



IHF Submission to Justice Committee from Irish Hospice Foundation on the on the Dying with Dignity Bill 2020

Date: Wednesday, 20 January 2021

Brief Introduction

Irish Hospice Foundation (IHF) is a national charity that addresses dying, death and bereavement. For 35 years the IHF has sought to bring excellence in care at end-of-life, into all care settings where people die. IHF has been at the forefront of dying, death and bereavement since its inception, advocating for change and proper investment. IHF is a thought leader on dying, death and bereavement. We are informed by the evolving views and opinions of the Irish public, who fund our work.

We believe that every person deserves a ‘good death’. Research, evidence and public consultation consistently emphasise that people’s understanding of this concept of a ‘good death’ is that their pain and suffering are managed to the best extent possible. Every person facing dying, death and bereavement has to deal with many personal challenges. We strive to ensure that they receive the optimal services, empathy and care. In the end, we all desire a solution which meets the needs of the Irish public, and which reflects the society we now live in.

Fundamental to a good death is the use of a 'hospice' or palliative care approach. Palliative care is an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention, assessment and treatment of pain, suffering and other physical, psychosocial and spiritual problems. Assisted dying, even if legalized, could be considered to run counter to the hospice philosophy, and challenges the principles of palliative care in a fundamental way, particularly the principle that palliative care 'Intends neither to hasten nor postpone death'. Given the complexity of assisted dying, and the specific concerns of the palliative and hospice care community, a more thorough investigation of all issues and concerns should be undertaken as part of the scrutiny and diligence surrounding the current legislation.

Our extensive research and public consultation show that underpinning a good death is an assurance that every person will be afforded optimal access to specialist palliative care – equity that is not yet in place in Ireland. Equally, each person must be assured that they will receive all necessary supports as they age – in particular homecare supports which allow older persons to live independently and without over reliance on family carers. These supports are not universally available.

IHF has longstanding experience of working in this area through programmes such as Hospice Friendly Hospitals and Compassionate End of Life (CEOL) programme for nursing homes;

through advance planning tools such as Think Ahead and through needs-based educational programmes for health care professionals and carers. Through these approaches, we have contributed to real improvements in providing people with dignified end-of-life care. We seek to bring dignity and compassion to dying through flagship programmes, ensuring access to palliative care and developing in-depth training programmes.

In December 2020, we invested in an in-depth comparative analysis of developments and experiences of Assisted Dying in other jurisdictions. This document, “The International Experience of Assisted Dying” is included as part of this submission, and key lessons from the analysis have been incorporated into the submission.

Our expert observations lead us to conclude that here has not yet been a sufficiently detailed and diverse debate and consultation in Ireland on Assisted Dying. IHF believes all potential perspectives on the Bill now need to be considered. There is a multiplicity of issues and range of viewpoints regarding the Bill and its implications for our society. In 2021, there should be a comprehensive, in-depth debate on assisted dying. All voices should be heard; nobody should be afraid to speak out.

IHF views and comments on each section of the Bill as they relate to the questions set out in the *Framework for Committee Scrutiny of PMBs* (using layout as set out)

Factual information IHF has to offer:

As part of its role as thought leader on dying, death and bereavement, IHF has undertaken an in-depth comparative analysis of developments and experience in other jurisdictions. This document, “The International Experience of Assisted Dying” is included as part of this submission.

Based on our comparative review, it is understood that in health systems in affluent societies such as ours, where Medical Assistance in Dying is legislated for and available, that it is chosen and implemented at the request of between 0.5 % to 4% of all of those dying, which is a considerable proportion. It is also evident that a similar proportion of people closely consider it, identify it as a possible option or contingency for themselves, but do not proceed to avail of it.

Should a Bill of this nature be passed by legislators in Ireland, this will need to be based on a thorough examination of issues and wide consultation. IHF analysis highlights the following, which will need to be considered in any future legislation:

- Assisted Dying has serious implications and risks for individual patients. Risks are likely to be more pronounced for vulnerable groups of patients such as older people, children, people with disabilities, people with dementia, people with illnesses that are stigmatised (e.g., AIDS), people who are disadvantaged and/or do not have access to good medical care, and people in minority groups who have experienced discrimination. If a Bill legislating for Assisted Dying were to be enacted, stringent procedural rules and safeguards must be in place to protect all patients.

- It is not presently clear exactly who will be involved in implementing Assisted Dying. The views of all healthcare practitioners expected to be involved in implementing Assisted Dying are not known, including whether practitioners believe that the Bill is necessary, or if they would want to be involved.
- The introduction of Assisted Dying could undermine investment in palliative care and in care of older persons.
- In any debate on Assisted Dying, there is a need to be respectful of the need expressed by some patients for autonomy with respect to dying and care choices. This needs to be supported through growing use of advanced healthcare directives and other supports.
- Decision-making capacity needs to be a central safeguard in legislation on assisted dying. However, it is not without its problems, and discussion needs to take place about what exactly is meant by ‘decision-making capacity’. Existing legislation, specifically the Assisted Decision Making (Capacity) Act 2015 ideally needs to be enacted. IHF believes that legislation for Assisted Decision Making should be fully considered and enacted as an essential piece of legislation, highly relevant to legislation on Medical Assistance in Dying.
- This legislation (‘Dying with Dignity’) must be underpinned by robust and equitable palliative care services – from specialist inpatient support to more general support in the community. These supports are not yet in place and we recommend that the committee seeks clarification on the timeline for development of specialist palliative care services as mandated in current Health policy. More information on gaps in service provision can be provided.
- A key element of good care at end-of-life is good homecare supports. IHF supports the development of a (long promised) statutory homecare scheme – such a scheme will provide invaluable supports to older people and provide assurances that they will not be ‘a burden’ on their families (a common concern). We recommend that the committee seeks clarification on the timeline for the statutory homecare scheme.
- Finally, dignity in dying is achieved through a variety of mechanisms – primarily but not exclusively through access to compassionate skilled care. We contend that this Bill ‘Dying with Dignity’ may impact on other service developments which seek to ensure dignity in dying.

