

**Failing People with Disabilities who Experience Systemic Suffering:  
Gaps in the Monitoring System for Medical Assistance in Dying**

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## Table of Contents

Introduction.....	1
Failures of the Monitoring System: Cases of Concern.....	1
Analysis of Gaps in the Monitoring System.....	8
Recommendations for Addressing the Gaps.....	10
The Case for Unilateral Federal Action.....	11

## Introduction

The system for monitoring medical assistance in dying (MAiD) in Canada is failing people with disabilities and not fulfilling Parliament's and the federal government's promise that the system would respect their equality rights. Evidence-based concerns reported in this brief demonstrate that to ensure a responsible and non-discriminatory MAiD system, Parliament and the federal government must act unilaterally to embed in the *Criminal Code* provisions for comprehensive monitoring and reporting. Provincial/territorial health care systems and medical practitioners must be required to act accordingly.

Reported cases that link MAiD deaths to the experience of systemic suffering raise significant concerns that eligibility criteria laid out in the *Criminal Code* are not being fully met before MAiD is administered. In their frequency and pattern, these accounts suggest that in many instances the suffering motivating the request is caused not by a disability or health-related condition but largely by lack of needed disability-related supports that assure dignity and inclusion. It is systemically-caused suffering that is at the root. And for this, people's lives are being terminated through the MAiD system.

Other cases of concern raise doubt about the extent to which communications about MAiD between practitioners and their patients may be undermining rather than enhancing patient autonomy. As MAiD becomes increasingly accepted in practice, reports from patients with disabilities who feel that a MAiD request is expected or demanded of them point to a gravely serious drift from the program's legislative intent.

Critically needed information about why people are requesting MAiD and whether alternative courses of action are fully explored and made available, is not being gathered or reported. As well, current monitoring protocols provide no mechanism for patient reporting when physicians overstep their authority in patient decision-making at end-of-life.

This brief:

- Reports a number of cases of concern
- Recommends changes to the existing monitoring and reporting system to address these gaps
- Makes the case for unilateral federal action to fix the monitoring and reporting system

## Failures of the Monitoring System: Cases of Concern

Several cases of people with disabilities who requested and received MAiD raise very serious concerns that the eligibility criteria for access are not being adhered to in all cases. Nor is the process for obtaining informed consent and guarding against "external pressure," as the legislation requires, always being managed in a way to fully explore alternative courses of action. In some cases, it appears that multiple pleas for access to needed supports have gone

unaddressed, eventually leading the person to give up and apply for and accept MAiD in apparent defeat.

Just as concerning is the fact that our current MAiD monitoring and reporting protocols collect no data about requests motivated by this kind of systemic suffering. This is because detailed proposals put forward in 2018 for more comprehensive information gathering and reporting were rejected by both the federal and provincial/territorial governments. The number of cases and anecdotal accounts that have since come to our attention, in which persons with disabilities surrender the will to live rather than endure the indignities, curtailments of liberty and isolation of institutional care, give rise to a serious concern that this may be a pattern underlying many MAiD deaths.

The cases summarized below evidence these concerns:

NAME	DETAILS OF CASE
<b>Archie Rolland</b>	<ul style="list-style-type: none"><li>• Eighteen months before his death by MAiD, Archie Rolland was transferred against his will from a residence that provided highly specialized care to a geriatric long-term care facility in Lachine Québec.</li><li>• Without staff adequately trained to communicate with him and provide essential care, he spent the remaining days of his life documenting the suffering that this caused and advocating for humane and capable care.</li><li>• When he began to lose hope and found continued life under these conditions intolerable, he made his request for MAiD, which was readily approved.</li><li>• At the time, Rolland told the Montreal Gazette that “it wasn’t the illness that was killing him. He was tired of fighting for compassionate care.”</li></ul> <p>SOURCE: <a href="https://montrealgazette.com/news/local-news/life-in-long-term-hospital-unbearable-montreal-man-with-als">https://montrealgazette.com/news/local-news/life-in-long-term-hospital-unbearable-montreal-man-with-als</a> and <a href="https://montrealgazette.com/news/local-news/saying-goodbye-to-archie-rolland">https://montrealgazette.com/news/local-news/saying-goodbye-to-archie-rolland</a></p>

