryan Salte: Certainly I understand it to be accepted quite nicely when you are talking doctor to doctor, doctor to another health care practitioner, but the legal term that has been developed when you are looking at court decisions, which is what lawyers do, is “mature minor”. It's a question of whether you want to go with a legal term that has a definition associated with it, which has been developed by various courts, with potential flaws in that particular term, or whether it's better to utilize a term that medical professionals better understand when they're performing their day-to-day duties.

Hon. Pamela Wallin: I'll just go back to Dr. MacIntosh. Even though you—

The Joint Chair (Hon. Marc Garneau): Ask very quickly.

Hon. Pamela Wallin: You said that age 12 would be a number you could live with for someone showing decisional capacity. Is that recognized anywhere else in the world or in any other field?

• (2025)

Prof. Constance MacIntosh: That number comes from the psychological literature on youth and medical decision-making. It's the youngest age that has been identified where it's considered to be plausible that a youth would have decisional capacity.

Hon. Pamela Wallin: Right. Thank you.

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

Senator Martin.

The Joint Chair (Hon. Yonah Martin): Thank you both for your testimony.

I'm still kind of shaken by 12-year-olds being considered youth. I think we call them “tweens”. In every other context we have parental consent, even to take photos in a classroom. I was a teacher for 21 years. I'm still quite shaken by that number. I think parental consent would absolutely be important.

Are you concerned how expansion to children might affect children in welfare systems, indigenous youth and children with disabilities? The CCA report notes a paucity of literature and therefore a failure to capture their voices.

We heard time and time again that the indigenous communities have not been consulted. Even considering an expansion of MAID just seems too soon and really against what we're trying to do, which is consult with many of these most vulnerable groups. Would you comment on this fact, please?

Professor MacIntosh.

Prof. Constance MacIntosh: If the youth is in distress or in foster care, these are all things that I would think would result in a physician concluding that they weren't making a free decision, if they came to them seeking medical assistance in dying.

I don't know if you're hearing from the voices of families with youth who are living with complex and painful illnesses. I would hope that you are. I would also hope that you continue a robust consultation with indigenous communities, because I certainly couldn't purport to speak for their views here.

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

Mr. Bryan Salte: Yes, thank you.

One of the very real challenges that the Council of Canadian Academies faces is that the viewpoints of indigenous communities are by no means common. The range of viewpoints is very large. Some of them would very likely be completely opposed to any concept of medical assistance in dying. Others would be much more accepting. That's the extent to which they were able to determine what the viewpoint of indigenous communities might be. Certainly consultation is an important aspect of how we operate in Canada. I do concur that there hasn't been a body out there to do those kinds of consultations.

If indeed the purpose is to alleviate suffering of individuals who are suffering intolerably, I would ask the question of whether it's an appropriate response to say that because there hasn't been enough consultation, the 16-year-old with terminal illness, who is in intractable pain that can't be controlled, will just have to wait while we make our decision. I personally would think that's an unacceptable approach.

Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you to our two witnesses, Professor MacIntosh and Mr. Salte. Thanks for taking the time to answer the committee's questions and for your opening remarks on this particularly challenging question of mature minors. We very much appreciate your input.

With that, colleagues, we will bring this panel to a close and prepare for the next panel.

We are temporarily suspended. Thank you.

- (2025) _____ (Pause) _____
- (2030)

The Joint Chair (Hon. Marc Garneau): I call this meeting to order so that we can begin our third panel.

Before we start, just for the benefit of our witnesses, before speaking, please wait until I or my co-chair recognizes you by name. All comments should be addressed through the joint chairs. When speaking, please speak slowly and clearly for the benefit of our interpreters because some of this will happen in English and French this evening.

Interpretation in this video conference will work like it does for an in-person committee meeting. You have the choice at the bottom of your screen of either the floor, English or French. When you are not speaking, please put your microphone on mute.

With that, I would like to welcome our witnesses for panel three who will discuss the issue of medical assistance in dying in the case of mature minors.

We have this evening two witnesses, Mr. Franco Carnevale, professor and clinical ethicist, as well as Dr. Alisha Montes as an individual.

Thank you for joining us.

We'll begin with opening remarks by Mr. Carnevale. He will be followed by Ms. Montes.

In each case, you will have five minutes for your opening remarks.

We'll start with Mr. Carnevale. Please go ahead.

Mr. Franco Carnevale (Professor and Clinical Ethicist, As an Individual): Good evening.

I'm honoured to have this opportunity to appear as a witness for this special joint committee.

I'm speaking to you as a clinical ethicist who works with young people, including dying children and youth, and their families. I'm also speaking to you as a childhood ethics researcher. I founded and lead a childhood research program called VOICE, which is based at McGill University. I'm here to share what I've learned from working with young people, their families and those who work with them.

My comments this evening are drawn from a report that I was asked to prepare in 2021 by Dr. Michel Bureau, chair of the Quebec end-of-life commission. I'll refer to this work as my 2021 Quebec report.

Dr. Bureau asked me to examine views within the McGill University network regarding the potential inclusion of some minors in the provision of MAID—medical assistance in dying—so that his commission could consider this information in their deliberations. I submitted my report to him on May 27, 2021, and he's given me permission to share that report with this committee, which I've submitted as an addendum to this statement.