Links to publications to which we refer:

Links to publications are listed below:

- Have your Say Report (2017). Available at: <https://hospicefoundation.ie/say-report-2017/>
- Survey of Bereaved Relatives: VOICES MaJaM (2017). Available at: <https://www.mater.ie/services/end-of-life-care/Survey-of-bereaved-family-members.pdf>
- Campbell, L. (2018) Current Debates about Legislating for Assisted Dying: Ethical Concerns, *Medico-Legal Journal of Ireland*, 24(1): 20-27.

- Ethical framework for end-of-life care (IHF, 2011). Available at <https://hospicefoundation.ie/publications/ethics/>. Specifically, modules 5 and 6 (ethics of managing pain and life prolonging treatments)
- End-of-Life Care: Ethics and Law, McCarthy J, Donnelly M, Dooley D, Campbell L, Smith D (2011)

The IHF document, “The International Experience of Assisted Dying” is included with this submission. This includes an extensive list of international publications on the subject.

Our recommendations to the committee;

Assisted Dying is a highly complex issue and the Dying with Dignity Bill 2020 an important piece of legislation that will, if enacted, have significant and far-reaching implications.

Our primary recommendation to the Justice Committee is that a much more robust and thorough debate on Assisted Dying is required.

The ethical, legal, social and policy implications of legislating for Assisted Dying must be thoroughly debated. There has not yet been sufficient public and professional consultation on this Bill and the matter of Assisted Dying. IHF’s main recommendation now is for a full and considered debate on this issue.

This debate needs to include a wide range of voices and views. Many national and international voices have yet to be heard and we urge the Committee to seek out these voices. Relevant case studies and international research can also inform this debate,

The debate needs to be open and inclusive. The Committee needs to ensure that there is a safe and effective space for people with a wide range of views to be heard. As this will impact Irish people, and in particular older people and people with a disability, their voices must be sought, and their views heard.

Other countries such as Australia, New Zealand and Canada invested in a very thorough consultation and debate process before introducing legislation on, and provisions for, Assisted Dying. We can learn from their processes and other international experiences while addressing what we need in Ireland.

We make this recommendation knowing that all sectors of Irish society have a stake in this issue and will have to work and live with the consequences. A full process of debate at this time will identify needs, issues, the range of understanding on the issue, gaps in policy and services all of which will need to be addressed, either with or without legislation regarding Assisted Dying.

Irish Hospice Foundation | Executive Summary of Submission

- As the national charity dedicated for 35 years to all matters relating to dying, death and bereavement in Ireland, Irish Hospice Foundation's mission is to work collaboratively towards ensuring the best end-of-life and bereavement care for all. Assisted Dying (voluntary euthanasia and assisted suicide) is a critical development, and if the proposed Bill is enacted, will impact on many people at the end-of-life on the island of Ireland. The proposed Bill has the potential to impact between 0.5% and 4.2% of all deaths in Ireland. An estimate based on the application of a rate of 2% to the projected number of deaths in 2030 suggest that approximately 740 people in Ireland would opt for assisted dying, equivalent to two deaths, per day. These numbers alone warrant deep consideration and discussion.
- Other countries considering Assisted Dying have underpinned their developments with a rigorous research and evidence base, alongside deep consultation with their citizens. We believe that the experience of other countries is helpful and can be usefully and carefully considered in the debate on this legislation. This now requires to happen in Ireland.
- We are not convinced that Assisted Dying as a policy issue has been adequately defined, nor that there is a clear understanding of the issue or, indeed that all of the policy issues or implications that arise as a result of legislating to permit Assisted Dying have been fully considered. Neither are we convinced that there is widespread acceptance and understanding of the need for such a Bill.
- For 35 years, Irish hospice Foundation has been informed by the hospice and palliative care movement which is to bring excellence and compassion to care at end-of-life and through bereavement. We respect that a core principle of the palliative care movement is that palliative care should neither hasten nor prolong death (Source WHO). Assisted Dying, albeit performed for compassionate reasons, will hasten death. Assisted Dying will challenge this core principle and warrants deep consideration of the implications for current healthcare, and health care providers, before proceeding.
- The debate to date on Assisted Dying in Ireland, whilst being driven by very genuine and passionate interests, has not, in our expert opinion, been robust or thorough. Many voices, both national and international, have not been heard. More worryingly, the voice of Irish people, particularly older persons (whom this Bill will impact the most) and people with a disability have not been part of robust public debate. Given the potential impact on our populations, Irish people deserve no less.
- Irish Hospice Foundation has 35 years of experience of development, research, innovation, training, education and advocacy work to improve Irish experience of dying, death and bereavement. Our research shows that people nearing end of life have real concerns regarding pain and symptom management. Older people show a strong concern about being a burden to their families. These valid and legitimate concerns need to be addressed. We strongly believe that fundamental supports for persons nearing end-of-life are not universally in place across Ireland. These supports would be required to underpin any future decision to legislate for Assisted Dying. By these supports we primarily mean equitable access to