NAME	DETAILS OF CASE
<b>Sean Tagert</b>	<ul style="list-style-type: none"> <li>• A devoted father, Sean Tagert had pieced together suitable care arrangements in his own home, including extensive personal supports and highly sophisticated communications technology.</li> <li>• Although he required 24-hour care, he received only 15 hours of care daily from Vancouver Coastal Health. This left him with a shortfall of \$263.50 daily, and a “constant struggle and source of stress”.</li> <li>• Once his personal savings were exhausted, Tagert’s only option was to move to a Vancouver residential care facility, more than 4 hours away from his home in Powell River. Such a move would have effectively curtailed his relationship with his 10-year-old son, who spent weekends with him in Powell River as part of a shared custody arrangement.</li> <li>• In 2019, exhausted from years of battling to secure funding for life-sustaining home care, Tagert chose to die by MAID.</li> <li>• In a final Facebook post chronicling his struggle Tagert wrote: “I know I’m asking for change. I just didn’t realize that was an unacceptable thing to do. Hundreds of British Columbians are dying horribly every year.” He described the funding decisions and institutional offerings advanced by the local health authority as “a death sentence.”</li> </ul> <p>SOURCE: <a href="https://www.cbc.ca/news/canada/british-columbia/als-bc-man-medically-assisted-death-1.5244731">https://www.cbc.ca/news/canada/british-columbia/als-bc-man-medically-assisted-death-1.5244731</a> and <a href="https://bc.ctvnews.ca/we-need-a-public-outcry-b-c-father-with-als-ends-life-after-struggle-to-stay-at-home-1.4543983">https://bc.ctvnews.ca/we-need-a-public-outcry-b-c-father-with-als-ends-life-after-struggle-to-stay-at-home-1.4543983</a></p>
<b>Alan Nichols</b>	<ul style="list-style-type: none"> <li>• Alan Nichols was admitted to Chilliwack General Hospital in June, suffering from acute dehydration and malnourishment.</li> <li>• While in hospital for treatment, Nichols was approved for and received MAID.</li> <li>• Nichols’ family members were notified of the scheduled procedure four days before it took place.</li> <li>• Aware that their brother had a history of intermittent severe depression and knowing that his patterns of behaviour during these episodes included failing to eat and care for himself, the family protested, demanding that the hospital provide Alan with the care he actually needed.</li> <li>• Because Nichols had been deemed capable and eligible for MAID, his family was unable to intervene to save his life.</li> </ul> <p>SOURCE: <a href="https://www.ctvnews.ca/health/family-says-b-c-man-with-history-of-depression-wasn-t-fit-for-assisted-death-1.4609016">https://www.ctvnews.ca/health/family-says-b-c-man-with-history-of-depression-wasn-t-fit-for-assisted-death-1.4609016</a> And <a href="https://www.ctvnews.ca/health/advocates-urge-better-safeguards-after-medically-assisted-death-of-b-c-man-1.4610949">https://www.ctvnews.ca/health/advocates-urge-better-safeguards-after-medically-assisted-death-of-b-c-man-1.4610949</a></p>