Moreover, I was part of a 14-member pan-Canadian expert panel working group on MAID for mature minors convened by the Canadian ministers of justice and health to examine the evidence regarding the inclusion of mature minors in MAID. The results of our analysis are documented within our final report, published in 2018. That report is likely the most comprehensive and robust examination of this topic, which I hope this committee will consider seriously.

A major concern highlighted within that report was that youth input has been largely absent in discussions about MAID for minors. To help redress this problem, I submitted as evidence videorecorded interviews that I conducted with disabled youth leaders at Holland Bloorview Kids Rehabilitation Hospital in Toronto. For details on those interviews, see pages 122 to 123 in the English version of the report. Translation is available in the French version as well.

In preparing my 2021 Quebec report, I conducted consultations with the Youth Advisory Council and the Indigenous Youth Advisory Council of the VOICE childhood ethics program. I also consulted with parent and family representatives within pediatric services, medical and nursing leaders within various clinical services, pediatric palliative care researchers, the clinical ethics committee at Le Phare, Enfants et Familles, which is a pediatric hospice, and the child and youth mental health ethics committee at the Douglas Mental Health University Institute in Montreal. The latter was to examine whether some minors should be considered eligible for MAID solely on the basis of a mental health problem. The detailed results of this investigation are described in the 2021 Quebec report, which I've submitted to this committee.

I'll briefly highlight some of the conclusions and recommendations from that report. They include the following.

There are strong disagreements among clinicians regarding the justifiability of MAID for some minors. Some clinicians described clinical trajectories that correspond with those of adults who could be eligible for MAID. A number of medical conditions are described in my report for which these clinicians considered MAID could be a reasonable option for some minors. In contrast, some clinicians stated categorical objections toward making any minors eligible for MAID.

Clinicians also stated concerns about ways in which potential risks or vulnerabilities associated with MAID could amplify existing inequities for some minors. There was a consensus among the groups that I consulted that MAID should not be made available for youth for whom a mental disorder is their sole underlying medical condition, chiefly because they could not identify any clinical scenarios that they could characterize as irremediable or in an advanced state of decline that could not be reversed.

Given the vulnerabilities that may be a concern for some minors, special attention should be devoted to the safeguards that should be in place to ensure that all minors are treated safely. At the same time, it is important these safeguards do not operate as onerous obstacles that can create discriminatory inequities regarding access to MAID.

• (2035)

While ensuring that minors' vulnerabilities are adequately safeguarded, we should not perpetuate common tendencies to under-recognize and devalue their capacities, aspirations and concerns as moral agents. Any initiatives to include or exclude minors from eligibility for MAID need to be based on the latest state of knowledge in child and youth studies, working in consultation with youth advisers.

In conclusion, an examination of whether or not some minors should be eligible for MAID should involve meaningful consultations with youth groups as well as youth leaders. Moreover, consultations with indigenous leaders and communities are necessary to ensure that concerns and impacts that may be specific to the experiences and vulnerabilities of indigenous youth are respectfully addressed.

I thank you.

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

We'll now go to Ms. Montes.

Ms. Montes, you have five minutes.

Dr. Maria Alisha Montes (Clinical Associate Professor of Pediatrics, Memorial University, As an Individual): Thank you, Mr. Chair.

Thank you for the invitation to speak. My name is Dr. Alisha Montes. I'm a clinical associate professor of pediatrics at Memorial University in St. John's, Newfoundland. I was also awarded a Rhodes Scholarship, and I completed my master's in bioethics and public health at Oxford University. My practice is comprised of

children from birth up until age 18, and I have a special interest in developmental pediatrics. I am also a mother of three children.

Some words I would use to describe my own adolescence are tumultuous, stressful, hopeless and traumatic. I was an obese teenager who came from a broken and chaotic home. I was abused as a child and raised by a single mother who had PTSD. I was severely bullied as a teenager. I found it very difficult to function while at school and in my social circles. I had many years when I felt hopeless and wanted to die due to intolerable social and psychological suffering. But with a lot of support, encouragement, mentorship and appropriate access to medical care, I was able to overcome my struggles. I have been able to live a very full and meaningful life. If MAID was legalized, that may have been the end of my story. My future life was full of potential, and I am so grateful to be here today, speaking with you.

Studies show that the frontal lobe is not fully developed until early adulthood. The frontal lobe is very important for coordinating executive functions, including the balancing of risks and rewards and decision-making. This explains why adolescence is a highly vulnerable time for risk-taking behaviours.

In pediatrics we practice harm reduction, which is a public health strategy that was developed to reduce the negative effects of risky behaviours and to mitigate the risk of injury and prevent premature death in adolescents. I would argue that MAID for mature minors carries the highest amount of risk, as the consequence is death. It's irreversible. We need to ask ourselves if we should be legalizing this for mature minors when biology shows us that the ability to balance risks and rewards is one of the last areas of the brain to mature.