specialist palliative care in all regions (noting 2 areas of Ireland still do not have access to a level 3 specialist palliative care unit/inpatient hospice) and equitable access to homecare supports to ensure vulnerable adults, mainly older people, can remain at home towards end of life.

- Investment in palliative care and home care will require resources and we are concerned that Assisted Dying will not in any way be seen as more ‘cost-effective’ approach to addressing the needs of those facing end-of-life.
- The proposed Dying with Dignity Bill 2020 is extremely light on detail and, were it accepted that such legislation is to be introduced, a much more comprehensive and robust Bill will need to be developed, to better protect and safeguard people on the island of Ireland against serious risks associated with Assisted Dying legislation. An indication of its brevity is that the proposed Bill amounts to 9 pages, as against the Voluntary Assisted Dying Act in the Australian State of Victoria which has 134 pages.
- IHF is also concerned about the low level of safeguards built into the legislation. If legislation to provide for Assisted Dying is enacted in Ireland, it will need to provide for a series of robust and carefully designed, carefully applied and monitored safeguards.
- The proposed Dying with Dignity Bill 2020 assumes that dignity in dying will be achieved through this Bill. In reality, it relates solely to a mechanism for dying (Assisted Dying). We contest that the title of this proposed Bill will mislead the public into assumptions that dignity in death can only be achieved through Assisted Dying. The title of the bill should more accurately be called “The Assisted Dying Bill”.
- We have also long called for the State to support citizens to think about, talk about and record their preferences for end-of-life and healthcare. This is legally strengthened by Assisted Decision Making (Capacity) Act 2015 (ADMA). However, this Bill has not yet been fully commenced. ADMA recognises that all people have equal legal rights and respects the rights of everyone to make choices for themselves, and, at all times be treated with respect and dignity. It sets out the legal framework for advanced care planning in Ireland. We contest that existing laws and mechanisms, well advanced but not yet fully complete or universally implemented, designed to enable persons record their preferences for care at end of life, and which support patient autonomy and decision making must be enacted as a matter of priority.

The following aspects of the submission have used the format as set out by the Justice committee. As such, there will be unavoidable repetition.

PART A: Policy and Legislative Analysis

The 'policy Issue' and the policy and legislative context

- 1. Define the problem/the policy issue which the Bill is designed to address; to what extent is it an issue requiring attention? What is the scale of the problem and who is affected? What is the evidence base for the Bill?**

Assisted Dying is a legal activity in a limited and growing number of countries across the world, but not in Ireland and many other countries. It is a highly complex issue. It is also highly controversial. Assisted Dying has not been high on the policy agenda in Ireland until now, and public and political debate on the issue has been extremely limited.

Legislation is one of the most important instruments that governments use to organise society and bring about a change in policy. In most countries that have considered legislative reform to permit some form of Assisted Dying, political debate and public dialogue had been ongoing over many years (see A.3). There has been limited discussion in Ireland. With the proposed Dying with Dignity Bill, 2020, currently being considered by the Oireachtas Joint Committee on Justice, having been referred to it by the Dáil, Assisted Dying has been quickly driven up the policy agenda. Demand for Assisted Dying is primarily led by those who make the argument that autonomous, capable individuals who are suffering unbearably with a terminal illness should have the right to determine the manner and timing of their death. It is thus considered and presented as a matter of personal choice and individual autonomy. While having the option of Assisted Dying at the end-of-life has been raised by people in Ireland (for example, in qualitative responses to a survey conducted by Irish Hospice Foundation (IHF) on illness, death and dying (O'Loughlin, 2017)), this cannot be taken as an indicator of broad acceptance of legislating to permit Assisted Dying in Ireland. Powerful arguments opposing Assisted Dying can also be put forward (Campbell et al., 2018; Oireachtas) such as fears about the consequences for vulnerable people, for society, and implications for the medical and other health professionals if doctors were permitted or required to actively induce death. Arguments of both those supporting the legalisation of Assisted Dying and those opposing it need to be heard and considered, as well as those who will be ultimately most affected by this policy change. Public consultation on Assisted Dying as a policy issue has been sporadic and limited in Ireland to date.

Assisted Dying as a policy issue does not stand alone. It is interconnected with other policy areas including policy on palliative care, on ageing, on decision making capacity, and on health and social care more broadly.

While the reasons for why people request Assisted Dying are complex, one of the arguments put forward in support of Assisted Dying is the alleviation of pain and suffering which is grievous and

extreme (Campbell, 2018). A survey conducted by IHF found that many people fear pain and suffering at the end-of-life and the potential impact that this will have on them and on their family. The loss of control and capacity to engage in activities as a result of illness also features a concern for people facing life limiting illness. Therefore, of tremendous importance to people as they consider living with an advanced illness and approaching end-of-life, is access to adequate pain relief, that pain is well controlled and, ideally, they die pain free.

