Mandates of the Special Rapporteur on the rights of persons with disabilities; the Independent Expert on the enjoyment of all human rights by older persons; and the Special Rapporteur on extreme poverty and human rights

REFERENCE: OL CAN 2/2021

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Excellency,

We have the honour to address you in our capacities as Special Rapporteur on the rights of persons with disabilities; Independent Expert on the enjoyment of all human rights by older persons; and Special Rapporteur on extreme poverty and human rights, pursuant to Human Rights Council resolutions 44/10, 42/12 and 44/13.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning the new policy on medical assistance in dying, enshrined in Bill C-7 as adopted by the House of Commons on 10 December 2020, which amends relevant provisions of the Criminal Code by expanding access to medical assistance in dying to persons with disabilities, whose natural death is not reasonably foreseeable.

According to the information received:

On 24 February 2020, the Minister of Justice proposed amendments to Canada's Criminal Code dealing with medical assistance in dying (MAiD). These proposed amendments were introduced in the House of Commons in the form of Bill C-7. Due to the prorogation of the first session of the 43rd Parliament, the Bill was then reintroduced in identical form and with the same number on 5 October 2020 and was adopted at a third reading in the House of Commons on 10 December 2020. Bill C-7 is currently under review in the Senate.

The Criminal Code was previously amended in 2016 (Bill C-14) to allow for medical assistance in dying, in limited circumstances.¹

The effect of the 2016 amendments was to allow physicians and nurse practitioners to provide medical assistance in dying and to allow pharmacists, family members or other people to assist in the process without facing criminal charges under the criminal law.

As a general rule, the Criminal Code (as amended in 2016) provides that only persons who have a 'grievous and irremediable medical condition that causes them enduring and intolerable suffering' are allowed to seek medical assistance in dying. The statutory definition of a grievous and irremediable medical condition includes disability². However, it also requires death to be 'reasonably foreseeable.' In practical terms, this means that only those persons with disabilities who are close to death are allowed to exercise the option of a medically assisted death. Under the 2016 amendments the 'right' was not

¹ Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). (2016). Assented to June 17, 2016, 42nd Parliament, 1st session. Retrieved from the Parliament of Canada website: http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent

² See A/HRC/43/41/Add.2, para. 68

extended to cover the broader disability population whose death was not 'reasonably foreseeable.'

More specifically, under the current Criminal Code (as amended in 2016), in order to be eligible for MAiD, a person must:

- be eligible for government-funded health services in Canada (sec 241.2(1)(a));
- be 18 years of age or older, and capable of making health-related decisions (sec 241.2(1)(b));
- have a "grievous and irremediable medical condition" (sec 241.2(1)(c));
- make a voluntary request for MAiD that is not coerced (sec 241.2(1)(d)); and
- after having been provided with information about ways to alleviate suffering, give informed consent to MAID (sec 241.2(1)(e)).

To satisfy the abovementioned criterion of "grievous and irremediable medical condition", a person must:

- have a serious and incurable illness, disease or disability (section 241.2(2)(a));
- be in an advanced state of irreversible decline in capability (section 241.2(2)(b));
- have enduring physical or psychological suffering "that is intolerable to them and that cannot be relieved under conditions that they consider acceptable" (section 241.2(2)(c));
- and be in a state in which "natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining" (section 241.2(2)(d)).[Italics added].

The proposed amendments pending before Parliament (Bill C-7) would, if adopted, provide for the elimination of the requirement for natural death to be 'reasonably foreseeable' in order to access MAiD. Clause 1 (1) of Bill C-7 provides for the elimination of the 'reasonably foreseeable' natural death criterion, repealing the abovementioned section 241.2(2)(d) of the Criminal Code and, consequently, enabling access to assisted dying outside of end-of-life circumstances. That means that a much broader swathe of persons with disabilities (whose deaths are not reasonably foreseeable) could have access to assisted dying.

The new draft Bill has spurred vigorous debate in the country. Many organizations of persons with disabilities, lawyers and experts have expressed serious

concerns about the expansion of MAiD eligibility and the societal implications of removing the requirement that natural death be 'reasonably foreseeable.' In addition, taking into account the proposed amendments aimed at reducing the number of required witnesses and accepting paid staff as independent witnesses, they have expressed serious concerns regarding the threat such legislation could pose to the lives of persons with disabilities. In particular, there is a real risk that those without adequate support networks of friends and family, in older age, living in poverty or who may be further marginalized by their racialized, indigenous, gender identity or other status, will be more vulnerable to being induced to access MAiD.