NAME	DETAILS OF CASE
<b>Mother of Jennifer Turton-Molgat</b>	<ul style="list-style-type: none"> <li>• In a Facebook post written in August 2020, Jennifer Turton-Molgat wrote: “My mom, the most positive, resilient, loving person I know has requested an assisted suicide. She wants to end her life, not because she is in pain or intolerable discomfort, but because she is being held prisoner in her long-term care home and has lost her will to live.”</li> <li>• Prior to the severe Covid-era restrictions in her long-term care home, Turton-Molgat wrote that her mother’s “only enjoyment in life was feeling the sunshine and fresh air on her face and spending time with her family. And that was enough for her. Despite [her significant disabilities] she would often say, ‘I’m so lucky’.”</li> </ul> <p>SOURCE: <a href="https://www.facebook.com/jturtonmolgat/posts/1015723622225925">https://www.facebook.com/jturtonmolgat/posts/1015723622225925</a></p>
<b>Mr. X</b>	<ul style="list-style-type: none"> <li>• A man in his 80s with chronic shortness of breath causing extreme fatigue wished to die by MAID because he was no longer able to perform the activities that are important to him. He reported that he had “lost his sense of purpose”.</li> <li>• Referred to as “Mr. X” in court hearings related to his approval for MAID, he had seven different MAID Assessors review his application. Some of these Assessors raised concerns of anxiety, depression, and dementia.</li> <li>• “Mrs. Y”, his wife of 48 years, sought to intervene, asserting that he lacked capacity to make this request and did not know what he was doing due to his mental illness.</li> <li>• Mrs. Y’s effort to stop her husband from receiving MAID ultimately was heard by the Court of Appeal for Nova Scotia, which ruled in favour of proceeding with Mr. X’s approved MAID.</li> </ul> <p>SOURCE: <a href="https://www.cbc.ca/news/canada/nova-scotia/nova-scotia-medical-assistance-in-dying-supreme-court-injunction-1.5691456">https://www.cbc.ca/news/canada/nova-scotia/nova-scotia-medical-assistance-in-dying-supreme-court-injunction-1.5691456</a>  And <a href="https://www.thestar.com/news/canada/2020/09/04/nova-scotia-woman-fails-to-win-stay-as-husband-seeks-medically-assisted-death.html">https://www.thestar.com/news/canada/2020/09/04/nova-scotia-woman-fails-to-win-stay-as-husband-seeks-medically-assisted-death.html</a></p>
<b>Yvan Tremblay</b>	<ul style="list-style-type: none"> <li>• For over a decade, Yvan Tremblay lived independently in his own apartment with many customized adaptations to accommodate his significant disability.</li> <li>• When new fire regulations deemed that he could not be safely evacuated from his apartment, he received notice of eviction.</li> <li>• With his alternative housing options extremely limited and certain to curtail his independence and quality-of-life, he made multiple attempts to protest this judgement and retain his apartment.</li> <li>• When these attempts failed, Tremblay committed suicide in September 2014. Although it was not an option at the time, under the proposed amendments to the current law, Tremblay would be eligible to receive MAiD.</li> </ul> <p>SOURCE: <a href="https://plus.lapresse.ca/screens/8d84a4bb-79fd-4cef-9a87-f8311d3a3160%7C_0">https://plus.lapresse.ca/screens/8d84a4bb-79fd-4cef-9a87-f8311d3a3160%7C_0</a>  See also: Beaudry, Jonas-Sébastien, The Way Forward for Medical Aid in Dying: Protecting Deliberative Autonomy is Not Enough (June 30, 2018). First published in the Supreme Court Law Review, Second Series, Vol. 85., Available at SSRN: <a href="https://ssrn.com/abstract=3189417">https://ssrn.com/abstract=3189417</a></p>

NAME	DETAILS OF CASE
<b>Gabriel Bouchard</b>	<ul style="list-style-type: none"> <li>• Gabriel Bouchard was a 57-year-old man with lifelong disabilities. As his disabilities progressed in late adulthood, he found it necessary to resign from the employment as a social service professional that had been a great source of pride and satisfaction for 35 years.</li> <li>• He then faced an existential question: “Would you prefer to leave this life as a man who gladly, proudly gave 35 years to social service? Or after another 15 or 20 years, leave a life of degradation? I have no one in my life, no family, I’m alone, I would have ended up on welfare. I would have ended up in a nursing home, and I had no desire to do that, I know too well the quality of life in there — or the lack of quality! Or to go out with the memory of a job well done. The choice was easy for me.”</li> <li>• Bouchard chose to die by voluntary starvation, while being provided comfort care in hospital.</li> <li>• When asked in a video recorded interview what might have made his life worth living, he responded “If I had good service, a livable income – welfare is not livable... Yes, if it were possible, but it’s a dream!” He explained that he had declined provincially available services “because although the people were good, they weren’t paid fairly.”</li> <li>• At the end of his interview, he muses “People with disabilities are costly, right? I’ll be one less expense, right?”</li> </ul> <p>SOURCE: <a href="https://youtu.be/duEC3TqpsV4">https://youtu.be/duEC3TqpsV4</a></p>
<b>To Phat “Tommy” Sec</b>	<ul style="list-style-type: none"> <li>• Tommy Sec was 41 years old and had been living his life from bed for several years, confined to a nursing home. His wife had divorced him, and he had lost custody of his only child.</li> <li>• Increasingly isolated from family and friends, he described himself in an autobiographical film as being “in a rage”, feeling “hatred towards everyone”.</li> <li>• Alert and articulate but with significant physical and sensory impairments, Sec described his life as “like being trapped in a coffin and buried alive”. Although he was able to communicate through his computer, he said that “no one listens”.</li> <li>• Sec was informed of his eligibility for MAID in May 2019.</li> <li>• After media attention to his plight, Sec began to have more visitors from local Vietnamese and Cantonese communities, and according to a reporter who helped bring his story into the public domain, this social contact elevated his spirits. In November he was reported to be demanding to be moved out of his nursing home into a private residence with a live-in caregiver. As well, he was taking steps to repair his relationship with his estranged family, particularly his teenage son.</li> <li>• Tommy Sec’s current status is unknown.</li> </ul> <p>SOURCE: <a href="http://jane-finch.com/articles/whyamistillalive.htm">http://jane-finch.com/articles/whyamistillalive.htm</a>  And <a href="https://www.thestar.com/news/gta/2019/11/18/confined-to-a-toronto-nursing-home-bed-24-hours-a-day-tommy-sec-wants-to-die.html">https://www.thestar.com/news/gta/2019/11/18/confined-to-a-toronto-nursing-home-bed-24-hours-a-day-tommy-sec-wants-to-die.html</a></p>

