

Submission to the Committee on Justice on the Dying with Dignity Bill 2020

Irish Human Rights and Equality
Commission

January 2021



**Coimisiún na hÉireann um Chearta
an Duine agus Comhionannas**
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Introduction

The Irish Human Rights and Equality Commission ('the Commission') is both the national human rights institution and the national equality body for Ireland, established under the Irish Human Rights and Equality Commission Act 2014 (the '2014 Act'). In accordance with its founding legislation, the Commission is mandated to keep under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights and equality and to examine any legislative proposal and report its views on any implications for human rights or, equality.¹

The Commission welcomes the opportunity to provide the Committee on Justice with submissions on the Dying with Dignity Bill 2020 (the 'Bill') which it hopes will assist the Committee in its scrutiny of the Bill. The Commission is due to be designated as the Independent Monitoring Mechanism under the United Nations Convention on the Rights of Persons with Disabilities (the 'UNCRPD')² and has engaged with the Commission's Disability Advisory Committee³ on this matter.

The prohibition on physician assisted dying⁴: Legal developments in Ireland and other jurisdictions

The Commission acknowledges the complexity of the sensitive issues being considered by the Committee in respect of this Bill.⁵ In particular the Commission acknowledges the difficult issues faced by people living with a life-limiting illness who can face significant suffering, especially where they fear a long and protracted death.⁶

¹ Section 10(2)(c) of the [Irish Human Rights and Equality Commission Act, 2014](#).

² As provided for in the Disability (Miscellaneous Provisions) Bill 2016 which lapsed in the previous session of Dáil Éireann.

³ The Disability Advisory Committee has been established by section 10(2) of the 2014 Act and is currently chaired by Commissioner Dr Rosaleen McDonagh.

⁴ For the purpose of this submission physician assisted dying means medically or, physician assisted suicide. There is no consensus in the different jurisdictions which have legislated for physician assisted dying on the terminology to be used to describe the process of physician assisted dying. The process has been referred to as assisted dying, physician assisted dying, self-administered assisted dying, medical assistance in dying, assisted suicide, and voluntary euthanasia. <https://www.bmj.com/assisted-dying>. See also glossary of terms in Joint Oireachtas Committee on Justice and Equality, [Report on the Right to Die with Dignity](#), June 2018, at pages 6-7.

⁵ Joint Oireachtas Committee on Justice and Equality, [Report on the Right to Die with Dignity](#), June 2018, at pages 36-55.

⁶ Hagart, AM Bush, SH, Talrico, R et al. Severe pain at the end of life a population level observational study BMC Palliat Care 19, 60 (2020) <https://bmc-palliatcare.biomedcentral.com/articles/10.1186/s12904-020-00569-2>. Assisted Dying for the

Legislating for physician assisted dying engages several rights, including; the right to life, respect for human dignity, personal autonomy and the protection of certain at risk groups, in particular disabled people, people with life-limiting illnesses and older people. The Commission and its predecessor body, the Irish Human Rights Commission (the 'IHRC') have engaged with the human rights and equality issues arising in connection with this Bill. In particular, the IHRC acted as amicus curiae ('friend of the Court') before the High Court and Supreme Court in *Fleming v Ireland and others* ('Fleming').⁷ The IHRC and the Commission have also provided commentary on related legislative proposals and policy reform.⁸

The ban on assisting another to die by suicide⁹ was challenged in *Fleming*.¹⁰ In *Fleming*, the IHRC, in its roles as amicus curiae, did not advocate "a right to die" rather it argued that the blanket ban on assisted dying engaged the appellant's right to personal autonomy and dignity and right to equality under the Constitution.¹¹ The Supreme Court rejected this argument, concluding that there is no constitutional right to die by, or to arrange for, the determination of one's life at a time of one's choosing. Moreover, the Supreme Court found that as there is no right to die by suicide, issues such as discrimination do not arise; nor do values such as dignity, equality, or any other principle under the Constitution.¹²

However, the Supreme Court also stated that although there is an obligation on the State to vindicate the right to life and to discourage suicide generally,

Terminally Ill Bill – First Report HL Paper 86-I, 2005, in particular para 77
<https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf>

Also, see for example, *Fleming v. Ireland*, at paras 9-19; *Pretty v. the United Kingdom*, at paras 1-14; and *Carter v. Canada*, at paras 12-18.

⁷ IHRC, [Submission to the High Court in the case of Fleming v. Ireland and others](#), 2012; and IHRC, [Submission to the Supreme Court in the case Fleming v. Ireland and others](#), 2013.

⁸ IHRC, [Observations on the Assisted Decision-Making \(Capacity\) Bill 2013](#), March 2014. See also, IHRC, [Submission to the public consultation on Deprivation of Liberty: Safeguard Proposals](#), March 2018.

⁹ Section 2, [Criminal Law \(Suicide\) Act, 1993](#).

¹⁰ [Fleming v Ireland & ors](#) [2013] IESC 19.

¹¹ *Supra* fn 7.

¹² *Supra* fn 10 at paras 137-139.

“[i]t does not, however, necessarily follow that the State has an obligation to use all of the means at its disposal to seek to prevent a person in a position such as that of the appellant from bringing her own life to an end”.

In this regard, the Supreme Court recognised the difficulties in Marie Fleming’s case which it considered raised difficult questions of policy involving complex issues of “principle and practicality”.

Accordingly, the Supreme Court clarified that nothing in the judgment

“should be taken as necessarily implying that it would not be open to the State, in the event that the Oireachtas were satisfied that measures with appropriate safeguards could be introduced, to legislate to deal with a case such as that of the appellant”.¹³

There have been constitutional and human rights challenges in other jurisdictions a number like Fleming, have been unsuccessful.¹⁴ However, in 2015, the Canadian Supreme Court in *Carter v. Canada*¹⁵ reached a different conclusion than the Irish Court in Fleming.¹⁶ The Canadian Supreme Court held that the blanket ban on assisted dying

¹³ In *Fleming v Ireland & ors*, the Supreme Court continued by stating that “if such legislation was introduced it would be for the courts to determine whether the balancing by the Oireachtas of any legitimate concerns was within the boundaries of what was constitutionally permissible. Any such consideration would, necessarily, have to pay appropriate regard to the assessment made by the Oireachtas both of any competing interests and the practicability of any measures thus introduced” (at para 108).

¹⁴ Physician assisted dying was legal in Belgium, Canada, Colombia, Luxembourg, Netherlands, Switzerland, the State of Victoria in Australia and 10 jurisdictions within the United States of America as of the end of 2019. New Zealand will give effect to legislation providing for assisted dying by the end of 2021 following the result of a referendum in November 2020.

¹⁵ In *Carter v. Canada* [2015] 1 SCR 331, at para 10 of its judgment, the Canadian Supreme Court noted the complexities of this issues at stake stating; “[t]he debate in the public arena reflects the ongoing debate in the legislative sphere. Some medical practitioners see legal change as a natural extension of the principle of patient autonomy, while others fear derogation from the principles of medical ethics. Some people with disabilities oppose the legalization of assisted dying, arguing that it implicitly devalues their lives and renders them vulnerable to unwanted assistance in dying, as medical professionals assume that a disabled patient “leans towards death at a sharper angle than the acutely ill — but otherwise non-disabled — patient” (2012 BCSC 886, 287 C.C.C. (3d) 1, at para 811). Other people with disabilities take the opposite view, arguing that a regime which permits control over the manner of one’s death respects, rather than threatens, their autonomy and dignity, and that the legalization of physician-assisted suicide will protect them by establishing stronger safeguards and oversight for end-of-life medical care.”

¹⁶ It is noted that in 2019 the Italian Constitutional Court found that assisted dying may not be unlawful in all cases. Turoldo, F. (2021). Aiding and Abetting Suicide: The Current Debate in Italy. *Cambridge Quarterly of Healthcare Ethics*, 30(1), 123-135. <https://www.cambridge.org/core/journals/cambridge-quarterly-of-healthcare-ethics/article/aiding-and-abetting-suicide-the-current-debate-in-italy/3DE74418ABE644EB43B2F1FC2E0458CB>. Most recently in 2020, the German Federal Constitutional Court held that the German Criminal Code criminalizing commercial assisted suicide was unconstitutional, stating that the general right to personality encompasses the right to self determine one’s life as well as the right to seek assistance to do so. See <https://www.loc.gov/law/foreign-news/article/germany-constitutional-court-strikes-down-provision-criminalizing-commercial-assisted-suicide/>.

was unconstitutional as it infringed fundamental rights including personal autonomy and dignity.

The Supreme Court stated;

“An individual’s response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The law allows people in this situation to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life-sustaining medical equipment, but denies them the right to request a physician’s assistance in dying. This interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty. And, by leaving people like Ms. Taylor to endure intolerable suffering, it impinges on their security of the person.”¹⁷

The Supreme Court in Canada also interpreted the right to life in a different manner, finding that the “right to life” does not require an “absolute prohibition” on assisted suicide. Rather the Supreme Court considered that

“[t]he right to life is engaged when the law of the state imposes death or an increased risk of death on a person, either directly or indirectly”.