Whilst we know that fear of pain is one of the common reasons for making a request for Assisted Dying, IHF and other research demonstrates that this fear is partly grounded in poor public understanding of modern pain management, cause of death or service provision.

The fear of pain and understanding of how pain will be managed highlights the important role for palliative care in pain management when caring for terminally ill patients as an alternative to Assisted Dying. The role of palliative care both as a key element in the relief of pain and suffering and as an alternative to Assisted Dying has not been adequately addressed in the Irish context, but is critical to the debate, given that palliative care services are not yet comprehensively provided across the country.

Another important concern for people requesting Assisted Dying is that they do not want to be a burden on their family. A systematic review revealed that ‘self-perceived burden’ is reported as a significant problem by between 19% and 65% of all terminally ill patients (McPharson et al., 2007). This finding was strongly echoed by the public in the IHF 2016 ‘Have your Say’ Survey. (IHF 2016, Have Your Say). Self-perceived burden has been clearly identified as a relevant factor in assisted dying among patients with life-threatening illness. The concern of being a burden to families is a legitimate concern, but raises a question, both for the individual and society, as to whether Assisted Dying is an appropriate response to ‘being a burden’. This question has not been the subject of considered policy debate in the Irish context. This discussion is vitally important, given that care to older people, who make up the majority of those opting for assisted dying, is based primarily on a family system of care and that Home Support in Ireland is underdeveloped, under-resourced and fragmented. For example, a statutory homecare scheme, discussed for many years, is not yet in place. Furthermore, the Covid-19 pandemic has highlighted again the damaging outcomes for older people of ageist strategies and discourses (Walsh, 2020).

Because a person requesting Assisted Dying has to have decision-making capacity, the Bill is closely related to the Assisted Decision Making (Capacity) Act 2015 (ADMA), which, although not yet been fully commenced, recognises that all people have equal legal rights and respects the rights of everyone to make choices for themselves and at all times be treated with respect and dignity. It sets out the legal framework for advanced care planning in Ireland. The enactment of this legislation has been seriously protracted and delayed and this is of huge and growing concern.

In 2018 there were 31,140 deaths in Ireland. This number is expected to grow in the coming years and is projected to reach approximately 37,000 in ten years’ time. The number of people affected, if the proposed Bill were to be enacted in Ireland, will depend on a number of factors,

including how restrictive or permissive the legislation is. There is no consensus on what, if any, is an acceptable death rate from Assisted Dying. Death rates due to Assisted Dying tend to be higher in those jurisdictions that permit both voluntary euthanasia and assisted suicide (as proposed in the Dying with Dignity Bill 2020). For example, in Oregon, where assisted suicide only is permitted, deaths due to Assisted Dying are relatively low (0.5% of all deaths) compared to the Netherlands (4.2%) where both voluntary euthanasia and assisted suicide are permitted and which has broader eligibility criteria. An estimate based on the application of a rate of 2% (as in Canada which permits both voluntary euthanasia and assisted suicide since 2016) to the projected number of deaths in 2030 suggest that approximately 740 people in Ireland would opt for assisted dying, equivalent to two deaths due to Assisted Dying per day. This is a crude estimate and needs to be treated with utmost caution. It does not take into account the number of people resident in Northern Ireland who may opt for Assisted Dying in the Republic of Ireland.

Adults over 18 years of age on the Island of Ireland who are terminally ill and have decision-making capacity will be most directly affected by the proposed Bill. In countries where it is permitted, both men and women avail of Assisted Dying in close to equal proportions. In these countries, most people who avail of Assisted Dying are older people (aged 65 years and over). In Canada, for example, 80% of Medical Aid in Dying cases occur at 65 years and over, which is consistent with other jurisdictions. In this sense, Assisted Dying is age related – for this reason alone, considered consultation with older persons and the organisations who work with older persons needs to be considered.

Assisted Dying is a complex decision, and family members may be involved and will be affected. However, family experiences of Assisted Dying are under-researched and often not considered in the development of legislation or guidelines on Assisted Dying (Gamondi et al., 2019). Impact on bereavement is difficult to discern and even where positive outcomes are recorded, these could be accounted for by the open communication process, planning and support as opposed to the actual Assisted Dying. Literature is clear that bereavement support is generally poor and those who have been bereaved through Assisted Dying may be doubly impacted by not wishing to reveal the manner of death to potential supporters (Gamondi et al 2019).

Registered medical practitioners, registered nurses, and members of any health and social care profession are identified in the proposed Bill and will be affected. These professionals work in all care settings – in primary care, community care, paramedical and ambulance services, acute hospitals, long-stay residential care settings, and hospices. With respect to medication management, pharmacists too will be affected, although they are not referred to in the Bill. Those medical practitioners, nurses, pharmacists and health and social care professionals who work in a variety of settings who will be affected need to be consulted and their views considered as part of implementation.