The Supreme Court of Canada recognizes that capacity for decision-making of children must take into account the child's mental, emotional, physical and developmental stage. The courts apply a sliding scale to capacity, meaning that decisions that carry grave consequences require more scrutiny. In some cases, a total prohibition is necessary to avoid future harms, such as with marijuana, alcohol, cigarettes and illicit drugs. I believe we have a duty to protect adolescents during this time of brain maturation. The legalization of MAID does the exact opposite of harm reduction. It exposes children to the very dangerous choice to end their lives prematurely and with the support of the Canadian government.

Based on my experience, giving adolescents the option to end their lives prematurely is not what they want or need, as the majority of their suffering is not because of their mental or physical conditions. It is due to social stigma, poverty, lack of access to resources and tumultuous home lives. Seventy-five percent of children with mental health disorders do not have access to specialized treatment. Here in Newfoundland, there's a one-year waiting list to see a child psychiatrist. We know that 70% of mental health disorders begin during childhood or adolescence. MAID is not the solution to these troubling statistics. We must spend our time and resources improving access to specialized care and listening to the voices of youth to ascertain how we can support them during this very difficult developmental period.

What kind of message does it send to suggest MAID when an adolescent is struggling through this difficult developmental time? Instead, we must believe in them. We must give them a reason to hope. We must delight in their individual talents, mentor them and teach them the important skills necessary to overcome their challenges and be resilient.

When adolescents want to end their lives, parents do everything they can to prevent them from committing suicide. I know this through my own clinical experience and as a mother. We know that the parental relationship is very important and integral to children's development. It even predicts such long-term health conditions as mental health wellness and the ability to cope and to maintain meaningful relationships. We need to carefully consider and study how this may negatively affect parental relationships and have the propensity to cause ripple effects through the family and cause trauma that may have lifelong negative effects.

• (2040)

Finally, the CCA report also noted that there is no robust evidence that captures the voices of the youth on this matter. It is troubling that the views of minors with disabilities, indigenous youth and those in the welfare system were not captured in the literature.

In medicine, we make decisions based on robust evidence. Why are we rushing to legalize this when there's a paucity of evidence and all of the integral voices have not been captured?

Thank you very much for your time.

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

I'll turn it over now to my Joint Chair, Senator Martin.

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

We'll begin the first round of questions with Mr. Cooper.

Mr. Michael Cooper: Thank you, Madam Chair.

My questions are for Dr. Montes.

Dr. Montes, in the last panel, we heard what I would characterize as pretty shocking testimony from one witness, Professor MacIntosh, who asserted that children as young as 12 have the potential capacity to make a decision to terminate their lives. Of course, 12-year-olds are years away from voting and from being able to make other adult choices. In the province of Quebec, the Consumer Pro-

tection Act bans commercial advertising that targets youth under the age of 13.

In 2017 the Senate unanimously passed Bill S-228 that prohibits the marketing of food and beverage products to those under the age of 17.

How do you square that with Professor MacIntosh's assertion that 12-year-olds can make a decision to terminate their lives?

• (2045)

Dr. Maria Alisha Montes: I think it's important, obviously, that we count the voices of children and adolescents. It's very important that we hear what they have to say, and, in pediatrics, we have to balance the voices of the children with many other things, one being the risk of the decision.

As I said, we use the principle of harm reduction, and some things just require complete prohibition because we know that, given their brain biology, they just do not have the ability to make these very risky decisions. Like you said, there are some things that we need to completely prohibit, and so I feel that, due to the fact that this is such a high-risk decision that's irreversible and ends in death, most definitely we need to have complete prohibition, because we know that developmentally their brains are not fully developed.

Mr. Michael Cooper: Thank you for that.

One could say that, in the case of a 12-year-old, that's extreme, but what about when we're talking about a seventeen-and-a-half-year-old? Professor MacIntosh said that it's arbitrary, obviously, establishing a floor of 18.

Could you maybe address that point?

Dr. Maria Alisha Montes: I'm not able to speak outside of my scope of practice, which is 18, but I would advocate that, for all children who come under the realm of pediatrics, which is zero to 18, there be complete prohibition, because we know that the science is that their brains are not fully developed.

Mr. Michael Cooper: You would submit that expanding this below 18 would put vulnerable young people at risk.

Going back to the testimony of Dr. MacIntosh, she said that a safeguard that she would advocate is the palliative care option.

What is the state of palliative care for young people in Canada today, and would you agree with that recommendation?

Dr. Maria Alisha Montes: The state of palliative care is that there's not good access to palliative care. I don't have the actual statistics, but I know that here in Newfoundland, for example, we do not have a palliative care specialist.

Before we go and legalize this, we have to make sure that we have appropriate access to these services, specifically palliative care, and we have very good technology now so that children should not endure intolerable physical suffering. I have seen, through my clinical practice and also personally—I had a nephew die of a congenital cardiac defect—that a lot of the suffering these families are enduring is because they're frustrated that there's a lack of access to care. They're not receiving the appropriate treatment. There are long wait times. We need to address these before we move ahead with this legislation. We need to make sure that everybody has equality and, specifically here in Newfoundland, we deal a lot with the indigenous population. There are no services in Labrador. They have to fly down for all of their pediatric services, so this is a problem we need to address before we move forward with this legislation.

Mr. Michael Cooper: Thank you.

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

Next, we have Mr. Hanley.

You have five minutes.