NAME	DETAILS OF CASE
<p><b>Jonathan Marchand</b></p>	<ul style="list-style-type: none"> <li>• Jonathan Marchand is 43 years old and fiercely independent but forced to live in a nursing home for the elderly in Québec. Because he relies upon a ventilator to breathe, he requires 24-hour care. With no appropriate supports available in the community, a long-term care facility was his only choice.</li> <li>• In a recent short documentary profile for the series “Tales from Pandemic”, Jonathan speaks powerfully of his experience of losing freedom, independence and privacy, as inescapable conditions of institutional living.</li> <li>• Marchand describes a satisfying life with good relationships and personal and professional success until he “hit the wall” of requiring government-funded assistance to support his life.</li> <li>• Marchand argues that “increasingly, euthanasia is offered as a solution to institutionalization. The idea is that if you don’t want to die slowly in a long-term care facility, we are going to help you kill yourself. Those ideas are based on false assumptions about people with disabilities and seniors with disabilities, like our lives are not worth living...”</li> <li>• By his own account, Marchand had friends who killed themselves rather than go into long-term care, adding that he “decided that I would not go ahead with euthanasia, but I would fight to get out of this place.”</li> <li>• To draw attention to his circumstances, and to force the government to provide the support that he needs to live independently in the community, Marchand set up a large cage outside the Québec legislature, where he lived for 5 days and 5 nights, in protest of the intolerable conditions of his life.</li> <li>• As a result of this extraordinary effort and the significant media attention that it attracted, he was promised that the eventual government would immediately set up a “working group” to advise on alternatives to institutionalization for people like Jonathan.</li> </ul> <p>SOURCE: <a href="https://www.cbc.ca/listen/live-radio/1-15/clip/15793158?fbclid=IwAR2pDbx4bJRpVXtLLC7WLweoYvYUQrQrhfTr6DsaX-Mc6rl3JcPyVXAG30A&amp;share=true">https://www.cbc.ca/listen/live-radio/1-15/clip/15793158?fbclid=IwAR2pDbx4bJRpVXtLLC7WLweoYvYUQrQrhfTr6DsaX-Mc6rl3JcPyVXAG30A&amp;share=true</a>  And <a href="https://youtu.be/MLvMh45I_Zc">https://youtu.be/MLvMh45I_Zc</a></p>