Our review of international literature shows that where patients have a choice between voluntary euthanasia (physician supported death) and assisted suicide (patient self-administers lethal dose), most opt for the former. Assisted suicide is what is proposed under the Dying with Dignity Bill, 2020,

As noted earlier, IHF research demonstrates there is a very mixed public understanding on the extent of pain and suffering at end of life. Undoubtedly, and notwithstanding the provision of excellent palliative care, a small proportion of people suffer unbearably as illness progresses. This highlights the dilemma in balancing the rights of an individual and the rights of society and potential harm to others. Further work is required to understand the extent and nature of pain control at end of life. In considering legislative reform in this area, it needs to be borne in mind that the notion of an evidence base is problematic when it comes to assisted dying; it is an expanding area of practice and frequently informed by polarised opinion (Campbell, 2018).

We are not convinced that Assisted Dying as a policy issue has been adequately defined. We are not convinced that there is a clear understanding of the issue or that all of the policy issues or implications that arise as a result of legislating to permit Assisted Dying have yet been fully considered. We are uncertain regarding the level of widespread acceptance of the need for such a Bill.

2. What is the current policy and legislative context, including are there any proposed Government Bills or general schemes designed to address the issue? Have there been previous attempts to address the issue via legislation?

In Ireland, in 1993, the Criminal Law (Suicide) Act 1993 decriminalised suicide. However, the act of “aiding, abetting, counselling or procuring” the suicide of another person remains a criminal offence and carries a maximum penalty of 14 years in prison (Campbell, 2018). Patients do have the right to refuse life-sustaining treatment. In Ireland, as in other jurisdictions, the law banning Assisted Dying has been subject to legal challenge and legal cases, and these form part of the legal context in Ireland relating to assisted dying. A case brought by Marie Fleming challenging the prohibition of Assisted Dying came before the courts in 2012. It was dismissed by the High Court in January 2013, and an appeal was dismissed by the Supreme Court later that year (Campbell, 2018). However, the Supreme Court made it clear that the Oireachtas is not precluded by the Constitution from legislating to decriminalise Assisted Dying in limited circumstances, and subject to appropriate safeguards. A legal case to come before the courts in 2014 related to the prosecution of Gail O’Rorke for allegedly assisting/attempting to assist her friend to die. She was found not guilty on three charges.

Politically, there have also been developments. A Private Members’ Bill, the Dying with Dignity Bill 2015, proposing to legislate for Assisted Dying, was introduced by John Halligan, TD, to the Dáil in November 2015, but did not advance through the legislative process at that time. As part of its Work Programme for 2017, the Joint Committee identified the Right to Die with Dignity as a priority issue for consideration and during November 2017, the Joint Committee examined the issue and reported in 2018 (Oireachtas Joint Committee on Justice and Equality, 2018). In this report the Committee stated that Assisted Dying was an important subject that would benefit from detailed consideration of the issues involved, given the gravity of the debate. They recommended “as rigorous an examination of the proposal as possible”.

A second, Dying with Dignity Bill 2020, also a Private Members’ Bill, was tabled by Gino Kelly, TD, in September 2020. TDs voted to send the Bill to committee stage. This Private Members’

Bill has not been subject to the appropriate scrutiny, as recommended by the Oireachtas Joint Committee on Justice (2018).

Irish Hospice Foundation (IHF) has consistently expressed concern that debate on the Dying with Dignity Bill, 2020, has been rushed and incomplete, and we have called for a robust and balanced debate on the issue of assisted dying.

3. Is there a wider EU/international context?

Assisted Dying is hotly debated and contested across the world. The issues are challenging and are medically, legally, politically, ethically and culturally complex.

There is a limited but growing number of jurisdictions across the world where Assisted Dying is permitted. Switzerland and a number of US states allow assisted suicide. Assisted Dying (i.e., both voluntary euthanasia and assisted suicide, as proposed in the Dying with Dignity Bill, 2020) are currently permitted in a small number of European countries (the Netherlands, Belgium and Luxembourg), and in Canada, Colombia and the Australian State of Victoria. It will be permitted in Western Australia and New Zealand by the end of 2021. The legislative framework for Assisted Dying varies considerably among these jurisdictions, as does the historical, political, social and cultural contexts.

Eligibility criteria (e.g., age, citizenship and residency, illness and other circumstances, and decision-making capacity) vary considerably by jurisdiction. A range of safeguards are commonly built into legislative frameworks, but these vary widely by jurisdiction. The States of Victoria and Western Australia which have recently or are in the process of introducing legislation to permit Assisted Dying have a relatively high number of safeguards in legislation.

Some countries such as the UK has maintained a firm stance against legislating for Assisted Dying. The issue is under review in several other European countries. In Finland, the view is that it is only possible to genuinely assess the actual need for legislative changes permitting Assisted Dying after palliative and terminal care services have been comprehensively put into practice. An Expert Working Group was established in Finland in 2018 to examine regulatory needs concerning end-of-life care and patients' right to self-determination including terminal care and euthanasia. The work of the Expert Working Group is ongoing but is expected to complete by mid-2021. Comparable work has not been undertaken in the Irish context.