In this connection, we would like to express concern about the proposed expansion of the right to access medically assisted dying for persons with disabilities who are not themselves close to death.

We wish to draw Your Excellency Government's attention to the fact that, in her 2019 report following on her country visit to Canada (<u>A/HRC/43/41/Add.2</u>), the former Special Rapporteur on the rights of persons with disabilities, had already expressed concern about the implementation of the 2016 legislation on medical assistance in dying from a disability perspective. She was concerned that there was, at the time of writing, no protocol in place to demonstrate that persons with disabilities deemed eligible for assistive dying had been provided with viable alternatives. She had received some worrisome information about persons with disabilities in institutions being persuaded to seek medical assistance in dying and of practitioners not formally reporting cases involving persons with disabilities. Some persons with disabilities said during her visit, that they were being offered the "choice" between a nursing home and medical assistance in dying³.

We wish to recall that the former Special Rapporteur had expressed extreme concern about the implications of the 2016 amendments from a disability perspective. In particular, in her report on her visit to Canada, presented to the Human Rights Council at its 43rd session, she had called for the federal government to investigate complaints related to medical assistance in dying and put into place adequate safeguards to ensure that persons with disabilities do not request assisted dying simply because of the absence of community-based alternatives and palliative care.⁴ In this connection, she maintained that "assisted dying must not be seen as a cost-effective alternative to providing personal assistance and disability services for persons with disabilities, in particular those with high support needs"⁵.

The former Special Rapporteur also expounded more fully on her general concerns about the impact of ableism and ableist assumptions in medical and scientific practice in 2019 (<u>A/HRC/43/41</u>). In her thematic report on the impact of ableism in medical and scientific practice, she addressed how ableist assumptions continue to influence important debates that impact the rights of persons with disabilities⁶. She asserted that outdated notions about 'normality' still dominate medical, legal and philosophical deliberations, including sensitive discussions related to scientific and medical developments and practice, including, but not limited to,

³ See A/HRC/43/41/Add.2, para. 69 and 99.

⁴ See also: end of Mission Statement by the United Nations Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, on her visit to Canada (2019) on <u>https://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=24481&LangID=E</u>

⁵ See A/HRC/43/41/Add.2, para. 69 See A/HRC/43/41

assisted dying⁷.

The general issues connected with the 2016 amendments did already receive some attention from the Committee on the Rights of Persons with Disabilities in its Concluding Observations on Canada (CRPD/C/CAN/CO/1). The Committee specifically recommended that Canada ensure persons who seek an assisted death (under the 2016 amendments) have access to alternative courses of action and to a dignified life made possible with appropriate palliative care, disability support, home care and other social measures that support human flourishing.⁸"

By expanding access to medical assistance in dying based on disability, the implementation of the proposed legislative amendments (Bill C-7) to the policy would, in our view, have a potentially discriminatory impact on persons with disabilities and older persons who are not at the end of their life or nearing death from natural causes and risk reinforcing (even unintentionally) ableist and ageist assumptions about the value or quality of life of persons with disabilities and older persons with or without disabilities.

We would like to draw the attention of Your Government to Article 4 (general obligations), specifically Article 4 (1) (d), of the Convention on the Rights of Persons with Disabilities, ratified by Canada on 11 March 2010, which provides for the obligation of States parties to refrain from engaging in any act or practice that is inconsistent with the Convention.

In particular, we are concerned that, if adopted, the new policy would not be consistent with the following international human rights standards.

Firstly, we are concerned that provisions contained in Bill C-7 would appear to violate the right of persons with disabilities to life, protected by Article 3 of the Universal Declaration of Human Rights, Article 6 (1) of the International Covenant on Civil and Political Rights (ICCPR), ratified by Canada on 19 May 1976, and by Article 10 of the Convention on the Rights of Persons with Disabilities (CRPD). Article 10 of the CRPD recognizes that "States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an *equal basis with others* [Italics added]." To be clear, the issue is not that Canada does not have latitude in introducing a legislative right to medical assistance in dying. The issue really concerns the underlying predicates of the legislation (pivoting as it does on disability) and how it expands the right to cover persons with disabilities who are not themselves close to death.