NAME	DETAILS OF CASE
"Kim"	<ul style="list-style-type: none"> <li>• Kim has significant disabilities and lives in a rented 300 square-foot RV in Ontario. She has received notice of eviction. She relies upon ODSP payments for the necessities of her life.</li> <li>• In a recent investigation of how Covid 19 affects people with disabilities, Kim declared "It's like I'm being punished for being born disabled, like I committed some kind of crime."</li> <li>• Kim has considered applying for MAiD. She says "I have no dignity left... I don't feel like I'm worth anything to anyone anymore."</li> <li>• Kim reports that she knows of many people in similar circumstances who have applied for MAiD, and has personally "lost six friends to suicide since [the beginning] of COVID.... They don't want to live this way anymore, there is no safety net at all for people that are disabled."</li> <li>• The same investigation described how others in similar circumstances have sought MAiD for relief from intolerable poverty. A Twitter posting from one woman read "I've enrolled in MAiD, seeing as I can no longer afford to live, nor can I afford the food &amp; medicine I need to get better."</li> </ul> <p>SOURCE: <a href="https://toronto.citynews.ca/2020/09/02/odsp-covid19-pandemic/">https://toronto.citynews.ca/2020/09/02/odsp-covid19-pandemic/</a></p>
Raymond Bourbonnais	<ul style="list-style-type: none"> <li>• When Raymond Bourbonnais was no longer able to manage all his personal care needs at home, he was relocated to a Québec nursing home. During the 13 months that he lived in this facility, he filed multiple complaints about inadequate staffing, unbearable temperatures due to a lack of proper ventilation or air conditioning, and stressful and unwelcome interactions with older residents with dementia with whom he could not avoid contact.</li> <li>• With conditions in his residence only deteriorating and his complaints seeming to go unheard, Bourbonnais hoped for a cure for his disease. When a physician confirmed that no cure was possible, she broached the subject of MAiD, and Bourbonnais is reported to have "jumped at the chance".</li> <li>• In a farewell video in which he recorded a final "crie de coeur", Bourbonnais spoke of a "constant degradation of services" at his long-term care facility, and pleaded for others to "do everything possible to put pressure on the government" to address the deplorable conditions in these facilities.</li> <li>• Before dying by MAiD, Bourbonnais said that he was "very happy to forget this bad part of my life".</li> <li>• Raymond Bourbonnais died by MAiD in December 2019.</li> </ul> <p>SOURCE: <a href="https://www.latribune.ca/actualites/denoncer-avant-de-mourir-video-6b5b5b9901c42d9660ec5ba19a0eda78?fbclid=IwAR0y-ihHsHkge1fONPqix2Qxte0YXzNWXu3MWqH7csvoz3FFyegEtCUI6e0">https://www.latribune.ca/actualites/denoncer-avant-de-mourir-video-6b5b5b9901c42d9660ec5ba19a0eda78?fbclid=IwAR0y-ihHsHkge1fONPqix2Qxte0YXzNWXu3MWqH7csvoz3FFyegEtCUI6e0</a>  And <a href="https://youtu.be/fyAIPID7c40">https://youtu.be/fyAIPID7c40</a></p>

NAME	DETAILS OF CASE
<b>Roger Foley</b>	<ul style="list-style-type: none"> <li>• Roger Foley is 42 years old and has significant disabilities that require 24-hour care. He seeks to receive that care at home, rather than in a London Ontario hospital where he has lived for at least 2 years.</li> <li>• Foley has advocated forcefully that his discharge from hospital must be to his home environment, with a commitment to provide the care that he requires in his home.</li> <li>• Foley has said that he is “always thinking I want to end my life” because his demands for appropriate care at home have been denied. He asserts that he is being pressured to end his life.</li> <li>• Foley publicly released audio recordings of hospital staff offering him an assisted death and outlining how much it costs to keep him in hospital instead of getting the home care he desires and requires.</li> <li>• His case attracted the attention of the UN Special Rapporteur on the Rights of Persons with Disabilities, Cataline Devandas Aguilar, when she visited Canada in spring 2019. Following her visit to Canada, she issued a statement that she had "received worrisome claims about persons with disabilities in institutions being pressured to seek medical assistance in dying." She urged the federal government to investigate and prevent such cases.</li> </ul> <p>SOURCE: <a href="https://www.ctvnews.ca/health/chronically-ill-man-releases-audio-of-hospital-staff-offering-assisted-death-1.4038841">https://www.ctvnews.ca/health/chronically-ill-man-releases-audio-of-hospital-staff-offering-assisted-death-1.4038841</a></p> <p>And <a href="https://www.ctvnews.ca/health/barely-hanging-on-to-life-roger-foley-shares-his-fight-for-home-care-with-un-envoy-1.4378334">https://www.ctvnews.ca/health/barely-hanging-on-to-life-roger-foley-shares-his-fight-for-home-care-with-un-envoy-1.4378334</a></p>
<b>Candice Lewis</b>	<ul style="list-style-type: none"> <li>• Candice Lewis is a 25-year-old woman with significant disabilities who lives in Newfoundland with her mother, Sheila Elson.</li> <li>• Elson reported that when Candice was receiving emergency medical treatment in hospital in 2017, a doctor approached her to propose MAiD for her daughter.</li> <li>• According to Elson, when she firmly stated that she would not consider MAiD for Candice, the doctor accused her of being selfish.</li> <li>• Candice recovered from her acute illness and was discharged home from hospital. However, both Candice and her mother were traumatized by this encounter. Elson spoke out about this experience publicly because, in her words “We don’t want it to happen to anybody else.”</li> </ul> <p>SOURCE: <a href="https://www.cbc.ca/news/canada/newfoundland-labrador/doctor-suggested-assisted-suicide-daughter-mother-elson-1.4218669">https://www.cbc.ca/news/canada/newfoundland-labrador/doctor-suggested-assisted-suicide-daughter-mother-elson-1.4218669</a></p> <p>And <a href="https://www.cbc.ca/news/canada/newfoundland-labrador/medical-assisted-dying-disability-reaction-1.4222833">https://www.cbc.ca/news/canada/newfoundland-labrador/medical-assisted-dying-disability-reaction-1.4222833</a></p>