Mr. Brendan Hanley (Yukon, Lib.): Thank you to the two panellists for the very interesting testimony.

I'm going to let you know that I'm new to this committee, but as a former practitioner and public health physician, I'm not completely new to the issue of MAID.

I want to ask you, Ms. Montes, a question on what you call the "prohibition" approach until a certain age, applied for certain conditions. Maybe you can comment. At what age do you consider the frontal lobes have achieved maturity and that executive functioning is, in fact, now at adult stage?

Dr. Maria Alisha Montes: I'm sorry, can you repeat the question?

Mr. Brendan Hanley: Yes, maybe I'll rephrase it.

In some of our deliberations—for instance, on adolescence and drug or cannabis use—we often consider the maturity of the adolescent. In fact, science tells us that maturity of the frontal lobes is not achieved until age 25. At some point, we have to make decisions about relative maturity. There is, obviously, no black and white cut-off.

I'm wondering where you apply that cut-off in your own experience and practice.

• (2050)

Dr. Maria Alisha Montes: I can't give you a number based on years. Obviously, as you said, it's early adulthood. It's outside of my area of expertise. I can't comment outside of age 18, because I only take care of children up to age 18. Therefore, my argument is that we should not have it for children aged 0 to 18. There should be complete prohibition.

Above that age, it's out of my scope of expertise, so I cannot comment.

Mr. Brendan Hanley: The point I'm trying to make is that these things are relational. To the point of the previous witnesses, decisional capacity is relative, and the severity of a situation has to be

considered in the context of the condition and maturity of that individual.

Mr. Carnevale, I wonder if you can comment.

When you say we need the youth voice, what have we neglected and where can we do better in bringing the voice of young people into decision-making?

Mr. Franco Carnevale: Well, these comments are against the backdrop of a very large body of literature and evidence highlighting being excluded from discussions in clinical care as well as in policy-making. In clinical care, it is many times very humiliating and distressing for young people to be excluded from discussions about their diagnosis and prognosis.

With children with various types of end-stage illnesses, there's legal recognition, through the mature minor doctrine, that they should be principle decision-makers in making decisions that sometimes would even result in their death, declining certain trials in terms of cancer treatment and other neurodegenerative, neuromuscular degenerative conditions. That's been very well documented.

There is an increasing view, and some of this really... This is why I worked with Holland Bloorview in preparing evidence for the CCA panel that I worked on. Holland Bloorview has probably the longest-standing youth advisory council. They have, through their youth advisory council, programs for developing youth leadership. These are youth who are living with various forms of disability, and therefore can be quite sophisticated in demonstrating their insights on the implications of different types of treatments and policies. It is within the institutional mandate of Holland Bloorview to incorporate youth on various committees to weigh in on decisions on the ways in which policies are made.

The UN Convention on the Rights of the Child, article 12, highlights that young people should be heard and that their voices should be attributed due weight in matters that affect them. It's fairly wide scale.

Dr. Hanley, I'd like to maybe ride on one of your comments, on the recognition that decisional capacity is a relational phenomenon. One of the areas where I work as a clinical ethicist is in a child and youth mental health centre. It is very clear that the way in which we present information, the way in which we create a trustworthy, safe, relational environment, can bolster or thwart a young person's capacity to participate in decisions.

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

Thank you, Mr. Hanley.

Monsieur Thériault, you have five minutes.

[*Translation*]

Mr. Luc Thériault: Thank you very much, Madam Chair.

I'd like to thank the witnesses for their testimony, which has been fascinating and enlightening.

Ms. Montes, you talked a lot about minors having access to medical assistance in dying when mental health disorders are their only medical conditions. I assume that you're aware of the expert report that was tabled recently.

Where does it say in that report that mature minors can obtain medical assistance in dying when they are in a crisis or a suicidal ideation situation?

• (2055)

[English]

Dr. Maria Alisha Montes: I'm so sorry. Do you think you could repeat that question, because the translation was not.... Could you just repeat the question?

[Translation]

Mr. Luc Thériault: I was saying that the report tabled by the experts talks about access to medical assistance in dying when mental health disorders are the only medical conditions involved.

You put a lot of emphasis on mental health disorders and you talked about crisis and suicidal ideation.

Where in the report would one find the recommendation to move forward on mature minors who are suffering from a mental health disorder or are in a state of crisis?

Where in the report did you see that?

[English]

Dr. Maria Alisha Montes: Are you referring to the CCA report? Which report are you referring to?

[Translation]

Mr. Luc Thériault: I'm talking about the report the minister commissioned from the expert panel that was to look into whether or not to include in Bill C-7 the sunset clause designating March 17, 2023, about when mental health disorders are the only medical conditions claimed.

That's okay, I will move on to another question.

Mr. Carnevale, you talked about additional safeguards for mature minors. You also stated that mature minors should not be granted medical assistance in dying if they are suffering from mental health disorders. I did understand what you said.

In your opinion, what should the additional safeguards be?

Mr. Franco Carnevale: It's really a work in progress. We need a lot more information to gain a solid grasp of what safeguards are needed.