In Carter the Supreme Court found that the blanket ban on assisted dying had the effect of forcing some individuals to take their lives prematurely for fear they would be incapable of doing so when they reached the point where suffering was intolerable.¹⁸

The European Court of Human Rights of Human Rights (the ‘ECtHR’) has considered physician assisted suicide in its case-law, however the focus has been primarily on the right to private life. The ECtHR has found that the right to private life, in general terms, encompasses; a person’s physical and psychological integrity; personal development and autonomy;¹⁹ and the right to establish and develop relationships with other human

¹⁷ Supra fn 15, at para 66.

¹⁸ Supra fn 15, at para 57.

¹⁹ Niemietz v. Germany, App No 13710/88, Series A no. 251-B; Botta v. Italy, App No 21439/93, ECHR 1998-I. Bensaid v. the United Kingdom, App No 44599/98, ECHR 2001-I; Pretty v. the United Kingdom, App No 2346/02, ECHR 2002-III.

beings and the outside world.²⁰ In *Pretty v. the United Kingdom*²¹ the ECtHR held that the applicant's choice to avoid what she considered an undignified and distressing end to her life fell within the right to private life under the European Convention on Human Rights ('ECHR').²² However, in *Pretty*, the ECtHR held that there had been no violation of the applicant's right to private life holding that the criminalisation of assisted suicide could be justified as "necessary in a democratic society" for the protection of the rights of others.²³

In *Haas v. Switzerland*, the ECtHR held that an individual's right to decide how and when his or her life will end falls within the right to private life provided he or she is capable of freely reaching a decision on this question and can act in consequence.²⁴ In *Haas*, the ECtHR, found that the applicant's right to private life had not been violated. Of note, the ECtHR held that the Swiss law regulating the access to certain medical prescriptions was legitimate in protecting the interests of others "from hasty decisions and preventing abuse, and, in particular, ensuring that a patient lacking discernment does not obtain a lethal prescription."²⁵

In 2019, the UN Human Rights Committee published a revised General Comment on Article 6 (right to life). In relation to end of life matters, the Committee state that,

"[w]hile acknowledging the central importance to human dignity of personal autonomy, States should take adequate measures, without violating their other Covenant obligations, to prevent suicides, especially among individuals in particularly vulnerable situations, including individuals deprived of their liberty."²⁶

²⁰ *Burghartz v. Switzerland*, App No. 16213/90 22 February 1994, opinion of the Commission, p. 37, § 47, and *Friedl v. Austria*, 31 January 1995, Series A no. 305-B, opinion of the Commission, § 45.

²¹ [Pretty v. the United Kingdom](#), Application no 2346/02, ECtHR, 29 April 2002.

²² *ibid*, at para 67.

²³ *Supra* fn 21, at paras 74-78.

²⁴ [Haas v. Switzerland](#), Application No 31322/07, ECtHR 20 January 2011, at para 57. In *Haas*, the applicant complained about the conditions required to obtain sodium pentobarbital, namely a medical prescription based on a thorough psychiatric assessment. Mr Haas complained that as he could not meet these conditions his right to choose the time and manner of his death was not respected.

²⁵ *Ibid*, para 56.

²⁶ Human Rights Committee, [General Comment No. 36 \(2018\) on Article 6 of the International Covenant on Civil and Political Rights, on the right to life](#), CCPR/C/GC/36, 3 September 2019, para 9.

However, the Committee also recognised situations where a state may introduce physician assisted dying to,

“facilitate the termination of life of afflicted adults, such as the terminally ill, who experience severe physical or mental pain and suffering and wish to die with dignity.”²⁷

Background to the Bill

While dying, or attempts to die by suicide are no longer crimes under Irish law, it is a criminal offence to assist another person to die by suicide.²⁸ As above, in Fleming, the Supreme Court, although upholding the constitutionality of this prohibition, also noted the complex policy issues arising and left open the possibility for the State to legislate in this area.

In 2017, the Joint Oireachtas Committee on Justice and Equality examined the Right to Die with Dignity, meeting with a focused group of stakeholders and academic experts both in favour for, and against, introducing legislation to regulate assisted dying.²⁹ In June 2018, the Committee reported that it did not achieve a clear consensus as to whether legislative change on assisted dying was justified and that it was therefore not in a position to recommend legislative change at that time.³⁰ However, the Committee did recommend that the matter be referred to the Citizens’ Assembly for deliberation and then to a Special Oireachtas Committee for further consideration.³¹

The present Dying with Dignity Bill 2020 was initiated as a Private Members Bill in Dáil Éireann on 15 September 2020. During the Second Stage Debate on 7 October 2020, the Minister for Justice tabled a motion to establish a Special Oireachtas Joint Committee for twelve months to consider submissions and hold hearings on the matter. This motion was defeated and the Bill progressed to Committee stage. In

²⁷Ibid. Also see [General comment No. 14 \(2000\) on the right to the highest attainable standard of health](#), E/C.12/2000/4, 11 August 2000, para 25.

²⁸ Section 2, [Criminal Law \(Suicide\) Act, 1993](#).

²⁹ Joint Oireachtas Committee on Justice and Equality, [Report on the Right to Die with Dignity](#), June 2018.

³⁰ Ibid, at page 56.

³¹ Ibid.

November 2020, the Committee on Justice invited written submissions to inform its scrutiny of the Bill.

Legislating for physician assisted dying: Overview of other jurisdictions

Relatively few jurisdictions globally have legislated to provide for assisted dying.³² However, momentum for legal reform in this area is growing and in recent years a number of states have engaged in debate and proposed legal reform that would permit physician assisted dying.³³

Two dominant legislative models for providing assistance in dying have been identified.³⁴ The 'Oregon' model, introduced in the U.S. state of Oregon in 1997 and since replicated in a few other U.S. jurisdictions, permits self-administered assisted dying,³⁵ but not euthanasia.³⁶ To be eligible, a person must be terminally ill with a maximum six months left to live and must have decision-making capacity. The 'Benelux Model', used in Belgium, Luxembourg and the Netherlands, permits both euthanasia and self-administered assisted dying. There is no requirement that the patient must be at the end of life to be eligible, but they must be suffering unbearably (physically or, psychologically) with no alternative way of easing the suffering. In certain cases, patients who have lost their decision-making capacity may access assisted dying, as a request can be made while the person has capacity to do so through an advance

³² Physician assisted dying was legal in Belgium, Canada, Colombia, Luxembourg, Netherlands, Switzerland, the state of Victoria in Australia and 10 jurisdictions within the United States of America as of the end of 2019. New Zealand will give effect to legislation providing for assisted dying by the end of 2021 following the result of a referendum in November 2020.

³³ Joint Oireachtas Committee on Justice and Equality, [Report on the Right to Die with Dignity](#), June 2018, at page 23.

³⁴ See Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018.

³⁵ Where the patient themselves conducts the decisive action to die by suicide.

³⁶ Where a person other than the patient themselves conducts the decisive action resulting in the patient's death.

healthcare directive. Countries in which legislation varies from these two models are Colombia,³⁷ Canada,³⁸ Switzerland,³⁹ and New Zealand.⁴⁰

Comparative research has found that, across the jurisdictions that permit it, physician assisted dying appears to be more common among people from higher socioeconomic backgrounds, higher levels of education, or resident in affluent areas. Cancer is the dominant diagnosis involved, making up almost three quarters of all physician assisted dying cases. The rate of physician assisted dying is generally evenly distributed between women and men.⁴¹ However, variations in outcomes across jurisdictions have also been identified. In Belgium and the Netherlands, where euthanasia is permitted and there is no requirement for terminal illness, rates of physician assisted dying are ten times higher than in the U.S. states of Oregon and Washington, where only self-administered assisted dying is permitted, and the patient must have a terminal illness.⁴² Research indicates that suffering without hope of improvement is the most common motivation for physician assisted dying in Belgium and the Netherlands, whereas in Oregon and Washington, the dominant motivations are fear of losing independence and

³⁷ In Colombia, physician assisted dying was decriminalised in 1997 when the Colombian Constitutional Court ruled that assisted dying is lawful provided the patient gives free and informed consent, a doctor carries out the act, and the patient has a terminal illness that causes suffering. A regulatory framework put in place in 2015 specifies that a patient must have had access to palliative care prior to accessing assisted dying. See Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018, at pages 46-47. See also [Decision C-239/97](#).

³⁸ In Canada, legislation enacted in 2016 provides for medical assistance in dying for patients with a grievous and irremediable medical condition whose natural death is reasonably foreseeable. In 2020, the Canadian Government introduced a Bill proposing to provide access to assisted dying for persons whose natural death is not reasonably foreseeable, provided that modified safeguarding requirements are met. The Bill also proposes to exclude eligibility for individuals suffering solely from mental illness, and allow the waiver of final consent for persons who may lose capacity to consent before being provided assistance in dying. See S. 241.2(1) of the [Criminal Code \(Canada\)](#); Department of Justice Canada, [Government of Canada reintroduces proposed changes to medical assistance in dying legislation](#), 5 October 2020.

³⁹ In Switzerland, there is no purpose-made legislation in place but rather assisted dying is provided based on how Swiss criminal law is interpreted. Providing assistance in suicide is only a criminal offence if the perpetrator commits the act due to a selfish motivation. Only self-administered assisted dying is permitted, there is no requirement for terminal illness, and patients must have decision making capacity. See Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018, at pages 43-45.