### Analysis of Gaps in the Monitoring System

In the preceding section, we have highlighted thirteen cases of concern when viewed through the lens of “the inherent and equal value of every person’s life and the importance of taking a human rights-based approach to disability inclusion,” a core affirmation of Bill C-7. In seven of

these cases MAiD was approved, and in at least six of these cases MAiD has been administered. In at least three of the remaining cases where MAiD was not the end result, there were conversations about a medically assisted death between healthcare practitioners and their patients. In the final three cases, MAiD was or would have been considered, if not actively discussed with a physician or other healthcare professional.

The vast majority of these cases have therefore already been entered as data points in the current federally coordinated MAiD monitoring system. Within that system as it is currently structured, none of these cases stood out as worthy of concern or interrogation. What has brought these cases, and many others, to the attention of disability rights watchdogs and advocates is therefore not any process of regulatory oversight, but rather a series of serendipitous accounts that captured attention on social or mainstream media.

Taken together, these cases evidence and indicate:

- A disrespect for the voices of patients with disabilities (“no one listens”) and an apparent disinterest in the myriad of ways they have customized their support and access arrangements which, if adequately financed and accommodated, would have created a viable alternative to MAiD;
- A brutalizing version of patient autonomy, which forcibly excludes the insights and knowledge of family members and loved ones from the practitioner’s interpretation of clinical indications and patient history, thereby compromising the practitioner’s duty to do no harm;
- A failure on the part of medical practitioners to appreciate the legal implications of a patient’s decision to request MAiD in a “moment of weakness” (due, for example, to an acute medical crisis and mental health issue, a profound life transition or disruption, or clinical depression), a concern explicitly recognized by the Supreme Court of Canada in the *Carter* decision as a risk factor to be safeguarded against;
- Little or no interrogation of the systemically-caused suffering that motivates requests (for example, deteriorating living conditions, maltreatment and chronic insecurity), which violates the *Criminal Code* requirement that it is the “illness, disease or disability or that state of decline” that “causes them enduring physical or psychological suffering that is intolerable to them.” (s. 241.2(2)(c));
- Lack of exploration of alternative courses of action to MAiD, which is essential to ensuring that the request is in fact voluntary (s. 241.2(1)(d), including palliative care, disability supports, income assistance, counselling, assistive technology, communication supports and environmental accommodations;
- The direct impact of the lack of community and institutional support on the likelihood of a request for MAiD;
- “External pressure” and forced choice (for example, feeling like one has to choose MAiD or “to die slowly in a long-term care facility”) operating in the patient’s decision-making process, contrary to the explicit requirement prohibiting any such inducement or coercion (s. 241.2(1)(d); and,

- A narrowing of perspectives in the MAiD assessment process to the exclusive domain of MAiD practitioners, without drawing insights from other fields of expertise in alternatives to MAiD including, for example, system navigators, social workers, occupational therapists, counsellors, communication experts, and financial and community resource specialists.

## Recommendations for Addressing the Gaps

Analysis of these cases of concern makes clear that current regulations for monitoring MAiD are nowhere near sufficient to ensure that MAiD is helping the people it is intended to serve, without putting others at risk. This is not a situation that fosters civic trust or professional accountability. Nor does it signal genuine levels of respect and regard for the human rights and equality of persons with disabilities – both the persons who are at the centre of each case, and that class of persons with disabilities whose precarious conditions of well-being and inclusion are imperilled by MAiD practices that violate both the letter and the spirit of the legislation.

It is for this reason that we conclude that our current monitoring and reporting system for medical assistance in dying is inadequate.