We can draw inspiration from what's done in the Netherlands and Belgium, which have safeguards. In certain situations, parental consent is required based on the child's age. We already have that in Canada in certain situations. It depends on the province. In Quebec, for example, if a minor refuses necessary treatment, it's possible to challenge the decision in the minor's best interest.

There are safeguards in place for the few minors who make a decision that is not in their best interest. For example, we need to make sure they're not under any pressure and that they have been well informed. This measure is also described in the report I filed

with the committee. Parents must also be considered another decision-making authority.

Mr. Luc Thériault: I'm eager to read the report.

You have extensive clinical experience. Do you often come across situations where the parents and child disagree on what is in the child's best interests given the progression of the illness? Making those decisions is definitely a process because measures can't be put in place overnight.

In your extensive clinical experience, do you come across many disagreements, or does the decision-making process tend to be healthy, such that the parents and child are in sync regarding the child's best interests?

• (2100)

[English]

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

[Translation]

Mr. Franco Carnevale: In my experience, disagreements over what the child wants and what is in their best interests are the exception, not the norm.

Mr. Luc Thériault: Thank you.

[English]

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

Mr. Alistair MacGregor: Thank you, Madam Chair.

Dr. Montes, I would like to start with you.

I'm from B.C., and you're practising in Newfoundland, is that correct?

Dr. Maria Alisha Montes: Yes.

Mr. Alistair MacGregor: I know that provinces all have laws in place to govern, like British Columbia, mature minor consent. It basically puts in place the ability of medical professionals to accept consent from a child if they understand that the child is informed of the risks.

For you as a pediatrician, what are your guidelines when you're treating a child and it's related to medical procedures only? How do you understand that concept of informed consent on medical procedures for minors who may be under your care?

Dr. Maria Alisha Montes: It's a very complex issue, obviously, and there are many voices that need to be heard. Pediatrics is not as straightforward as adult medicine. It's not just talking to the adult. First and foremost, we talk to the child. When I go into any sort of consultation room, the first person I greet and try to establish a rapport with is the child, and hear what the child has to say.

Obviously, I try to get a sense if the child understands the medical procedure, and is the child able to say back to me the risks and benefits? It's not just that. It's a very complex thing, because children are part of a wider social network. They're part of a family, and there are many other voices that you have to balance along with protecting them, because we look at their developmental stage. Having a special interest in their development, we have to look at that, as well.

Mr. Alistair MacGregor: What if, for example, you were treating a child who had an incurable disease, an irremediable medical condition, and you were having this discussion with the parents and the child about end of life care. And then, in the confines of your office, just you and the child, the child was expressing an interest to go into palliative care, would you consider that to be consent, assuming the child understood the circumstances? Would you feel the need to go to the parents, or would you accept that child's desire to go into palliative care?

Dr. Maria Alisha Montes: It's context specific, but obviously, as I've said, there's not just one voice. I would have to talk to the parents as well. You have to think about the decision the child is making and how this is going to affect the parents. That's one thing we haven't really discussed, especially with MAID. The death of a child, as I've seen in my practice, is literally one of the most heart-wrenching things, and some parents never recover. I've actually personally gone through this in losing a nine-month-old—

Mr. Alistair MacGregor: I fully believe you there. I'm a parent of three children.

Dr. Maria Alisha Montes: Yes.

Mr. Alistair MacGregor: It would be the worst thing ever.

Dr. Maria Alisha Montes: In answering your question, I wouldn't just take the child's view; I would have to take multiple people's. That's just the way it works in pediatrics.

Mr. Alistair MacGregor: Just to be clear, because you talked about changing the law, I want it to be very clear for you, and for whoever is listening to this, that this committee is not talking about a piece of active legislation. We're conducting a study into this, which, hopefully, will inform decisions going forward. As of currently, there is no legislation before the Parliament of Canada that is looking at changing the Criminal Code with respect to medical assistance in dying, just so you're very clear on that.

The other question I had was with regard to Bill C-14 and Bill C-7. Bill C-7 opened up that other track: where death is not “reasonably foreseeable”. I'm just wondering.... It's a very personal decision. For children under the age of 18, if they do have an incurable disease, and if it is quite evident that every day of their life they are going through intolerable suffering, are you personally opposed to that child ever getting medical assistance in dying?

Or would you be open to it if you'd had a conversation with the parents and everyone knew that this was an incurable situation and the child was suffering? I'm just curious about your personal views on that particular aspect of the Bill C-14 track, the original track.

• (2105)

Dr. Maria Alisha Montes: Right now, we have an inequality of access to care. It's very hard to answer that question, because we

don't actually have the proper care we need. They don't have access.

My view is that before we can look at this, we need to make sure that there's access to palliative care, that there's good symptom management and that all of those things are put in place. We also need to parse out other things.

It's a very complex question to answer, and I can't answer it because right now there's an inequality of access to care. I believe that we really need to invest in that first before we move forward with this.

Mr. Alistair MacGregor: I appreciate that. Thank you.

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

I now will hand this over to my Joint Chair.

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

[Translation]

We now go to Senator Mégie, for the senators' round.

Go ahead, Senator Mégie.

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

My question is for Mr. Carnevale.

Can you talk more about the concept of children's agency?

What are the main reasons for using it? How would it help the committee's work?