⁴⁰ Once commenced, New Zealand's End of Life Choice Act 2019 will grant access to assisted dying for persons who are suffering from a terminal illness that is likely to end their life within six months, showing a significant decline in physical capability, and have decision making capacity. Both euthanasia and self-administered assisted dying will be permitted. The law specifies that a person cannot be eligible for assisted dying on the basis of advanced age, mental illness, or disability alone. See [End of Life Choice Act 2019 \(New Zealand\)](#).

⁴¹ Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018; Trudo Lemmens, 'Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice', (April 3, 2018), (2018) 85 Supreme Court Law Review (2nd Series) 459-544, Available at SSRN: <https://ssrn.com/abstract=3155994>; Sigrid Dierickx et. al. 'Commonalities and differences in legal euthanasia and physician assisted suicide in three countries: a population-level comparison', International Journal of Public Health (2020) 65:65-73.

⁴² Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018.

quality of life at the end of life.⁴³ In Oregon and Washington, physician assisted dying is not available to patients with psychological conditions or dementia, as these conditions in themselves are not terminal. However, in Belgium and the Netherlands these groups represent a growing proportion of cases.⁴⁴

Robust and adequate safeguards

Positive obligation to protect the right to life

States that legislate for physician assisted dying are under a legal positive obligation to ensure that adequate safeguards are in place to protect the right to life, especially where particular groups are placed at a heightened risk.⁴⁵ This duty includes an obligation to put in place preventive operational measures to protect an individual whose life is at risk from the criminal acts of another individual and to provide a regulatory framework of laws and procedures, in the context of healthcare to protect life.⁴⁶ This obligation applies in the context of any activity, whether public or not, in which the right to life may be at stake.⁴⁷

The UN Human Rights Committee has warned that states that legislate for physician assisted dying “...must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and unambiguous decision of their patients, with a view to protecting patients from pressure and abuse.”⁴⁸

⁴³ Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018.

⁴⁴ Trudo Lemmens, ‘Charter Scrutiny of Canada’s Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice’, (April 3, 2018). (2018) 85 Supreme Court Law Review (2nd Series) 459-544, Available at SSRN: <https://ssrn.com/abstract=3155994>. In the Netherlands specifically, for example, in 2016 some 17% of all assisted deaths did not concern terminal illness but rather other conditions including mental illness, dementia and multiple geriatric symptoms. See Robert Preston, ‘[Death on demand? An analysis of physician administered euthanasia in The Netherlands](#)’, British Medical Bulletin, 2018, 125:145–155.

⁴⁵ *Morris v. Farrell* [2004] IEHC 127, Ó Caoimh J, 12 March 2004, the High Court found that Article 40.3.2 of the Constitution provided no less protection to the right to life than Article 2 ECHR, and accepted that the Strasbourg jurisprudence on the procedural aspect of Article 2 in cases where death was caused by an agent of the State was representative of Irish law. It is of particular note, that the High Court in *Fleming v. Ireland* [2013] IEHC 2 considered in detail the risks for disabled people, where states legislate for assisted dying.

⁴⁶ [Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania](#) [GC], no. 47848/08, ECHR 2014, para 130. See *Calvelli and Ciglio v. Italy*, App No 32967/96, ECHR 2002-I;

⁴⁷ [Centre for Legal Resources on behalf of Valentin Câmpeanu v. Romania](#) [GC], no. 47848/08, ECHR 2014, para 130.

⁴⁸ Human Rights Committee, [General Comment No. 36 \(2018\) on Article 6 of the International Covenant on Civil and Political Rights, on the right to life](#), CCPR/C/GC/36, 30 October 2018, para 9.

The UN Special Rapporteur on the Rights of Persons with Disabilities has also cautioned that legislation of this kind must be accompanied by strong measures to protect the right to life of persons with disabilities.⁴⁹ The Special Rapporteur notes such measures include: the exclusion of disability as grounds for eligibility; safeguards ensuring free and informed consent for disabled people; access to alternatives including appropriate palliative care, rights-based supports and other social measures; provision of accurate information about the prognosis and of peer-support counselling; and accountability regulations requiring the collection and reporting of detailed information about each request and intervention for assistance in dying.⁵⁰

Free and informed consent

The Constitution and the ECHR also place an obligation on the State to secure the right to effective respect for physical and psychological integrity, in particular in the context of health related matters.⁵¹ States must put in place measures to provide effective and accessible protection, including that the relevant legal framework protects a person's free and informed consent to medical treatment.⁵²

In respect of end of life care, the UN Special Rapporteur on the Right to Health has stated that people must be in a position to make autonomous, informed decisions on the quality of care during the process of dying. These include; choices about access to adequate pain relief and other necessary interventions, location of death, and the ability to refuse treatment designed to prolong life when it is not desired by the patient.⁵³ The United Nations High Commissioner for Human Rights has noted with concern that older persons are often denied adequate and sufficient information, time and opportunity to

⁴⁹ See Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 70.

⁵⁰ Ibid.

⁵¹ Article 40.3 of the Constitution protects the right to bodily integrity. See for example (Re a Ward of Court (withholding medical treatment) (No 2), 1996 Also see the ECtHR judgments, *Sentges v. the Netherlands* (dec.) no. 27677/02, 8 July 2003; *Nitecki v. Poland* (dec.), no. 65653/01, 21 March 2002.

⁵² ECtHR, *V.C. v. Slovakia*, no. 18968/07, 8 November 2011.

⁵³ The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, [Thematic study on the realization of the right to health of older persons](#), A/HRC/18/37, July 2011, para 59. Also at para 25, the Special Rapporteur has observed that health-related information provided to older persons should be tailored to suit the needs of an older person and communicated to them in an appropriate and comprehensible manner which would allow them to make fully informed decisions about their health condition and treatment.

give prior, free and informed consent on their medical care and treatment, including end-of-life decisions.⁵⁴

The right to health and palliative care

Neither the Irish Constitution nor, the ECHR expressly recognise the right to health.⁵⁵

The Supreme Court has held that there is no express constitutional requirement that the State provide specific medical services.⁵⁶ Furthermore, there is no statutory right to palliative care.⁵⁷ However, the introduction of legislation to regulate the provision of assistance should not diminish the obligation of the State to provide appropriate and adequate health and palliative care to alleviate the suffering of those with terminal or long-term illnesses who do not wish to end their life.⁵⁸

The right to health without discrimination is recognised under various international treaties.⁵⁹ In relation to the realisation of the right to health of older persons, the UN Committee on Economic, Social and Cultural Rights has stated that measures should be aimed at maintaining functionality and autonomy of older people and “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”⁶⁰

Palliative care is recognised as a component to the right to health and dignity in relation to end of life matters.⁶¹ In this regard, the UN Independent Expert on the enjoyment of all human rights by older persons has recommended that;

⁵⁴ United Nations Economic and Social Council, [Report of the United Nations High Commissioner for Human Rights](#), E/2012/51, April 2012, para 57. See also the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, [Thematic study on the realization of the right to health of older persons](#), A/HRC/18/37, July 2011, para 71(i)-(j). The Special Rapporteur recommends States establish and implement safeguards to ensure that free and informed consent is required for any medical treatment and to provide a mechanism to protect the rights of older people when they are not in a position to provide informed consent to treatment.

⁵⁵ North West Health Board and HW [2001] 3 IR 622.

⁵⁶ TD v. Minister for Education [2001] 4 IR 259.

⁵⁷ The HSE is responsible for administering the palliative care programme – see <https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/>

⁵⁸ Calvelli and Ciglio v. Italy [GC], § 49; Vo v. France [GC], § 89; Lopes de Sousa Fernandes v. Portugal [GC], § 166.

⁵⁹ See Article 25 of the Universal Declaration of Human Rights and Article 11 of the European Social Charter (revised).

⁶⁰ Committee on Economic, Social and Cultural Rights, [General comment No. 14 \(2000\) on the right to the highest attainable standard of health](#), E/C.12/2000/4, 11 August 2000, para 25.

⁶¹ In the United Nations Secretary-General report on the Implementation of the Madrid International Plan of Action on Ageing it states that “discussion of palliative care is progressively shifting from the narrow perspective of “end of life” care and “death with dignity” to the idea that its access is a basic human right.” United Nations Economic and Social Council,

“[t]he right to palliative care should be enshrined in the legal framework so that older persons can enjoy the last years of their lives in dignity and without unnecessary suffering. States should ensure the availability and accessibility of palliative care for all older persons in need, particularly those who suffer from a life-threatening or life-limiting illness. Training, and adequate and affordable medication and therapeutic measures, should be provided in public and private care settings.”⁶²

The right to participate in decision-making

The active participation of persons with disabilities in decision-making is a requirement of the ‘human rights model’ of disability.⁶³ This is reflected throughout the UNCRPD – as a general principle,⁶⁴ and as an obligation for consulting and actively involving persons with disabilities in decision-making processes concerning issues relating to disabled people.⁶⁵ According to the UN Special Rapporteur on the Rights of Persons with Disabilities:

“[e]fforts to involve persons with disabilities in decision-making processes are important, not only because they result in better decisions and more efficient outcomes, but also because they promote citizenship, agency and empowerment.”⁶⁶

[Further implementation of the Madrid International Plan of Action on Ageing, 2002: Report of the Secretary-General](#), E/CN.5/2014/4, December 2013, para 32. The Committee on Economic, Social and Cultural Rights have stated that health measures for older people include physical as well as psychological rehabilitative measures aimed and include measures maintaining the functionality and autonomy of older persons; and attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity. Committee on Economic, Social and Cultural Rights, [General comment No. 14 \(2000\) on the right to the highest attainable standard of health](#), E/C.12/2000/4, 11 August 2000, para 25.