In order to understand whether, in authorizing the terminations of human lives through MAiD, the legislative regime has the effect of discriminating against persons with disabilities or vulnerable individuals we recommend that the legislation require that the Minister make regulations as follows. The legislation must require that in all MAiD cases:

- MAiD Practitioners must report in appropriate detail any and all factors in a patient's living conditions or life circumstances that may be causing or compounding their suffering.
- MAiD Practitioners must specifically report other treatments or interventions, including but not limited to palliative care, disability supports, income assistance, counselling, assistive technology, communication supports and environmental accommodations that were offered to relieve their patient's suffering, and the steps taken to make them available.
- The monitoring and reporting system must not rely solely on what MAiD Practitioners have to say about their patients and the practice of MAiD. Patients must be supported to offer their own perspectives if they wish. Similarly, members of a patient's primary health care team must be permitted to contribute their knowledge and insights as well.
- The monitoring and reporting system must provide us with a deeper understanding of the reasons that patients choose MAiD.

- The monitoring and reporting system must provide sufficient information to the public so that our government can be held accountable for achieving the law’s objectives to respect autonomy and protect people from harm.

In addition, we recommend that the legislation commit the government to further study:

- The ways in which people can be induced, in moments of weakness, to end their lives including how mental health and environmental factors may be operating in such moments, and the implications of these findings for enhancing safeguards in the legislation.
- The appropriate role of families in the MAiD assessment process, taking account of both privacy rights and autonomy, as well as the insights and knowledge that family members may have, including but not limited to: 1) the factors underlying a person’s experience of suffering; 2) the ways that suffering could be ameliorated; and, 3) the possibility that the person may be being induced to make a MAiD request and decision in a moment of weakness.

Proposed amendments are consistent with the legislative objectives for Canada’s MAiD regime. These are set out clearly in the Preamble to the existing law and in Bill C-7 which, as noted above, includes recognition of “the inherent and equal value of every person’s life and the importance of taking a human rights-based approach to disability inclusion.”

Taken together, these amendments would go far toward ensuring that the limited exemption from the *Criminal Code* provided to MAiD practitioners is used responsibly and free from error and abuse, coercion, and inducement. It would also ensure that persons in vulnerable circumstances are protected.

## The Case for Unilateral Federal Action to Legislate Monitoring and Reporting Requirements

The existing monitoring and reporting system is the result of a federal-provincial negotiation. At the time it was first being developed in 2018, comprehensive proposals for a more robust system were put on the table by a broad cross-section of experts and disability organizations. However, they were rejected by the federal government as unnecessary, too costly, or imposing time requirements on medical practitioners that were unreasonable.

Given federal jurisdiction over the criminal law, the gaps now visible in the monitoring and reporting system, and the existing evidence-based concerns that MAiD could in some instances be used irresponsibly and in a discriminatory manner, Parliament and the federal government must act unilaterally to embed in the legislation a more robust monitoring and reporting system to impose requirements on provincial/territorial health care systems and medical practitioners as outlined in recommendations above.

The federal government is well within its authority to monitor life-ending practices under its criminal law power because MAiD provides for an exemption to the prohibition on assisted suicide that still operates in the *Criminal Code*. While true that exemptions under the MAiD regime are delivered by provinces pursuant to their jurisdiction over health services, it remains within the federal jurisdiction to ensure that the criteria for accessing the exemptions are strictly adhered to when what is at stake is the termination of a person's life. There are already other instances in which the federal government uses its criminal law jurisdiction to impose robust monitoring and reporting requirements in the healthcare system, for example in matters relating to controlled drugs and substances.

The evidence presented above casts significant doubt that all of terminations of the lives of people with disabilities through MAiD are clear and proper applications of the narrow exemption to the current criminal law prohibition against the termination of another life. A much more robust, comprehensive, and stringently enforced reporting and monitoring system is required to foster trust that exemptions to the prohibition are in fact applied responsibly and legally justified. Doing so may impose additional costs on provincial/territorial health care systems, just as already occurs in other fields of shared federal/provincial jurisdiction (including in relation to controlled drugs and substances and the gun registry). Needed federal-provincial/territorial fiscal arrangements to implement the monitoring system could surely be worked through.

Given that the administration of MAiD involves the deliberate termination of the lives of people with disabilities, the federal government is within its constitutional authority to design, implement and enforce a comprehensive regulatory and monitoring scheme. Equal respect for the lives of people with disabilities demands that Parliament and the federal government do so.