Mr. Franco Carnevale: First of all, the French translation of the term “children's agency” is problematic. Generally, the term used in French is “*l'agentivité de l'enfant*”. It's a concept that emerged from an area of research known as childhood studies, which raises many concerns about how children are judged—in other words, they are not considered to be capable or competent. They are excluded from important decisions. As I said earlier, it is very clear that they do not cope well with being excluded from those decisions. Agency is a concept that recognizes that young people have aspirations and concerns, and have the capacity to be empowered. For example, children with diabetes can learn how to look after themselves and ensure they stay as healthy as possible by managing their diet, taking their insulin, exercising and so forth. It is very clear that the way in which we engage young children in the decision-making process and show respect for their views can support and strengthen their agency.

Does that answer your question?

Hon. Marie-Françoise Mégie: Yes, more or less, but since you both said that it was important to give children a voice, how do you think we can give those voices an outlet?

What impact would engaging young people on future MAID decisions have?

Mr. Franco Carnevale: The pivotal question is this: To what extent should the voice of young people factor into clinical, individual and policy decisions?

On a clinical level, that is already happening. As I mentioned, if a child with a neuromuscular disease no longer wishes to have long-term ventilation and decides that enough is enough, we have ways to assess their decision-making capacity. We really have an obligation to give significant weight to their wishes.

The process for determining the decision-making control of a mature minor varies by province. In some situations, for instance, the process is subject to a best interests of the minor assessment. Accordingly, even if the minor's decision-making capacity has been established, others can determine that the minor's choice goes against their best interests, thereby limiting the weight given to that choice.

• (2110)

Hon. Marie-Françoise Mégie: Thank you.

The Joint Chair (Hon. Marc Garneau): Thank you, Senator. [English]

Go ahead, Senator Kutcher.

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

I have a few questions for Dr. Montes. The first three are very short—I'd like factual information for those—and then there's one I'd like your thoughts on.

MAID for mature minors has been available in some countries for a number of years. Can you tell this committee for what circumstances or conditions MAID has been provided in those countries? That's the first question.

Dr. Maria Alisha Montes: Are you referring to the other countries? I'm not sure. I can't answer that question.

Hon. Stanley Kutcher: In those countries, how many young people have received MAID annually?

Dr. Maria Alisha Montes: I know that the number is very low, but there's not a lot of data on it. I'm not sure of the exact numbers, but I can get them to you after the committee.

Hon. Stanley Kutcher: That would be great.

In that group of people, how many young people received MAID while in a mental health crisis?

Dr. Maria Alisha Montes: Again, I'm not sure of those numbers.

Hon. Stanley Kutcher: Can you get them?

Dr. Maria Alisha Montes: Yes, I can get you that information after the committee. I don't have the exact numbers with me.

Hon. Stanley Kutcher: Great. Thank you.

In your pediatric practice, let's say you have a young person who has decision-making capacity. That person has a glioblastoma multiforme at grade IV. For the group here, that's the worst kind of cancer. You don't want to have that one. Their parents support their decision not to have treatment of any kind.

How would you proceed?

Dr. Maria Alisha Montes: That's a difficult question, and I think this comes back to the gravity of this decision. What I would say is that we have to also look at, first of all, the abuses that could happen in other populations, so things we haven't—

Hon. Stanley Kutcher: Excuse me. We have very limited time.

Do you respect that child's and their parents' decision not to take treatment for a glioblastoma multiforme at grade IV?

Dr. Maria Alisha Montes: It's a complex issue, so what I would say is we need to make sure.... It's very difficult to parse out whether or not they're asking for MAID because of a lack of services or a lack of access to—

Hon. Stanley Kutcher: Wait a second. I'm sorry.

I'm not asking about MAID. I'm asking if you accept their decision not to seek treatment for the glioblastoma.

Dr. Maria Alisha Montes: You're asking if I would?

Hon. Stanley Kutcher: Yes.

Dr. Maria Alisha Montes: That's outside my area of expertise. I don't practise oncology, so I'm not able to comment on that. However, what I can comment on is that it's very difficult to discern whether or not they're requesting this because of a lack of access to care. In my clinical experience, a lot of the times—

Hon. Stanley Kutcher: No. I'm sorry. This is not lack of access to care. It's a simple question.

This is a competent patient who refuses treatment for terminal cancer. Would you accept that patient's decision—and that of the parents? Answer yes or no.

Dr. Maria Alisha Montes: I'm not able to comment on that, Senator Kutcher.

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

We'll go to Senator Dalphond.

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

My question is for Dr. Montes.

Maybe it's a variation on the same theme that I'm following up on Senator Kutcher's questions.

I understand that you feel concerns about access to MAID by those who are under 18 and maybe even at a higher age. Would you feel less concerned if access was limited to the first track, which is for those whose death is imminent? In such a case, a person would come with a clear medical diagnosis that they are going to die within a few months or weeks. That person is going through unbearable suffering, according to that person. That person is 17 years old, wants to have MAID and the parents, who you have spoken with, are saying that yes, they agree the child has suffered enough.

Are you saying that we should deny access in such a case and oblige the person to go through unbearable suffering?