Secondly, we wish to express our grave concern that provisions contained in the Bill may be contrary to Canada's international obligations to respect, protect and fulfil the core right of equality and non-discrimination of persons with disabilities. The ICCPR, the ICESCR, as well as the thematic international human rights treaties to which Canada is a Party⁹ aim to establish equality and eliminate discrimination,

³ See <u>CRPD/C/CAN/CO/1</u>, para. 24.

⁷ A/HRC/43/41, para. 16

These include: the International Convention on the Elimination of All Forms of Racial Discrimination, ratified on 14 October 1970; the Convention on the Elimination of All Forms of Discrimination against Women, ratified on 10 December 1981; the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, ratified on 24 June 1987; and the Convention on the Rights of the Child, ratified on 13 December 1991.

and contain provisions on equality and non-discrimination. In particular, the core rights to equality and non-discrimination are at the heart of the CRPD (Article 5). Further, all rights in the CRPD are to be secured 'on an equal basis with others' which explicitly applies to Article 10 on its face.

In its General Comment no. 6 (CRPD/C/GC/6) on equality and nondiscrimination (2018), the Committee on the Rights of Persons with Disabilities expounded its understanding of equality (Article 5 of the CRPD) as applied to persons with disabilities. Article 5 means, in its view, that there should be no laws that allow for specific denial, restriction or limitation of the rights of persons with disabilities, and that disability should be mainstreamed in all legislation and policies¹⁰. Importantly, the Committee specifically stated that, in its view, equality is grounded, *inter alia*, on a recognition of the inherent equal worth of each person with a disability – equal personhood. This element of recognition of the equal human agency, personhood and inherent worth of all persons with disabilities is said by the Committee to underpin its conception of 'inclusive equality' in the CRPD.

Thirdly, related to the above and perhaps most importantly, Article 8 of the CRPD (awareness raising) calls on States Parties to "nurture receptiveness to the rights of persons with disabilities", to "promote positive perceptions and greater social awareness towards persons with disabilities" and to "combat stereotypes, prejudices and harmful practices" relating to persons with disabilities. Article 8 reinforces the position of the Committee with respect to equal recognition of personhood and the inherent value of each persons with a disability. At a minimum, this would appear to require extra vigilance to ensure that public policy and legislative initiatives do not even unwittingly - reinforce negative stereotypes or negative perceptions about disability and persons with disabilities. To the contrary, Article 8 envisages a positive policy eco-system that takes great care to ensure that otherwise sound and wellintentioned legislation does not indirectly pivot on, or subtly reinforce, ableist assumptions in society. It is hard to see how a legislative proposal that extends a right to medically assisted dying to persons with disabilities who are not themselves close to death could send a signal that is compatible with Article 8 (obligations to combat ableism) combined with Article 5 (obligation to secure equal respect for rights) of the CRPD.

From a disability rights perspective, there is a grave concern that, if assisted dying is made available for all persons with a health condition or impairment, regardless of whether they are close to death, a social assumption might follow (or be subtly reinforced) that it is better to be dead than to live with a disability. Therefore, a major concern must be that persons with a disability (and perhaps especially those with newly acquired impairment) may opt too readily for assisted dying, based on the internalisation of prejudices, fears and low expectations of living with a disability, even before having the chance of coming to terms with and adapting to their new disability status.

It is not beyond possibility that, if offered an expanded right as *per* Bill C-7, persons with disabilities may decide to end their lives because of broader social factors, including loneliness, social isolation and lack of access to quality support services. Indeed, persons with disabilities, particularly older persons with disabilities, may be vulnerable to explicit or implicit pressures arising from their context,

¹⁰ See CRPD/C/GC/6, para. 14.

including expectations from family members, financial pressures, cultural messages ¹¹.

Generally, when life-ending interventions are normalized outside the end stage of terminal illness, persons with disabilities (and older persons with disabilities) may disproportionately feel the need to end their lives¹².