Belgium offers an example of a country where legalisation of Assisted Dying was enacted quite quickly. However, in most countries Assisted Dying has been the subject of much political debate and public dialogue for many years before legislative reform. New Zealand, where a referendum was held on Assisted Dying in October 2020, and Canada, which introduced legislation in 2016, offer examples. In the development of Canada's legislation on medical aid on dying, there was a period of extensive study including a close examination by the federal government of international regimes. There was also a period of extensive public consultation on the issue of Assisted Dying before the introduction of legislation on medical aid in dying in 2016 (Health Canada, 2020).

In New Zealand, to fully investigate public attitudes, the Parliament's Health Committee sought written submissions from the public between August 2015 and February 2016. It also held oral hearings. The written submission and oral hearing process were considered to be important as it provided a platform for people to share their views and discuss the issues with the Health Committee. The Committee received more than 21,000 unique submissions from individuals and organisations. It also held oral hearings and heard from 944 submitters at meetings in Auckland, Wellington and Christchurch or by teleconference. There were over 108 hours of hearings. The Health Committee prepared a detailed report to summarise what they heard (NZ Health Committee, 2017). In addition, over 35,000 submissions were made to the Justice Committee. Parliamentarians on the Justice Committee visited 14 cities to hear views. There were over 2,000 oral submissions. The Justice Committee, which holds diverse views, reported in April 2019.

We believe that the experience of other countries is helpful and can be usefully and carefully considered in the debate on this legislation. It is clear from the examples above that deep consultation and reflection is shaping the development of Assisted Dying in other countries.

Implications and implementation of the Bill's proposals

Policy implications/implementation

4. How is the approach taken in the Bill likely to best address the policy issue?

Assisted Dying is a highly complex issue and there is no consensus as to how best to address this policy issue in Ireland or internationally. Both voluntary euthanasia and assisted suicide are currently illegal under Irish law. As the Oireachtas Joint Committee on Justice and Equality (2018) pointed out, maintaining the current law as it stands is one course for the future in Ireland, and another possibility is the enactment of legislation to allow for some form of assisted dying. If legislation on Assisted Dying is to be enacted in Ireland, other questions need to be considered. What should this legislation look like? What are the ethical, social, legal and policy implications of enacting such legislation?

In most other countries that have debated the issue (both those who have and have not introduced legislative reform in this area), the topic has been the subject of political debate and public dialogue for many years before legislative reform, and the debate has been extensive and inclusive. We have not had an adequate debate here yet.

Neither the future direction that Ireland should take, the form that legislation could take nor the policy implications or implementation of the legislation have been fully considered or debated in Ireland.

IHF believes that Assisted Dying as a policy issue has yet been sufficiently defined and it would be unethical and mistaken to take a definitive legislative solution at this point in time.

We believe that an issue as complex and as fundamental to humanity as Assisted Dying needs a full and proper debate with all perspectives. There is much to be learned from other countries

with respect to how closely the issue needs to be examined due to inherent complexities and the approaches that can be taken for an extensive and inclusive debate and dialogue. A similar process in Ireland might include;

- Extensive public consultation and listening through variety of formats – e.g. citizens assembly or other such vehicle,
- Expert opinion sought – both nationally and internationally,
- Formalised debate to develop thinking and inform legislators,
- Formal research and benchmarking of public understanding and attitude towards Assisted Dying and related matters,
- Clarification on timelines for implementation of existing policy commitments - palliative care, statutory homecare and Assisted Decision Making (Capacity) Act 2015 as examples.

Polls of the general public, as reported periodically in media in Ireland, suggests a majority of people (research below) are in favour of legalising Assisted Dying. However, we contend that this public attitudinal survey work alone is not sufficient – a subject as complex as Assisted Dying, when explored leads to questions around people’s fears and concerns at end-of-life – fear and concerns we contend are not yet addressed in Ireland.

The experience of Covid-19 for example uncovered the inadequacy of home care supports which enable people remain in their own homes as they age. Most people in Ireland wish to die at home. Inadequate home care is a very real issue in Ireland and needs to be addressed urgently. Burden is a strong theme when looking at reasons why people do not want to continue living. Is it right that a person will request Assisted Dying for the sole reason that adequate Home Support is not available to enable the person to live the end of their life at home, or, that the person does not wish to be a burden on his/her family? It begs the question: What should be the compassionate response to a person who feels they are a burden?

This fear of being a burden is a real concern – raising issues such as the rights of frail and vulnerable people to supports and assistance without fear. It certainly points to the need for more supports to allow people remain at home, more supports for carers and more community services to support this care. There is a plan to develop a statutory Home Support scheme for many years. Progress on this plan has been further hampered by Covid-19 pandemic and there is no clear timeline for the introduction of this scheme.

For the majority of people facing end of life, comprehensive palliative and end-of-life care is a person-centred and compassionate way of ensuring holistic care for those with life-limiting illness. While it cannot always guarantee complete freedom from all distress at the end of life, it is proven to greatly improve the quality of life of patients facing life-limiting illness and their families. Well-organised hospice and palliative care services respond to complex needs, facilitate a trusting environment and provide dignity and respect for those facing death and their families. However, there remain huge gaps in palliative and end-of-life care in Ireland – which must be

funded and guaranteed as an option to everyone in Ireland – even today two areas of the country do not have an inpatient specialist palliative care unit. It follows that an urgent priority in Ireland is to ensure end-of-life & palliative care services that are properly resourced and widely available.

