**End of Life, Equality, and Disability: A National Forum on Medical Assistance in Dying**

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Nicolas Rouleau, Constitutional Lawyer

Thanks to the Ministers and parliamentarians who have attended today. The inclusion of an end of life criterion in the legislation continues to be essential – that’s the point we’re making today. The failure to include this criterion would significantly discriminate against persons with disabilities. I'll explain why and I’ll end off by offering a roadmap to ensure the respect of the Charter of Rights to equality of all persons with disabilities in this context.

Let me briefly look at where MAiD currently fits into the Canadian medical legal landscape and I’ll make two points to that effect. First, that MAiD provided according to according to an end of life criterion, functions strictly as an end of life option premised on patient autonomy, and that’s conceptually similar to other things that we’ve done: palliative care, the decision to refuse life-saving treatments, pulling the plug. It’s different from what we did before, pre-MAiD, but not that different. Let’s call it a difference of degree. Obviously, there can still exist heated societal debate as to whether it’s something we want, that’s what Parliament’s there to decide, but it falls within a limited end-of-life framework. The second point, and this is the important one, is that the permissibility of MAiD in an end-of-life context following the Supreme Court’s Carter decision is also premised on patient equality, that where as most Canadians have access to a peaceful and painless death, some Canadians including Gloria Taylor, who is the plaintiff in the Carter decision, did not. And what the Supreme Court effectively tells us is that that’s not fair. Canadians such as Gloria Taylor merely want what others take for granted, which is an end-of-life option that is ultimately painless. So, let me expand of the implications of this last point, that MAiD provided according to a legislative end-of-life criterion is premised on the concept of patient equality. So as I mentioned, by making people eligible for MAiD at the end of life, the State seeks to ensure that all people have access to a painless death, but the most important point is the negative of that statement – which is also true – that by providing MAiD on an end-of-life basis the State treats the suffering of all people who are not at the end of their lives equally. That is a situation worth addressing through means other than the termination of the life. In other words, the solution to suffering, not in an end-of-life context, isn’t the termination of that life, and that’s a universal proposition. It’s important to note, this doesn’t deny the suffering of these people, which in many cases can be extensive, there are people who aren’t at the end of their lives who suffer tremendously, beyond what most can imagine, whether from disease, personal circumstances and history, psychological trouble, whatever it is. There are also groups, and we’re very aware of this, that suffer disproportionately. So historically it was true for women, it may also still be true in many contexts. If we think of modern-day transgender individuals, they suffer tremendous stigma in our society. Indigenous people, particularly in some areas, who suffer stigma, abuse, psychological trauma, resulting from the history of residential schools and other awful policies. Individuals who are addicted to substances. And yes, persons with disabilities. The refusal of the State to agree to the termination of their lives isn’t a denial of their suffering and we have to keep that in mind, but rather an affirmation of the worth of their lives. By treating their suffering equally in a non end-of-life context, the State also recognizes that if we treated the suffering of one group differently from the suffering of all the others we would be making this distinction based on personal Charter-protected characteristics. It would have an impact on their dignity, their self-worth, the worth ascribed to them by others, and the likelihood that this group would be stereotyped. This would be true for any group, all the groups I mentioned, be it women, transgender individuals, indigenous people, individuals who are addicted to substances, person with disabilities, any other group you can think of. Instead we agree that the suffering of these groups must be treated as a crisis situation worthy of State mobilization and intervention but not - and absolutely not - through the termination of their lives. That’s a good thing. That’s what we want. One last point about suffering. Society assumes that persons with disabilities are unhappy and live a life of misery whereas the empirical evidence reveals that this is a perception, and that reality is completely different. This was the evidence that came out from Tom Shakespeare who testified in the Truchon case that persons with disabilities are often happy, believe they have a good quality of life, not to say that some of them don’t suffer and don’t wish tragically that they could die, but that’s the same for any broadly defined group. Persons who become disabled over the course of their lives at first experience a period of trauma and difficulty where they perceive their situation as being devoid of quality of life but that changes after some time and they are able for the most part to adapt and live full lives. The majority of persons come to terms with their disability over time. The hopelessness decreases after three months and remains high throughout the first year but ultimately decreases. So, here’s where rubber meets road. The failure to include an end-of-life criterion in MAiD legislation would be discriminatory. And here’s why – the removal of an end-of-life criterion would treat the suffering of persons with disabilities differently from the suffering of other groups. If someone with a disability who suffers requests MAiD, what happens? Or someone without a disability who suffers requests MAiD, what happens? The State would refuse it on the grounds that their lives are worth fighting for or in the words of Catherine Frazee “we can’t afford to lose these individuals”. If someone with a disability who suffers requests MAiD without the end of life criterion, what happens? The State would approve it. Again, on the grounds that we can afford to lose you. Let’s remember, persons with disabilities suffer and persons without disabilities suffer. Some persons with disabilities want to end their lives and tragically, they do. And some people without disabilities