⁶² United Nations General Assembly, [Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte](#), A/HRC/30/43, August 2015, para 131.

⁶³ Ireland ratified the UN Convention on the Rights of Persons with Disabilities (the ‘UNCRPD’) in March 2018, which marked a paradigm shift in the perception of disabled people- moving from the ‘medical model’ to the ‘human rights model’ of disability. The ‘medical model’ sees disability as a medical phenomenon of impairment, while the ‘human rights model’ locates the “problem” of disability outside the person and within society, framing persons with disabilities as rights holders rather than objects of charity, protection, or care. See Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 39.

⁶⁴ Article 3 UNCRPD.

⁶⁵ Article 4 (3) UNCRPD. In addition, Article 4 (3) UNCRPD requires the State to closely consult with and actively include disabled people in decision-making processes concerning issues relating to persons with disabilities. Also, see Article 33(3) of the UNCRPD.

⁶⁶ Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 46.

Similarly, the need to include older people in designing law and policy that affects them has been recognised at both international and regional level.⁶⁷ The UN Principles for Older Persons⁶⁸ and the UN Madrid Action Plan⁶⁹ urge states to ensure the participation of older people in decision-making processes. On the right to health, the UN Independent Expert on the enjoyment of all human rights by older persons has stated that;

“[i]n order to achieve the full realization of the right to health, States must adopt and implement national health policies or strategies and plans of action based on an assessment of the needs of older persons. Such assessments should be adapted to the needs of older persons and be carried out in consultation with, and with the full participation of, older persons. Older persons living in institutions or alternative settings or at home should not be left behind”.⁷⁰

General observations

The title and purpose of the Bill

The title and purpose of the Bill are potentially misleading. The proposed legislation is primarily about physician assisted dying. However, it is entitled “the Dying with Dignity Bill” the purpose of which is to “make provision for the assistance in achieving a

⁶⁷ Council of the European Union, [Council Conclusions on Human Rights, Participation and Well-Being of Older Persons in the Era of Digitalisation](#), October 2020, para 28. In its Council Conclusions on Human Rights, Participation and Well-Being of Older Persons in the Era of Digitalisation, the Council of the European Union invites EU Member States and the EU Commission to “[a]ctively involve older persons, in particular older women, in all decision-making processes affecting their lives”. Furthermore, the Office of the High Commissioner for Human Rights has stated that “[t]he direct and informed participation of older persons in the design of public policy is also critical to their integration as rights-holders, protected against social exclusion and isolation. Ensuring the political participation of older persons is necessary to guarantee that States develop age sensitive laws and policies to implement and mainstream access to the required protections”. Office of the High Commissioner for Human Rights, [Normative standards in international human rights law in relation to older persons: Analytical Outcome Paper](#), August 2012, at pages 32-33.

⁶⁸ [United Nations Principles for Older Persons](#). Adopted by General Assembly resolution 46/91 of 16 December 1991. Principal 7 states, “Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations”.

⁶⁹ [UN Madrid International Plan of Action on Aging](#), April 2002, para 22. Objective 2 of the UN Madrid International Plan of Action on Aging is “[p]articipation of older persons in decision-making processes at all levels”. Actions to support achievement of this objective include “(a) Take into account the needs and concerns of older persons in decision-making at all levels; (b) Encourage, when they do not already exist, the establishment of organizations of older persons at all levels to, inter alia, represent older persons in decision-making; (c) Take measures to enable the full and equal participation of older persons, in particular older women, in decision-making at all levels”.

⁷⁰ Report of the Independent Expert on the enjoyment of all human rights by older persons, [Impact of the coronavirus disease \(COVID-19\) on the enjoyment of all human rights by older persons](#), A/75/205, July 2015, para 82.

dignified and peaceful end of life.”⁷¹ As outlined above achieving a dignified and peaceful end of life engages a range of human rights and equality obligations, including the palliative care needs of people at the end of their life. If the purpose of the Bill is to achieve “dying with dignity” then the Bill would need to be substantively revised to take account of the palliative care needs and wishes of people at the end of life.

The current legal framework does not provide for equal protection before the law

The UNCRPD requires “supported decision making” to ensure that disabled people can make their own decisions. The UNCRPD Committee has stated that; “states parties must respect and support the legal capacity of persons with disabilities to make decisions at all times, including in emergency and crisis situations”.⁷² The UNCRPD Committee has also noted that the reliance on an individual's ‘impaired’ mental capacity and/or decision-making skills as a basis for denying or restricting that person's legal capacity amounts to a discriminatory denial of that person's right to equal protection before the law which is not permitted by Article 12.⁷³

As will be examined below, and with due respect to the drafters, the Bill does not reflect a “supported decision making” model. This is further complicated by the fact that the Assisted Decision Making (Capacity) Act (the ‘2015 Act’) is not fully commenced and questions of legal capacity are currently managed through the wardship system. The wardship system is wholly a substituted-decision making model which is at odds with Article 12 of the UNCRPD.⁷⁴ The 2015 Act introduces a “functional approach” to

⁷¹ Explanatory Memorandum, The Dying with Dignity Bill 2020.

<https://data.oireachtas.ie/ie/oireachtas/bill/2020/24/eng/memo/b2420d-memo.pdf>

⁷² Committee on the Rights of Persons with Disabilities, [General Comment No. 1: Article 12: Equal Recognition before the law](#), CRPD/C/GC/1, May 2014, para 42.

⁷³ Ibid, at para 32.

⁷⁴ The wardship system is operated by the President of the High Court under section 9 of the Courts (Supplemental Provisions) Act 1961 and the Lunacy Regulation (Ireland) Act 1871 and remains wholly a substituted-decision-making model. This appears to be at odds with Article 12 UNCRPD, although it is noted Ireland has made a declaration to the contrary and a reservation reserving the right to permit substituted decision-making arrangements in appropriate circumstances and subject to appropriate and effective safeguards.

disability – an improvement to the current system – but one which continues to fall short of Ireland’s obligations under the UNCRPD.⁷⁵

Choice and decision-making are inseparably linked to a person’s dignity and personal autonomy. The purpose of the Bill is to facilitate choice on end of life issues. Therefore, introducing legislation without first addressing the wider legal and procedural issues relating to capacity will likely impact negatively on disabled people. First, it could potentially have the effect of excluding certain disabled people from eligibility under the Bill on the ground of disability. Second, the lack of clear and formal processes could lead to “substituted decision making” in respect of physician assisted dying.⁷⁶ The assessment of capacity, in decision making, accessible support and advocacy must be independent and available to disabled people. Before legislation of this nature is introduced the State must ensure that a legal and regulatory framework is in place to ensure that all people have equal protection before the law.

The Commission recommends that prior to passing the Bill, or any legislation of this nature, the State must ensure that a UNCRPD compliant legal and regulatory framework that provides for “supported” decision making is in operation to ensure that disabled people have equal protection before the law.

The Bill should be guided by the ‘human rights model’ of disability and legislators should actively engage with at risk groups

The ‘medical model’ of disability is evident throughout the Bill, which takes a medical oriented approach to the process and assessment of physician assisted dying.⁷⁷ This is of particular concern where the ‘medical model’ views persons with disabilities and

⁷⁵ The UNCRPD has raised concerns regarding the functional approach, which it has identified is problematic for two reasons: (a) it is discriminatorily applied to people with disabilities; and (b) it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right — the right to equal recognition before the law. Committee on the Rights of Persons with Disabilities, [General Comment No. 1: Article 12: Equal Recognition before the law](#), CRPD/C/GC/1, May 2014, para 15. See also IHRC, [Observations on the Assisted Decision-Making \(Capacity\) Bill 2013](#), March 2014, and IHREC, [Submission to the public consultation on Deprivation of Liberty: Safeguard Proposals](#), March 2018.

⁷⁶ New Zealand Human Rights Commission, [Submission of the Disability Rights Commissioner on the End of Life Choice Bill](#), 2016, para 15.

⁷⁷ For example, the process and assessment of eligibility for dying is a matter for the attending medical practitioner and an independent medical practitioner.

older people with high dependency needs as the “problem” that needs to be “fixed” or “cured”.⁷⁸ This is even more problematic given the deeply rooted negative perceptions about the value of disabled people⁷⁹ and older people⁸⁰ in society.

Participation with disabled people, people with life-limiting illness and older people is critical. It is clear that individuals from these groups hold a broad spectrum of viewpoints and concerns surrounding the scope and application of legislation of this nature. Active participation is central to the ‘human rights’ model of disability, and Ireland’s obligations under the UNCRPD the UN Principles for Older People and the UN Madrid Action Plan. In particular, it is noted that in 2018 the Oireachtas Joint Committee on Justice and Equality, given the gravity of the issues engaged, urged the Houses of the Oireachtas to consider referring the issue to the Citizens’ Assembly for deliberation, in circumstances where it would benefit from detailed consideration of issues by a representatives sample of citizens.⁸¹

⁷⁸ Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 9.