Dr. Maria Alisha Montes: I am advocating for is that, in some cases, we have to practise what we call harm reduction. If it's a very high-risk situation, we have to protect children and adolescents during their developmental time because it's a very vulnerable time where they take a lot of high-risk decisions, so—

Hon. Pierre Dalphond: Yes, I understand. I'm sorry to interrupt, but the time is limited.

The harm reduction principles for a group are fine, but that individual here is suffering irremediably and is near death, so it's no longer a harm reduction principle. It's a matter of whether we should respect the desire to put an end to the unbearable suffering.

• (2115)

Dr. Maria Alisha Montes: I've been listening to other panels. There have been a lot of stories of abuses of the safeguards, so it's just too high risk for me.

Again, I'm going to stick with my argument, which is total prohibition due to the biology and due to the lack of access to services and palliative care right now.

Hon. Pierre Dalphond: You don't care that, in a sense, you discard the best interests of the child?

Dr. Maria Alisha Montes: There are some things that are just so high risk. We have age limits for alcohol, marijuana, illicit drugs and even driving because we know that children are highly vulnerable in this stage of development.

Hon. Pierre Dalphond: Thank you.

The Joint Chair (Hon. Marc Garneau): Senator Wallin.

Hon. Pamela Wallin: I'd like to get some thoughts from both of you on this. We'll start with Dr. Montes.

As you said, you were listening to the testimony. We've discussed this notion of decisional capacity versus actual age. As someone who works with children under 18 all the time, would you agree that there are children who are nine, 12, 14 or 17, but who have life experiences or who have lived with profound illnesses or pain, who might well be in a place to have the ability to make key decisions, perhaps in some cases as well as or even better than somebody who's 45 or 70 and who doesn't make wise decisions? Is that possible?

Dr. Maria Alisha Montes: Thank you for the question.

That is definitely possible, but a lot of the time, from my clinical experience, these requests are very hard to parse out. A lot of the time, it's actually due to social stigma, poverty or a very difficult home life. It's very difficult to piece out what is really going on. Yes, definitely that is possible, but—

Hon. Pamela Wallin: Let's take an example where that's not the case. We have lots of situations where young children are very well supported by families and they come to a decision on their own because they might have been living through any kind of illness for quite some time. They've decided that this is not going to get better, it's not going to change and it's not fixable. Because they have that personal experience—that life experience that you agree is so important when talking to children—they could come to that decision

with their parents' blessing or at least concurrence. They're capable of doing so.

Dr. Maria Alisha Montes: It is so difficult to live with a chronic illness. I take care of many families, but we need to also consider the possible abuses so that the children who are suicidal and who are looking for a way to complete suicide.... We haven't discussed that.

Hon. Pamela Wallin: Yes, but we're not talking about that category.

Dr. Maria Alisha Montes: Right.

Hon. Pamela Wallin: We have to make a distinction, because not everybody is in that category.

Dr. Maria Alisha Montes: Right.

Hon. Pamela Wallin: We have lots of other situations. I'm just trying to focus on this, because obviously if there are big social concerns or they have no access, that's a different set of problems.

Dr. Maria Alisha Montes: Yes, it's just very difficult in practice to parse that out, and the decision is too high risk because it's irreversible and it results in death.

Hon. Pamela Wallin: So you would just say that the child, regardless of their lived experience, should not be allowed to make those decisions?

Dr. Maria Alisha Montes: No, that's not what I'm saying. I'm just saying it's a very complex issue, and we also need to balance that child with other children who may use MAID to complete suicide or may use MAID—

Hon. Pamela Wallin: But I'm really trying to not have that category. It's not a balancing act of how many people are in each category. I'm talking about children who are well supported, who have had access to all sorts of treatments and support, psychologically and medically, and who have come to a decision.

Dr. Maria Alisha Montes: In my clinical practice, I haven't come across cases in which all of those boxes have been checked, so, unfortunately, I don't know—

Hon. Pamela Wallin: Okay. I don't know how much time we have left. Is there a moment for Professor Carnevale to respond?

• (2120)

The Joint Chair (Hon. Marc Garneau): I'm afraid we've used up the time, Senator.

Hon. Pamela Wallin: Okay. I'm so sorry.

The Joint Chair (Hon. Marc Garneau): That's no problem.

Senator Martin.

The Joint Chair (Hon. Yonah Martin): I have a question for each of our witnesses as well.

Dr. Montes, your story demonstrates the incredible ability of children to overcome life suffering with support. And as we know from prior witnesses, psychosocial suffering is not irremediable in those struggling with mental illness issues or disability and often can be remediated with good care and support.

Can you speak about the impact that social injustices such as bullying and trauma may contribute to a desire to die? Do you have concerns that the root of a MAID request by youth might be overlooked by a MAID assessor, especially if they don't have expertise in these specialized fields? Would you comment on that, please?

Dr. Maria Alisha Montes: Thank you for your question.

Yes, we have a study called the adverse childhood experiences study. It shows that children who have undergone traumatic events in their childhood are three times more likely to have depressive symptoms and have a very increased risk of suicide. So one of my concerns is that with these children, there may be abuses, and it's very difficult to parse out what the actual root cause of the request is. These children do very well with supports and actually can overcome these challenges like those in my story. I've seen many children in my practice who, with the right support, have been able to overcome the trauma, but in those crisis moments, it's very difficult to ascertain this, and it is very concerning. It's something we need to really consider before moving forward.