Fourthly, when considering legalizing any form of assisted dying, States should conduct extensive discussions with the active participation of organizations representing persons with disabilities. Article 4.3 of the CRPD seeks to reverse decades if not centuries of practice whereby the voices of persons with disabilities were not heard in imprtant policy and legislative debates affecting them. One impact of not having these voices central to the policy-making process is that ableist and ageist assumptions could easily slip through and become encoded in legislation and thus reinforce circles of exclusion and devaluing.

Those most directly affected by ableist assumptions – and the legacy of ableist assumptions – must be heard and heeded. They are best placed to spot the unintended consequences of otherwise well-intentioned legislation, and their heightened sensitivity deserves the utmost respect.

In sum, we are deeply concerned that the eligibility criteria set out in Bill C-7 to access medical assistance in dying may be of a discriminatory nature, or have a discriminatory impact, as by singling out the suffering associated with disability as being of a different quality and kind than any other suffering, they potentially subject persons with disabilities to discrimination on account of such disability.¹³

In its present formulation, this legislation risks furthering the devaluation of life with disability and reiterating the ableist stereotype that significant disability can be worse than death. What if the term 'disability' were to be removed from the draft Bill? That would leave standing 'serious and incurable illness, disease.' However, what is a 'serious and incurable illness, [or] disease' but a disability? Put another way, many if not most such illnesses or diseases either stem from or cause disability. Thus, we remain to be convinced that a removal of the word 'disability' would cure the Bill of its potentially indirect discriminatory effects against persons with disabilities or purge it entirely of ableist predicates.

The accumulated disadvantages that flow from disability may give rise to indirect pressure for persons with disabilities to make their choice one way rather than another under the proposed Bill. This would apply in particular for those lacking adequate family and network support, and effective restrictions that arise from their circumstances on their access to health services, such as suicide prevention, on an equal basis with others. In this regard, safeguards provided in Bill C-7 would appear to not be adequate or far-reaching enough to guard against the dangers that vulnerable

¹¹ A/HRC/43/41

¹² A/HRC/43/41, para 38

³ "Discrimination" under the CRPD includes "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms[.]"A/RES/61-106, Article 2, "Definitions," available at https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-2definitions.html (last visited June 15, 2017). As I will explain, the Act treats people with serious and incurable medical conditions unequally under Luxembourg's criminal and civil laws simply because they are impaired.

persons with disabilities, including older persons with disabilities, would face should it become law. Nor are such safeguards able to rectify failings of support services to address avoidable suffering. If adopted, we are concerned that this legislation would result in a two-tiered system in which some would get suicide prevention and others suicide assistance, based on their disability status and specific vulnerabilities. We believe that in the current climate where there are some questions about the relative lack of access to palliative care and social support means that free choice may not exist, the threat to the lives of persons with disabilities posed by such legislation is real and significant.

In view of the above mentioned concerns, we respectfully urge your Government to reflect on its international legal obligations when determining the underlying predicates and parameters of the proposed Bill. We wish to recall that concern was already raised by the former Special Rapporteur on the rights of persons with disabilities, as well as the Committee on the Rights of Persons with Disabilities on the previous set of amendments (2016). These concerns appear heightened with respect to the current Bill and especially because it appears irremediably entangled in ableist assumptions about persons with disabilities.

As it is our responsibility, under the mandates provided to us by the Human Rights Council, to seek to clarify all cases brought to our attention, we would be grateful for your observations on the following matters:

- 1. Please explain how the current Bill, configured as it is, does not subtly or indirectly reinforce ableist assumptions contrary to Article 8 combined with Articles 4 and 5 of the UN convention?
- 2. Please indicate how or whether you have considered alternative approaches/wording to avoid imparting or reinforcing ableist and ageist assumptions contrary to the above provisions?
- 3. Please indicate measures taken in order to consult closely with representative organization of people with disabilities and older persons, when developing, adopting and implementing the new national policy on medical assistance in dying.

This communication, as a comment on pending or recently adopted legislation, regulations or policies, and any response received from your Excellency's Government will be made public via the communications reporting <u>website</u> after 48 hours. They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

Please accept, Excellency, the assurances of our highest consideration.

Gerard Quinn Special Rapporteur on the rights of persons with disabilities

Claudia Mahler Independent Expert on the enjoyment of all human rights by older persons

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