also want to end their lives and tragically, do. Without the end-of-life criterion the State would agree to the termination of the lives of persons with disabilities while urging the other suffering individuals, rightfully so as it should for everyone else, to live. Let put this another way, in the Truchon case one of the plaintiffs testified movingly that she was at the bottom of the basement staircase and had no chance of ever climbing back up any steps. If the end-of-life criterion is ultimately removed the State would effectively be telling a person with a disability who suffers “You, person with a disability, and only you, are at the bottom of the basement staircase. We know there are other groups, we know that they suffer, but they have hope. You are irremediable. We agree that you will never again have a good quality of life, unlike all those other people who suffer. For this reason, only you can have access to the choice that ends all choices. Other individuals who suffer greatly can’t because they’re not at the bottom of the basement staircase.” And that’s an incredibly discriminatory and powerful message for the State to put forward. The impact of treating persons with disabilities in this way would fuel, how could it not, the existing stereotypes that persons with disability are better off dead. That they are a burden on the State and their loved ones. That they have a lousy quality of life. That their lives have less value than the lives of others and that they are at the bottom of the basement staircase of life, without the chance to move back up. This is literally unlike every single other group of persons who disproportionately suffer, whose suffering we treat as indicating the need for more social programs, more help, and whose lives are perceived as essential, lives that we can’t afford to lose in our society. These stereotypes would impact the thoughts and perceptions of those with and without disabilities and would over time lead persons with disability to access MAiD. This explains why, and the Ministers might recall this from the legislative debates following the Carter decision, virtually every single disability organizations supported the end-of-life criterion. Judging by media coverage you might think support was divided but it wasn’t. Every disability organization save one that I’m aware of fought for an end-of-life criterion because it’s what we need so that persons with disabilities are not stereotyped, marginalized, and ultimately offered death as a State ‘benefit’ for their condition. You can imagine the uproar if the State offered death as a benefit to suffering members of other groups based on protected personal characteristics. Continuing to ignore the equality rights of persons with disabilities will ultimately result in further litigation and I use the words ‘continuing to ignore’ because, and here’s what’s particularly galling, despite so far two cases on MAiD in the last few years, Carter and Truchon, the court still hasn’t addressed the argument that I’ve made on the equality of persons with disabilities. Specifically, whether the objective of ensuring the equal protection of every life and the avoidance of negative stereotypes about the lives of persons with disabilities, can justify the existence of an end-of-life criterion. In Carter, the court found that well we were dealing with old legislation and so it just wasn’t the objective of that legislation to protect persons with disabilities. In Truchon, there were extensive parliamentary debates on the point but the court claimed that on the evidence it actually wasn’t a legislative objective to protect persons with disabilities but rather merely a guiding principle, which allowed the court then to ignore this guiding principle. This is obviously frustrating given that parliamentary debates were quite clear that this was a fundamental objective of the legislation. More importantly in my mind, this is why the government’s justification under section 1 of the Charter failed in Truchon. The Court circumvented the need to assess whether the equal protection of every life and the avoidance of negative stereotypes justified the existence of the end-of-life criterion. Despite arguments on this point, it never considered that removing the end-of-life criterion would provide for disability or illness to serve as a justification for the termination of life in a way that no other personal characteristic could. And that it would mark disability as a burden worse than death while compounding existing discrimination and devaluation. I repeat, the Courts haven’t considered this argument in any substantive way. They’ve run around the issue to this point. What does it mean? It means that first, through carefully crafted legislation, it’s still very reasonable and very credible to make this argument as a justification for an end-of-life criterion. In other words, an end-of-life criterion of some kind can – and I would say must – be defended on the grounds that it protects the equality of persons with disabilities. Conversely, if a new legislation fails to include an end-of-life criterion, it will obviously expose itself to litigation from the communities that the government has abandoned. The message it would send is that the government agrees that the lives of some persons who suffer aren’t worth protecting at all costs. That’s a very solid ground for litigation. Let’s be clear, the new law isn’t going to make everyone happy. The government’s in a very, very difficult position and regardless of where it lands there could be litigation. What does this mean? It means two things, and I’ll close on this – first we need legislation that includes some form of an end-of-life criterion. We’ve heard why I think in very powerful terms today. Not only can this criterion be justified, but it has to be justified. We can’t afford not to justify it for the sake of persons with disabilities. Second, given the potential for litigation from all sides, the creation of new legislation is a fine balancing act. The draft legislation as a result should be put before the Supreme Court of Canada in a reference to ensure its constitutionality and limit subsequent litigation. This will allow the Court to balance the competing rights at stake, something as I’ve mentioned, the Courts have consistently refused to do so far. It will establish the constitutionality of the new MAiD legislation once and for all and put an end to what’s effectively been a decade-long process of constitutional challenges. It will be most effective way I think to ensure the constitutionality of this legislation. Thank you.