Why people opt for Assisted Dying is complex, but a common concern is pain at end-of-life – there is a real fear among Irish people, which we believe, is partly responsible for driving debate on Assisted Dying. We must respond to the fears of the public and provide assurances that;

1. They will receive good end-of-life care regardless of their illness.
2. They have local access to palliative care.
3. Their relatives will get the support they need.
4. They understand what palliative and end-of-life care can provide.
5. They are assured that Health care professionals are trained in end-of-life care – IHF has been at the forefront of advocating in this area for 35 years.

Assisted Dying runs counter to a central principle underpinning the practice of palliative care, which is that death should neither be hastened nor postponed. Research from countries that permit Assisted Dying shows that palliative care and Assisted Dying are inextricably linked, but the relationship is complex. It shows that the relationship between Assisted Dying and palliative care is variable ranging from supportive to conflicted, but little is known about how this plays out at a practice level (Gerson et al., 2020), how it impacts on service provision and how investment in Assisted Dying services impacts the investment in palliative and care at end of life.

Irish Governments have successfully invested in the expansion of palliative care across Ireland. This is to be commended. Within Ireland, the palliative care movement remains ideologically (in the main) opposed to the practice of Assisted Dying and it would be likely to be the main source of conscientious objectors. If the proposed Bill were to be enacted, it will undoubtedly pose challenges for palliative care at the policy and practice level, as guidance and oversight will be needed (Gerson et al., 2020), and this clinical guidance will need to be produced. These challenges will likely be exacerbated if prior consideration is not given to the complex relationship between Assisted Dying and palliative care.

5. What alternative and/or additional policy, legislative and non-legislative approaches were considered, including those proposed by the Government and what, does the evidence suggest, are the differences between and the merits of each?

Alternative or additional policy, legislative and non-legislative approaches have not been considered. Maintaining the current law as it stands is one course for the future in Ireland, and this has not been adequately considered, even though there are many countries / jurisdictions that have chosen not to introduce legislation to permit assisted dying. As discussed in Section A.3,

jurisdictions that have introduced Assisted Dying have introduced different forms, and the legislative framework in these such countries differs substantially. The extent to which legislative frameworks and lessons from other countries has informed the development of the proposed Bill is not evident.

Moreover, in stark contrast to most other jurisdictions, a comprehensive debate on this issue has not taken place in Ireland on the merits of the different approaches that could potentially be taken.

Key to any debate on Assisted Dying are the arrangements in place for palliative care and terminal care, and, as Assisted Dying is age related, policy on ageing. Yet, the Dying with Dignity Bill 2020 has been proposed without any reference to or discussion of Ireland's health and social care system, national policy on palliative care, or policy on ageing. There has been no consideration given to how Assisted Dying inextricably links with palliative care services or indeed the wider health and social care system, or how Assisted Dying stands in relation to ongoing developments and resourcing of palliative care and wider health and social care services. The context, (e.g., lack of progress on implementing a national policy on palliative care, the development of a statutory Home Support scheme) is important and needs to be considered. In contrast, in Finland, the Ministry of Social Affairs and Health has stated that palliative and terminal care services must be comprehensively put into practice, as it is only then that the actual need for legislative changes permitting Assisted Dying can be genuinely assessed.

There has been no consideration of the Assisted Decision-making (Capacity) Act, 2015, as discussed in more detail in section A.6.

6. Are there Government-sponsored Bills (or General Schemes) which are related to and/or broadly aim to address the same issue? Are there merits in combining them?

The proposed Bill deals specifically with the current law on Assisted Dying and there are no related Government-sponsored Bills which broadly aim to address the issue of Assisted Dying.

However, it is vital that the Dying with Dignity Bill 2020 is considered in the context of relevant legislation such as the Assisted Decision-Making (Capacity) Act, 2015 (ADMA), which has not yet been fully commenced. While the ADMA is highly relevant, there is no reference to it in the proposed Bill. Consideration of the ADMA is particularly important as Ireland is among a few countries internationally that has moved to provide support for the exercise of legal capacity based on the individual's 'rights, will and preferences' (Flynn, 2018), and because assessment of decision-making capacity is a fundamental provision in the proposed Bill. The implications need to be thoroughly considered.

The ADMA provides a legal framework for Advance Healthcare Directives in Ireland. In some countries, such as the Netherlands and Belgium, an individual may write an advance healthcare directive outlining the circumstances in which they would want Assisted Dying to be performed, meaning that they need not have capacity to make the decision at the time of their death (Nicol

and Tiedemann, 2015). There is no reference to Advance Healthcare Directives in the proposed Bill or whether or not consent to Assisted Dying through an Advance Healthcare Directive is applicable. Neither has the role of assisted decision makers been addressed (we feel there is no role for Assisted Decision Makers). The proposed Bill would need to reflect a determination whether or not an Advance Healthcare Directive is applicable in this area, and also given the broader legislative framework of the ADMA Bill, whether there is a role for assisted decision makers in this area. In the Province of British Columbia, where the Representation Agreement Act provides for supported decision-making (Flynn, 2018), and where Assisted Dying has been permitted since 2016, consent through an alternate or substitute decision maker or through a personal advance directive is not applicable.