⁷⁹ In light of these concerns the Special Rapporteur advised that when engaging with disabled people on this issue, that particular attention should be paid to the social factors that may affect the decisions of persons with disabilities in relation to assisted dying, including ableism, social stigma and discrimination, societal views on the quality of life of persons with disabilities and the availability of community support and services, social protection programmes and palliative care. Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 69. The Special Rapporteur defines ableism as “a value system that considers certain typical characteristics of body and mind as essential for living a life of value” and explains that “[b]ased on strict standards of appearance, functioning and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage and invariably devalues human life. As a result, it is generally assumed that the quality of life of persons with disabilities is very low, that they have no future to look forward to and that they will never live happy and fulfilling lives”. Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 9.

⁸⁰ Notably, in relation to older people, the United Nations has recognised the persistent challenge of stigma, discrimination and ‘ageism’ in respect of older persons enjoyment of equality and human rights – see United Nations, [Follow-up to the Second World Assembly on Ageing: Report of the Secretary-General](#), A/66/173, July 2011. The UN Independent Expert on the enjoyment of all human rights by older persons has noted in particular the detrimental effect of age discrimination on the right of older persons to the highest attainable standard of physical and mental health - see United Nations, [“Ageism should not be downplayed: it is an infringement of older person’s human rights,” says UN rights expert](#), press release, October 2016. Concerns have been raised that Covid-19 is disproportionately impacting the rights of older persons, while at the same time escalating ageism, stigmatization and discrimination; see United Nations, [Policy Brief: The Impact of COVID-19 on older persons](#), May 2020, at page 9; United Nations, [Older persons remain chronically invisible despite pandemic spotlight, says UN expert](#), press release, 1 October 2020.

⁸¹ Joint Oireachtas Committee on Justice and Equality, [Report on the Right to Die with Dignity](#), June 2018, at page 56.

The Commission recommends that if legislation permitting physician assisted dying is to be enacted, the design and development of this legislation should be guided by the 'human rights model' of disability and accordingly, must involve extensive discussions through active participation of particular groups, specifically disabled people, people living with life-limiting illness and older people.

The Bill cannot be considered in isolation from the current health and social services provided to particular groups

The Bill must be considered in light of the circumstances of disabled people, people with life-limiting illness and older people, in respect of which there are significant gaps and shortcomings in terms of rights, services and supports. Specifically, it has been noted that many of the issues leading people to request physician assisted dying in other jurisdictions, such as loss of dignity, independence and control over bodily functions, are also disability rights issues.⁸² From a rights perspective, accepting these issues as grounds for seeking physician assisted dying – rather than as grounds for improving supports to ensure dignity in living – may undermine respect for and acceptance of persons with disabilities, or older people, as part of human diversity.

There is no legal right in Irish law to receive specific personal social care services including supports that enable people to live independently, such as home help or personal assistant services.⁸³ The provision of personal assistance services in particular is often inadequate to enable independent living.⁸⁴ Progress on the State's programme to de-congregate residential disability services has been slow and the target timeframe for implementation by 2021 will not be met.⁸⁵ Disabled people living in congregated settings continue to be at greater risk of having a poor quality of life and not being able

⁸² Not Dead Yet, [Disability Rights Toolkit for Advocacy Against Legalization of Assisted Suicide](#).

⁸³ North West Health Board and HW [2001] 3 IR 622 and TD v. Minister for Education [2001] 4 IR 259. The legal framework for the delivery of health and social services in Ireland is the Health Acts 1947 to 2017. Under section 7 of the Health Act 2004, statutory responsibility for the provision of health and personal social services is the responsibility of the HSE. Section 7 provides that it is for the HSE to decide how the resources allocated to it are to be expended.

⁸⁴ See for example: Independent Living Movement Ireland, [ILMI submission to the Joint Committee on Disability Matters, 2020](#), at pages 5-6; Disability Federation of Ireland, [Personal Assistant Services: Presentation to the Joint Oireachtas Committee on Public Petitions](#), 16 May 2018.

⁸⁵ NDA, [Mid-term Review of Progress: The National Disability Inclusion Strategy and Indicators](#), April 2020.

to exercise their rights, often being separated from their local communities and living in unsuitable, outdated accommodation.⁸⁶

In relation to older people, the number of persons over 65 years of age is projected to increase from 532,000 in 2011 to 991,000 in 2031, and an increase in demand for palliative care services is expected to accompany this demographic change.⁸⁷ The evolving use of palliative care to treat patients based on need rather than diagnosis of a specific disease is also increasing the demand for services.⁸⁸ A recent HSE review of palliative care identified a number of gaps in provision, including: inadequate recognition of palliative care need; variable access according to age, socioeconomic considerations, geographic location, and medical diagnosis; inconsistent referral criteria and processes across regions; and a lack of guidance on standards for palliative care.⁸⁹ Research shows that the lack of statutory entitlement to palliative care and decline in State investment in home-care services have resulted in uneven distribution of home-care services, significant waiting times, and growth in the private (for-profit) sector.⁹⁰ These combined factors limit people's choices about their end-of-life care and the quality of that care.⁹¹

Ensuring independent living options are accessible to all who need them, including adequate personal assistance and home care support, is crucial to respecting a person's dignity and autonomy, including choices in life. Furthermore, timely, effective and

⁸⁶ HIQA, [Annual overview report on the inspection and regulation of disability services in 2019](#), 2 September 2020.

⁸⁷ HSE, [Palliative Care Services Three Year Development Framework \(2017 to 2019\)](#), at pages 8-9.

⁸⁸ HSE, [Palliative Care Services Three Year Development Framework \(2017 to 2019\)](#), at page 9.

⁸⁹ HSE, [Adult Palliative Care Services Model of Care for Ireland](#), 2019, at page 25.

⁹⁰ See Timonen, V., Convery, J., Cahill, S. (2006) 'Care revolutions in the making? A comparison of cash-for-care programmes in four European countries', *Ageing and Society*, 26(3): 455–474. Timonen, V., Doyle, M. (2007) 'Worlds apart? Public, private and non-profit sector providers of domiciliary care for older persons in Ireland', *AGISTU Journal of Aging Studies*, 21(3): 255–265. Timonen, V., Doyle, M. (2008) 'From the workhouse to the home: evolution of care policy for older people in Ireland', *International Journal of Sociology and Social Policy*, 28(3/4): 76–89. O'Neill, D. (2017) HIQA (Health Information and Quality Authority) (2017) Submission to the Department of Health's consultation on homecare services, Dublin: Health Information and Quality Authority. Mercille, J and O'Neill, N. 2020. The growth of private home care providers in Europe: The case of Ireland. *Social Policy and Administration*.

⁹¹ Studies show that choice ideology is deeply bound up with market metaphors (or consumer choice). When applied to matters of life and death, it conceals the moral, relational, spiritual and psychological complexity of patient choice, especially at the end of life. This matter has been examined in depth by the Dutch medical scholar and ethicist, Anne Marie Mol. Mol's longitudinal studies of choice among people with serious life-limiting illnesses show that the 'logic of choice' often undermines the 'logic of care'. The patient is left to 'choose' when in reality, due to lack of good care, they have no choice about how they are cared for, or how they die, at the end of life. Mol, A. (2011) *The logic of care: Health and the problem of patient choice*. London: Routledge. Also see, Puig, de la Bellacasa, M. 2012. 'Nothing Comes Without Its World': Thinking with Care. *The Sociological Review*, 60 (2): 197-216.

accessible palliative care is particularly critical to protecting a person’s dignity and autonomy at the end of life.⁹² The Bill must not have the effect of diminishing these fundamental rights. Disability and older person services focused on autonomy, independent living and palliative care must be adequately funded and properly resourced to ensure that the proposed Bill does not become the only option. Also, to address gaps in legal protection the Bill should be accompanied by law that provides for basic legal rights to independent living and palliative health care.⁹³

The Commissions recommends that any examination of this Bill, or any legislation of this kind involve consideration of the adequacy of health and social services provided to particular groups, including disabled people, people with life-limiting illness and older people.

The Commission recommends that the Bill be accompanied by law that provides for basic legal rights to independent living and palliative health care.

Specific limitations of the Bill

Principles underpinning the Bill (Section 6)

Section 6 provides that it shall be lawful for a medical practitioner to provide assistance to a “qualifying” person to end their life in accordance with the procedure set out in the Bill.⁹⁴ However, beyond clinical assessment, the Bill is silent on the principles that a medical or, any person should have regard to, when performing a function under the Bill.

In Tasmania the End of Life Choices (Voluntary Assisted Dying) Bill 2020 provides a comprehensive list of principles that a person performing functions under the relevant legislation must have regard to when providing physician assisted dying.⁹⁵ The principles include for example, the equal value of every life; respect for autonomy and

⁹² Palliative care, as an approach that improves quality of life through treatment of pain and other problems, is an essential means of ensuring dignity in life for persons with a life-limiting illness.

⁹³ For example, in Belgium the law decriminalising euthanasia was accompanied by a law which made palliative care a basic right of all patients. See Joint Oireachtas Committee on Justice and Equality, [Report on the Right to Die with Dignity](#), June 2018, at page 53.

⁹⁴ Section 6 and section 11 of the Bill.