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

Mr. Carnevale, you mentioned the importance of safeguards, but I want to know whether you could articulate some of those if you haven't yet done so.

Dr. Maria Alisha Montes: At this point, I—

The Joint Chair (Hon. Yonah Martin): That was for Mr. Carnevale.

That's regarding the safeguards and whether you want to specify what you were referring to in your testimony.

Mr. Franco Carnevale: I described a little bit before in a French reply.

The safeguards that are commonly referred to and that are also described in my report are the way in which we evaluate decisional capacity, mindful of some of the concerns that Dr. Montes has raised, to make sure that those are all properly assessed and evaluated.

I think the other big one that is commonly looked at and is in place as well in the Netherlands and Belgium is the situations under which parental corroboration might also be needed.

I'd also like to highlight that in the cases I've been involved in involving minors, in which there were questions about MAID, these were very different from situations in which a minor might be seeking contraception. When we're looking at life-limiting illness, it's very, very uncommon that we're speaking only with the minor. They have significant care requirements, and my experience has usually been that it's the parents who've actually sought the possibility of MAID for their minors. As I said to Mr. Thériault before, it's very uncommon in those kinds of situations that the minor is asking for their life to end, for treatment to be stopped so that they would end where there's a categorical objection on the part of the parents.

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

I want to thank you, Professor Carnevale and Dr. Montes, for coming tonight. Thank you for answering our questions and providing your testimony. I know it's late for you. It's particularly late for

Dr. Montes, who's in Newfoundland. It must be about 11 o'clock there now.

Again, we very much appreciate your taking the time and giving us your candid commentary. Thank you.

With that, panel three is completed.

Colleagues, if you could hang around, we have to talk about what's left between now and June 23. I'll do this very quickly. We're in a situation where, in all likelihood, we will have two more meetings. One will be next Monday and the other the following Monday, which is June 20. It doesn't look like we're going to get a Thursday night meeting, because the BOIE wants to meet on...at the moment, for both of those.

As you know, on June 13 we're going to look at the draft of the interim report on mental disorders that is currently being put together, which we have to table by June 23. We'll have the whole three hours to do that. The following Monday, we've reserved two hours, hopefully to finalize it, and then we'll have a subcommittee meeting that will look at what's ahead of us, only in the broadest terms. There have been a lot of questions asked about where we go from here after we rise for the summer.

That's just to let you know the schedule. Now here's the complicated part.

You're going to get the interim draft report this Friday, the one that we have to table by June 23. It will be provided this Friday. It will be considered on Monday. That can be a very involved process, as we know. It's a very tight turnaround time, so what we're asking you to do is to look at that report and to essentially be ready to discuss it in specific terms on Monday night. That means a little bit of weekend homework. This is so that we are in a situation where we're trying to ensure that we're going to be ready to finalize the report at the very latest on June 20.

It's a very tight turnaround time. If there are huge revisions to the report next Monday, that will also mean that we'll still have quite a ways to go on June 20, when we look at the final draft, or hopefully the final draft.

Any changes to that second version, the version that will come after June 13, will have to be minimal, or the work involved to present the report in the House cannot be completed prior to June 23.

We're hoping that, if there's wording you want to add or change, you'll come with that specific wording and, if possible, provide your commentaries to the clerk by noon on Monday. That way there's also a chance to translate it, in some cases. It may or may not be ready by Monday night, but at least the analysts will have an idea of what you're really going for.

All of that is to say that you're going to get the report on Friday, and we're hoping that you'll provide commentary on Monday. Our strategy is to try to make sure that we get most of it done Monday night. That way, we can just do the cleanup the following Monday, because we have only two meetings left.

• (2125)

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

I see Senator Wallin's hand, but perhaps I can add to what MP Garneau has said.

In terms of next Monday and our proposed revisions or additions, if we're ready to read them at the meeting, we can get the interpretation as we read. That will facilitate the tight timeline in which we have to work. It does require some homework on our part so that next Monday we're ready to discuss the revisions and edits.

The Joint Chair (Hon. Marc Garneau): Yes. You've made a good point.

The Joint Chair (Hon. Yonah Martin): Senator Wallin has her hand up.

The Joint Chair (Hon. Marc Garneau): Hopefully, we'll be saying "this is what I propose" and reading it so that everybody hears it, as opposed to saying "I think we should change it to something like this", which unfortunately means extra work to decide what that should be, which has to be looked at the following week. Being as precise as you can be on Monday night would be great.

Go ahead, Senator Wallin.

Hon. Pamela Wallin: I want to say a word about the legislation because one of the witnesses raised it.

This legislation is not designed to be pre-emptive. It's a bit of reality. The Senate takes a little bit longer than the House of Commons to do things, and we will not get to this issue until the fall.

It was important to get it on the record so that those who wanted to address it could, but we won't be doing anything pre-emptive. This is just an FYI.

Thank you for the moment.

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

Is there anything anybody else wants to add?

Thank you to everyone for another very long evening.

This meeting is adjourned.

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