⁹⁵ [Tasmanian End-of-Life Choices \(Voluntary Assisted Dying\) Bill 2020](#), section 3..

end of life choice; the right to be supported in decision making; the right to end of life high quality care, including palliative care; and the right to access therapeutic services. Section 42 of the IHREC Act 2014, which imposes a similar statutory obligation on public bodies in the performance of their functions may also be instructive in this regard.⁹⁶

The Commission recommends that the Bill be amended to impose a statutory duty on persons exercising functions under the Bill to have regard to relevant and specific human rights and equality principles in respect of persons accessing (or seeking to access) physician assisted dying under the Bill.

The definition of 'terminally ill' (Section 8)

A person must be determined as "terminally ill" to access physician assisted dying under the Bill. A person is defined as being "terminally ill", if that person "has been diagnosed by a registered medical practitioner as having an incurable and progressive illness which cannot be reversed by treatment, and the person is likely to die as a result of that illness or complications relating thereto."⁹⁷

This definition potentially captures a wide range of conditions, including certain severe and profound disabilities, including for example neurological disorders (such as dementia),⁹⁸ and chronic health conditions. That is, that certain disabilities which might give rise to complex health issues could be considered as "an incurable and progressive illness which cannot be reversed by treatment, and from which the person is likely to die as a result of or complications relating thereto." Also, it is noted that "terminal illness" under the Bill's criteria is not expressly limited to physical conditions. People experiencing a range of mental and psychological conditions could potentially fall within the meaning in its current form.

⁹⁶ Section 42 provides "[a] public body shall, in the performance of its functions, have regard to the need to— (a) eliminate discrimination, (b) promote equality of opportunity and treatment of its staff and the persons to whom it provides services, and (c) protect the human rights of its members, staff and the persons to whom it provides services."

⁹⁷ Section 8 of the Bill.

⁹⁸ Neurological conditions affect the nervous system, including brain, brain stem, spinal cord, root, plexus, peripheral nerves and muscle. Neurological conditions include for example, Dementia, Parkinson's disease, and strokes; etc.

The UNCRPD Committee has raised concerns in respect of states that have included disability as a ground for physician assisted dying.⁹⁹ The Special Rapporteur has recommended that physician assisted dying should be restricted to terminally ill persons who are approaching end of life and should never be provided on the ground of disability.¹⁰⁰ Proposed legislation must clearly and expressly state that no person should qualify solely on the ground of 'disability' or 'age'.¹⁰¹

The Bill, unlike approaches in other jurisdictions such as the Netherlands,¹⁰² does not seek to provide for assisted dying for "non-terminal" persons. Moreover, it should be flagged that in 2020, Canada introduced a Bill proposing to extend the scope of physician assisted dying to circumstances where death is not reasonably foreseeable.¹⁰³ The developments in Canada highlight the complex issues that may arise when designing legislation on these issues, which in turn highlights the need for meaningful and close consultation with disabled persons, those with life-limiting illnesses, older people and other relevant at risk groups.

The Commissions recommends that the Bill, or any other legislation on physician assisted dying, clearly and expressly state that no person should qualify solely on the ground of disability (neurological, mental or physical), or age.

The Bill states that to qualify a person must have an incurable and progressive illness that cannot be reversed and from which a person "is likely to die". With respect, this is too vague and could lead to legal uncertainty. The purpose of the Bill is to provide for

⁹⁹ The UNCRPD Committee, [Concluding observations on the initial report of Canada](#), CRPD/C/CAN/CO/1, 8 May 2017, para 24. The UNCRPD Committee stated that it was "concerned about the adoption of legislation that provides for medical assistance in dying, including on the grounds of disability".

¹⁰⁰ Human Rights Council, [Report of the Special Rapporteur on the rights of persons with disabilities](#), A/HRC/43/41, 17 December 2019, para 70.

¹⁰¹ See the Oregon Model and also the New Zealand: End of Life Act, 2019.

¹⁰² Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002. In the Netherlands, there is no requirement for a patient to be at end of life and the determining criterion is that a patient's suffering is lasting and unbearable.

¹⁰³ This is in response to the 2019 Quebec Superior Court decision in [Truchon c. Procureur général du Canada](#), 2019 QCCS 3792 (CanLII) which found that the requirement that death be reasonably foreseeable was constitutionally invalid on several grounds, including that it impinges on equality rights for persons with disabilities. See Department of Justice Canada, [Government of Canada reintroduces proposed changes to medical assistance in dying legislation](#), 5 October 2020. The Canadian Government introduced a Bill in October 2020 proposing to remove this requirement and introduce a two-track approach to procedural safeguards (with more stringent safeguards to be applied when death is not reasonably foreseeable) based on whether or not a person's natural death is reasonably foreseeable.

physician assisted dying to terminally ill adults approaching end of life. Therefore, what is meant by end of life should be tangible and clearly defined. A concrete time-frame and an objective threshold for making such a determination would strengthen this provision. In this respect, other jurisdictions have inserted specific timeframes, and also require that any such assessment be based on 'reasonable medical judgment.'¹⁰⁴

The Commission recommends that the Bill be amended to include appropriate thresholds in relation to likelihood of dying (for example, a maximum 6 months).

The Commission recommends that the wording "is likely to die" be replaced by a more robust and objective test; for instance, 'reasonable medical judgment' such that there is a high degree of probability that the person will die within the time-frame as a result of the illness.

Witnesses (Section 9)

The Bill provides that the person must make a declaration in the presence of a witness.¹⁰⁵ The Bill expressly excludes individuals who will benefit through inheritance, the attending medical practitioner and the independent medical practitioner¹⁰⁶ from being witnesses.¹⁰⁷

Other jurisdictions have introduced stronger safeguards in relation to witnesses. For example in Oregon a declaration must be witnessed by at least two individuals who attest their knowledge and belief that the patient is capable, acting voluntarily, and is not being coerced to sign the request. One of the two witnesses must not be: a relative of the patient by blood, marriage or adoption; a beneficiary of the patient's estate; or an owner, operator or employee of a health care facility where the patient is receiving medical treatment or, is a resident.¹⁰⁸ In addition, Canadian law precludes a person who

¹⁰⁴ For example, in Oregon to qualify under the respective legislation the person must have a terminal illness that based on reasonable medical judgment will produce death within six months. Terminal disease is defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months". Section 1(12), [Death with Dignity Act](#) (Oregon).

¹⁰⁵ Section 9(1)(b) of the Bill.

¹⁰⁶ It is further noted that the Bill does not define "independent" medical practitioner. Like witnesses further consideration of who can be deemed to be independent for the purpose of the Bill would seem important.

¹⁰⁷ Section 9(1)(b) and 9(1)(c)(iii) of the Bill

¹⁰⁸ Section 2(2), [Death with Dignity Act](#) (Oregon).

is directly involved in providing the patient with a health service or personal care from acting as a witness to a request for physician assisted dying.¹⁰⁹

The risk of coercion or duress are real, in particular, for at risk groups and those reaching the end of life. The Bill must ensure that witnesses involved in the process are acting independently and in line with the wishes and interest of the person concerned.

The Commission is of the view that further consideration should be given to the categories of individuals who should be precluded from being a witness, e.g. relatives, individuals who are responsible for providing care to the person concerned (such as for example, an operator of health facility where person is living or, receiving treatment) in order to protect against undue influence and/or duress.

Free and informed consent (Section 9)

The Bill provides that a qualifying person must have “a clear and settled intention to end his or her own life which has been reached voluntarily, on an informed basis and without coercion or duress”.¹¹⁰ It also states that medical practitioners when deciding whether to countersign a declaration must be “satisfied that the person making it has been fully informed of the palliative, hospice and other care”.¹¹¹

Informed consent engages the right to personal autonomy of choice and is based on the concept that a person cannot make informed autonomous choices about medical procedures, including end of life matters, without all of the relevant information.¹¹² As set out above, the ECtHR and relevant international human rights treaty monitoring bodies have stressed that states that legislate for physician assisted dying must ensure

¹⁰⁹ Section 241.2(5) [Criminal Code](#) (Canada).

¹¹⁰ Section 9(3)(c) of the Bill.

¹¹¹ Section 9(4) of the Bill.

¹¹² Article 25 UNCRPD which provides for the right to enjoyment of the highest attainable standard of health, which includes the right to health care on the basis of free and informed consent. According to the UN Committee on the Rights of the Persons with Disabilities: “states parties have an obligation to require all health and medical professionals (including psychiatric professionals) to obtain the free and informed consent of persons with disabilities prior to any treatment. In conjunction with the right to legal capacity on an equal basis with others, States parties have an obligation not to permit substitute decision-makers to provide consent on behalf of persons with disabilities. All health and medical personnel should ensure appropriate consultation that directly engages the person with disabilities. They should also ensure, to the best of their ability, that assistants or support persons do not substitute or have undue influence over the decisions of persons with disabilities.” AUN Committee on the Rights of Persons with Disabilities, [General Comment No. 1: Article 12: Equal Recognition before the law](#), CRPD/C/GC/1, May 2014, para 41

that the necessary safeguards are in place to ensure that free and informed consent has been provided.

The Bill does not explicitly recognise the need for free and informed consent based on all the available information.¹¹³ In this regard, it is noted with concern that key terms have not been defined, namely 'free and informed consent', 'voluntary', 'coercion' or 'duress'.¹¹⁴ Also, the Bill is silent on the steps that medical practitioners must take to ensure that consent has been given freely and on the basis of all relevant information. This may present significant issues where persons with disabilities require that information be provided in accessible formats. Notably the Bill does not place an obligation on the attending medical practitioner to fully inform the individual. Rather, it states that the medical practitioner must be satisfied that the person "has been fully informed of the palliative, hospice and other care."¹¹⁵

There is no express obligation on the medical practitioner to provide information on the person's medical diagnosis, prognosis, the potential risks associated with taking the medication to be prescribed, the probable result of taking the medication to be prescribed, options to access counselling services, or their right to withdraw at any stage. Nor is there an obligation on the medical practitioner to seek an expert opinion where the information falls outside their clinical expertise.¹¹⁶ The provision of palliative care, or clinical opinions on the diagnosis and prognosis of specific chronic life-limiting conditions are specialist medical and nursing fields. A general practitioner, for instance, may not have the requisite expertise to provide information on any or all of these matters. Other jurisdictions have enacted similar legislation which explicitly recognises the need for genuine informed consent based on full provision of relevant information

¹¹³ It is also of note that there is no provision for listening to or, accommodating significant others in the person's life. One of the features of the Bill is that it presents persons who are seeking assisted dying in atomistic terms. See for example Archer, M.S. 2000. *Being Human*. Cambridge: Cambridge University Press. 2000; Puig, de la Bellacasa 2017. Also see; *Matters of Care Speculative Ethics in More Than Human Worlds*. Minneapolis: University of Minnesota Press. 2017. Both Irish and international research on persons in palliative care shows that people are highly conscious of their relations with others in making their decisions about how and where to die – See Timonen, V., Doyle, M., & Prendergast, D., 2006. *No Place like Home: Domiciliary care services for older people in Ireland*. Dublin: The Liffey Press.

¹¹⁴ Section 9(3)(c) of Bill.

¹¹⁵ *Ibid.*

¹¹⁶ Other clinical experts might include for example, psychiatrist, clinician with expertise in specific medical area, such as oncologist, neurologist; etc, or psychologist. Non-clinical experts might include, pharmacist, counsellor, or social worker.

and addresses the meaning and process for determining free and informed consent in detail.¹¹⁷

The Commission recommends that the Bill be amended to recognise the need for genuine, free and informed consent that is based on all relevant information. This must include clear and specific definitions and set out processes to establish that free and informed consent has been provided, including in respect of persons with disabilities.

Capacity (Section 10)

The Bill proposes that an individual will only be provided with assistance in dying if both the attending medical practitioner and the independent medical practitioner are satisfied that the person has the capacity to make the decision to end their own life.¹¹⁸ Section 10 of the Bill sets out the procedure for assessing capacity in this context.

Section 10 of the Bill mirrors Section 3(1) of the Assisted Decision-Making (Capacity) Act 2015 ('the 2015 Act')¹¹⁹, which asserts that capacity should be construed functionally. However, no reference is made to the 2015 Act within the Bill. Therefore, it is not clear whether it is proposed that the definitions and processes related to capacity, as outlined in the 2015 Act, are to apply to this Bill. This may give rise to legal uncertainty.

In any event, as already noted the 'functional approach' to 'capacity' in the 2015 Act falls short of Ireland's obligations under the UNCRPD.¹²⁰ In order to fulfil the vision of capacity as set out by the UNCRPD, the Bill would need to be amended to "provide that

¹¹⁷ Oregon legislation provides that an "informed decision" means "a decision by a qualified patient, to request and obtain a prescription to end his or her life in a humane and dignified manner, that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of:

- (a) His or her medical diagnosis;
- (b) His or her prognosis;
- (c) The potential risks associated with taking the medication to be prescribed;
- (d) The probable result of taking the medication to be prescribed; and
- (e) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control."

(at s127.800 para 1.01 (7))

¹¹⁸ Section 7 and 9 of the Bill.

¹¹⁹ This section has not yet been commenced.

¹²⁰ IHRC, [Observations on the Assisted Decision-Making \(Capacity\) Bill 2013](#), March 2014. See also, IHREC, [Submission to the public consultation on Deprivation of Liberty: Safeguard Proposals](#), March 2018.

a person either has capacity or requires decision-making support.”¹²¹ Given the provision for the establishment of the Decision Support Service under the 2015 Act, it is surprising that no reference has been made to decision-making support in the Bill.

The Commission recommends that the Bill should be revised to recognise that all individuals have capacity and provide for decision-making support in line with the UNCRPD.

Section 10 of the Bill does not include a provision equivalent to Section 3(5) of the 2015 Act which provides that;

“The fact that a person lacks capacity in respect of a decision on a particular matter at a particular time does not prevent him or her from being regarded as having capacity to make decisions on the same matter at another time.”

Article 12(4) UNCRPD requires a recognition of the time and issue bound nature of any mental capacity assessment.¹²² Also, and linked to the issue of capacity and the 2015 Act, the Bill is silent on the issue of advance health care directives, which may require further examination.¹²³

The Commission recommends that the Bill be amended to recognise the time and issue bound nature of any mental capacity assessment.

In addition, Section 10 is silent as to who will carry out an assessment of capacity. However, Section 9(3)(b) provides that:

¹²¹ Ibid.

¹²² IHRC, [Observations on the Assisted Decision-Making \(Capacity\) Bill 2013](#), March 2014.

¹²³Part 8 of the 2015 Act provides that a person who has capacity may make an advance healthcare directive setting out their will and preferences concerning treatment decisions that may arise in respect of them if they subsequently lacks capacity; including the refusal of treatment. However under the 2015 Act, the making of an advance healthcare directive does not affect the operation of Section 2 of the Criminal Law (Suicide) Act 1993. See in particular, section 85(5)(b) of the 2015 Act. In countries and jurisdictions that permit assisted dying, there is no clear preference for advance healthcare directives for assisted dying. Canada, New Zealand, Oregon, and Washington do not permit advance directives. See Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018, at pages 128, 131. Belgium, Luxembourg, Netherlands, and Columbia allow advance directives for assisted dying subject to eligibility criteria and safeguards - Council of Canadian Academies, [The State of Knowledge on Advance Requests for Medical Assistance in Dying](#), 2016; Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018, at pages 13, 31.

“the attending medical practitioner and the independent medical practitioner, having separately examined the person and the person’s medical records and each acting independently of the other, must be satisfied that the person

...

has the capacity to make the decision to end his or her own life.”

It is arguable, on one reading of the Bill that the assessment of capacity must be carried out by the attending medical practitioner and an independent medical practitioner within the meaning of the Bill. However, another reading of the Bill could suggest that both the attending medical practitioner and the independent medical practitioner may be satisfied as to an individual’s capacity having reviewed the medical records, which may include a declaration as to capacity i.e. they do not themselves have to carry out an assessment of capacity.¹²⁴ This gives rise to ambiguity in the current draft of the Bill. The explanatory memorandum to the Bill does not provide any guidance on this issue either.

The 2015 Act provides for a declaration as to capacity by a court. In addition, when a court makes a declaration as to capacity,¹²⁵ the court is obliged to set intervals at which the capacity declaration will be reviewed.¹²⁶ The Bill gives rise to legal uncertainty as to whether the 2015 Act should apply in this respect.

The Commission recommends that the Bill be amended to provide legal clarity in terms of the procedures for the assessment of capacity, particularly in terms of who is to undertake this assessment and what is involved in the assessment.

Cooling-off period and the right to withdraw at any stage (Section 11(3) and 11(4))

The Bill provides for a cooling-off period of at least 14 days after a declaration has taken effect, which can be reduced if the medical practitioners agree that the person’s death

¹²⁴ IHRC, [Observations on the Assisted Decision-Making \(Capacity\) Bill 2013](#), March 2014, para 49.

¹²⁵ Section 37(1) of the 2015 Act.

¹²⁶ Section 49(2) of the 2015 Act.

is reasonably expected to occur within one month from the day that the declaration takes place.¹²⁷

The New Zealand Disability Rights Commissioner noted, in considering a comparable legislative proposal that terminal and non-terminal conditions give rise to “periods of grief, despair and depression of varying intensity and duration” and “quick or reactive decisions could be made in times of low mood without a reasonable opportunity for proper consideration.”¹²⁸ Therefore, the cooling-off period is a welcome safeguard and one followed in other jurisdictions.

However, it is noted with concern that there is no requirement for practitioners to inform qualified persons of their right to withdraw from the process at any stage during.¹²⁹ This is a significant gap specifically given the serious and irreversible nature of such a decision.

The Commission is of the view that a cooling-off period is a necessary and essential safeguard in legislation relating to physician assisted dying. The Committee may wish to consider whether the 14 or 6 day period prescribed in the Bill should be extended.

The Commission recommends that there should be an explicit requirement on the medical practitioner to advise a qualified person of their right to withdraw from the process at any stage, and that this process is witnessed and formally recorded.

¹²⁷ Section 11 (3)(c) and 11 (4) of the Bill. For example, in Oregon medication may not be issued until a minimum of 48 hours has passed and before the patient’s physician prescribes the medication, the patient must wait 15 days to make an additional oral request. In addition, the physician must establish that the decision is informed and offer the patient an opportunity to withdraw their request. In Canada, a minimum of ten days from submitting the written request must elapse before assisted dying is administered, although a shorter period is possible if the patient risks dying or losing their ability to provide their consent. See Swedish National Council on Medical Ethics, [Assisted dying: A state of knowledge report](#), September 2018.

¹²⁸ New Zealand Human Rights Commission, [Submission of the Disability Rights Commissioner on the End of Life Choice Bill](#), 2016, para 44.

¹²⁹ In Oregon physicians must offer the patient an opportunity to rescind their request at section 127.815, para 3.01(h).

Regulations (Sections 3 and 11)

The Bill does not prescribe the form or, content of a declaration. Further, the Bill does not define or, prescribe the substances that can be administered to a qualified person.¹³⁰ The Bill provides that the Minister “may” by regulations specify the substance or substances which may be prescribed, the form and manner in which prescription are to be issued and the manner and conditions under which substances or substances are to be dispensed, stored, transported, used and destroyed.¹³¹

Other jurisdictions prescribe the form and content of declarations under law, and by regulation.¹³² A standard and specified approach to declarations would provide for further safeguards on the process itself. Moreover, the lack of clarity on the “substances” that can be administered raises concern. Clarity is required on the substances and the procedure to administer said substances. The discretionary requirement that the Minister “may” provide for such matters by regulation is inadequate.

The Commission recommends that the Bill be amended to ensure that the form and content of declarations are prescribed under the Bill, or by regulation.

The Commission recommends that the Bill be amended to provide that the Minister “shall” by regulation specify the substance or substances which may be prescribed, the form and manner in which prescription are to be issued and the manner and conditions under which substances or substances are to be dispensed, stored, transported, used and destroyed.

Independent oversight

The Bill sets out the process for an attending medical practitioner and an independent medical practitioner to countersign a qualifying person’s declaration to end their life.¹³³

¹³⁰ Section 11(2)(a) of the Bill.

¹³¹ Section 11(7) of the Bill.

¹³² See for example 241.31(3) of Criminal Code (Canada).

¹³³ Section 9 of the Bill.

There is no ex ante independent mechanism to review either the declaration or, the process. Also, the procedure does not address a situation whereby medical practitioners may have diverging opinions, or where a person wishes to challenge a decision of either or both medical practitioners not to grant a declaration.

The process and decision to sign a declaration to end a person's life has the most real and irreversible implications for the rights of the person concerned, most fundamentally their right to life. In cases that engage fundamental rights the Irish Courts have recognised the need for procedural safeguards such as an independent review mechanism.¹³⁴ The UN Human Rights Committee has recommended that States consider introducing ex ante reviews of decisions by independent or judicial oversight of requests for physician assisted dying.¹³⁵ In relation to the Netherlands, the UN Human Rights Committee stated that given the "limited ex ante review of decisions to terminate life" the Netherlands should;

"strengthen the institutional safeguards to regulate euthanasia (assisted suicide) in accordance with the Committee's General Comment No. 36 (2018) on the right to life, including by considering the introduction of an independent ethics committee to conduct ex ante reviews of medical decisions on requests for termination of life or assisted suicides".¹³⁶

Separately, the UNCRPD Committee recommended that Canada establish an effective and independent mechanism to ensure that compliance with the law and regulations on assisted dying is strictly enforced and that no person with disability is subjected to external pressure.¹³⁷

¹³⁴ See most recently for example [Damache v. Minister for Justice](#) [2020] IESC 63.

¹³⁵ The UN Human Rights Committee recommended that Switzerland should consider amending its legislation in order to ensure independent or judicial oversight to determine that a person who is seeking assisted dying is acting with full free and informed consent. See Human Rights Committee, [Concluding observations of the Human Rights Committee: Switzerland](#), CCPR/C/CHE/CO/3, 3 November 2009, para 13.

¹³⁶ Human Rights Committee, [Concluding observations on the fifth periodic report of the Netherlands](#), CCPR/C/NLD/CO/5, 22 August 2019, para 29.

¹³⁷ Committee on the Rights of Persons with Disabilities, [Concluding observations on the initial report of Canada](#), CRPD/C/CAN/CO/1, 08 May 2017, para 24(c).

It is noted that an independent review mechanism will formalise an inherently private decision. However, given the grave implications of a decision to end life an independent review body seems necessary and proportionate. The review body could be structured in a manner similar to other independent review bodies and comprise individuals with relevant experience and specialist knowledge in areas such as medicine, nursing, bioethics, social science, psychiatry, law, ethics, and lay persons (including older people, people with a life-limiting illness, and disabled people).¹³⁸

The Commission recommends that the Bill be amended to provide for the establishment of an independent oversight mechanism responsible for reviewing and affirming declarations to end life.

Reporting requirements (Sections 14 and 15)

The Bill provides for the establishment of the Assisted Dying Act Review Committee, and requires the attending medical practitioner to forward a record of the procedure to the Assisted Dying Act Review Committee.¹³⁹

The Bill does not prescribe the membership or terms of reference of the Assisted Dying Act Review Committee. Specifically, the Bill is silent on data collection and public reporting obligations of the Committee. There are similar reporting requirements under the Health (Regulation of Termination of Pregnancy) Act 2018 (the '2018 Act').¹⁴⁰ However, the 2018 Act provides greater detail on the contents of the notification. Also, under the 2018 Act, the Minister is then required to publish an annual report on the notifications received, which is to be laid before the Houses of the Oireachtas.¹⁴¹

¹³⁸ See for example Mental Health Tribunals which review the involuntary detention of persons in mental health settings. The tribunals comprise three persons: a chairperson (who is a barrister or a solicitor); a consultant psychiatrist (who is not the patient's consultant psychiatrist); and a lay person (who is not a registered medical practitioner or registered nurse or one of the above).

¹³⁹ Sections 14 and 15 of the Bill.

¹⁴⁰ Section 20(1) of the [Health \(Regulation of Termination of Pregnancy\) Act 2018](#).

¹⁴¹ Section 20(3) of the [Health \(Regulation of Termination of Pregnancy\) Act 2018](#). The first annual report was published on 30 June 2020, available: <https://www.gov.ie/en/publication/b410b-health-regulation-of-termination-of-pregnancy-act-2018-annual-report-on-notifications-2019/>

The UNCRPD Committee has criticised States for the absence of data to assess compliance with the procedural safeguards regarding assisted dying and the lack of sufficient support to allow for civil society engagement with monitoring of the practice.¹⁴² To address this, the U CRPD Committee has recommended the introduction of regulations that require the collection and reporting of detailed information on each request and intervention on assisted dying.¹⁴³

The Bill should be amended to set out in detail the role and membership of the Assisted Dying Act Review Committee. This Committee should be independent, and its membership should include a variety of experts and lay representatives from particular groups, including disabled people, older persons, and those with life-limiting illnesses. The role of the Assisted Dying Act Review Committee should include the collection and reporting of disaggregated data¹⁴⁴ on each intervention to ensure strict compliance with procedures, and allow for trend analysis relating to assisted dying.

The Commission recommends that the Bill be amended to prescribe membership and terms of reference of the Assisted Dying Act Review Committee, particularly with regard to its independence, and the participation of civil society including persons with disabilities, people with life-limiting illnesses and older people.

The Commission recommends that the Committee's role include the collection and publication of relevant disaggregated data on each request and intervention for medical assisted dying.

¹⁴² Committee on the Rights of Persons with Disabilities, [Concluding observations on the initial report of Canada](#), CRPD/C/CAN/CO/1, 8 May 2017, para 24.

¹⁴³ Committee on the Rights of Persons with Disabilities, [Concluding observations on the initial report of Canada](#), CRPD/C/CAN/CO/1, 8 May 2017, para 24(b).

¹⁴⁴ The disaggregated data should include equality data on protected characteristics, such as: socioeconomic status, age, disability, gender, race (nationality), membership of the Traveller community, sexual orientation, family status, religious belief.

Conclusion

Legislation of this kind raises important issues of dignity and personal autonomy for people with life-limiting illnesses, including the stark realities of the pain and suffering they face due to these illnesses. However, notwithstanding these important issues, this Bill, or any legislation of this kind, which seeks to give effect to physician assisted dying must be scrutinised carefully, with particular with regard to at risk groups, including disabled people, people with life-limiting illness and older people.

Legislation that provides for physician assisted dying must be informed by human rights and equality standards and the 'human rights model' of disability. Moreover, civil society, including at risk groups must have a meaningful opportunity to actively engage with the design, development and implementation of legislation of this nature.

The Bill cannot be examined in isolation. The Bill or, any legislation of this kind – fundamentally concerns choice and decisions to end life. Therefore, prior to enacting legislation of this kind, the State must ensure that a legal and regulatory framework that provides for supported decision making for disabled people is in operation to ensure equal protection before the law. Also, the Bill must be examined against the adequacy of current health and social care services available in the State and it must not have the effect of diminishing already inadequate services.

Finally, in respect of this particular Bill, significant amendments are required to ensure the Bill meets its obligations to provide for robust and effective safeguards, as is required under the Constitution and human rights law. These amendments specifically relate to: the definition of 'terminally ill', the definition of witnesses, free and informed consent, capacity, the introduction of an ex ante review mechanism and detailed reporting requirements.



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