If the proposed Bill is to be enacted, it is essential that it is consistent and cross-referenced with the ADMA.

In addition, we would question the practicality and functionality of enacting the proposed Bill, when the ADMA has not yet been fully commenced. The current legislation dates back to the 1781 Lunacy Act. The ADMA is a highly important piece of legislation, and which though not yet fully enacted, has already impacted in terms of clinical practice, and the commencement of a programme of activity to underpin its enactment. It needs however to be completely resourced and implemented.

Advance care planning that involves a refusal of life-sustaining treatment is distinct from Assisted Dying. IHF programme ‘Think Ahead’ provides tools that support advance planning for end of life. Support at state level for initiatives, such as Think Ahead programme, that facilitate better conversations on end-of-life, need to be provided.

7. What are the specific policy implications of each proposal contained within the Bill (environmental / economic / social / legal)? Has an impact assessment (environmental / economic / social / legal) been published (by Government or a third party) in respect of each proposal contained within the Bill?

The proposed Dying with Dignity Bill 2020 in its entirety will have profound policy and other implications for Irish society.

The title of the Bill - Dying with Dignity – implies that Assisted Dying is the only or a better way to die with dignity. It undermines the work of IHF (and many others) over the past 35 years in developing services across all settings to ensure people can die with dignity, whether at home, Hospice or in hospital. The title of the Bill should accurately reflect what is proposed in the Bill and should be called “The Assisted Dying Bill”.

IHF’s overall observation is that the Bill is brief and short on detail. An indication of its brevity is that the proposed Bill amounts to 9 pages, as against the Voluntary Assisted Dying Act in the Australian State of Victoria which has 134 pages. We are also concerned about the low level of safeguards built into the legislation. If legislation to provide for Assisted Dying is enacted in Ireland, it will need to provide for a series of robust and carefully designed, carefully applied and monitored safeguards.

Section 11(2) c. provides that ‘in the case that it is not possible for a patient to self-administer the substance [to end their life], then the substance or substances may be administered’. There is potential for confusion within the Bill as it seeks, in this section, to legalise both voluntary euthanasia (medically administered) as well as assisted suicide/dying (self-administered). Based on IHF review of other jurisdictions, each will require separate consideration, processes and safeguards. We note that legislating for euthanasia was not endorsed by the Supreme Court in the Marie Fleming case.

Some specific implications of provisions contained within the proposed Bill are set out below.

Qualifying persons: Citizenship and eligibility – The proposed Dying with Dignity Bill 2020 states that a person must be resident on the island of Ireland. It is not clear if this is potentially open to residents of Northern Ireland.

It would be helpful and necessary to explore with medical practitioners in Ireland how a probable requirement to know a patient well before administering support for Assisted Dying could be assured in practice.

Definition of terminal illness: Section 7 of the proposed Dying with Dignity Bill, 2020 states that a person is a qualifying person if the person is terminally ill. Under Section 8 of the Irish Dignity with Dying Bill, 2020, a person is terminally ill if that person –

(a) has been diagnosed by a 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; and

(b) treatment which only relieves the symptoms of an inevitably progressive condition temporarily is not to be regarded for the purposes of paragraph (a) as treatment which can reverse that condition.

In comparison to legislation in some other jurisdictions such as in the US states and New Zealand, the definition of terminal illness in the proposed Bill is much broader, as the person does not have to be nearing death, does not have to have significant and ongoing decline in physical capability and does not have to be experiencing unbearable or intolerable suffering. This definition is too broad and unsafe. People with conditions such as motor neurone disease, multiple sclerosis and dementia that are not imminently terminal would potentially be eligible under the definition of terminal illness under the proposed Bill. It is not clear if this was the intention when the Bill was drafted. We suggest in-depth consultation with medical professionals and the public on this aspect. In addition, despite the prevalence of treatable depression in patients with serious illness, the Bill does not require a mental health assessment.

Finally, we have seen how difficult a definition of ‘terminally ill’ is when used in the administration of medical cards for terminally ill – in recent years, access to medical cards has been inconsistent using this same floating definition of ‘terminally ill’ – and we have noted that medical card eligibility has been withdrawn and the ‘terminally ill’ status revoked in practice.

Assessment of capacity: Under the proposed Dying with Dignity Bill, 2020, a person must have the capacity to make the decision to end his or her own life. Under Section 10 of the Bill, the approach taken to the assessment of a person's capacity to make the decision is based on a functional test of capacity, which requires the person to demonstrate they can understand, retain, use and weigh information in order to make the decision, and can communicate the decision to others. The assessment of capacity for a person requesting assisted dying is to be undertaken by two medical practitioners independently. Where a person is unable to complete one of these tasks in respect of the decision, she or he will be deemed to lack the capacity to make the decision, and as a consequence, his or her legal capacity to make the decision will be denied. The Bill requires that the attending doctor and an independent doctor are satisfied that the person has decision-making capacity. Reliable and consistent capacity evaluation in healthcare is complex and remains poor. Section 10 of the Bill does not provide for a robust system of assessment or recording of decision-making capacity. By contrast, the ADMA legislation highlights the importance and value of the input of a Doctor who has the benefit of a long-term relationship and knowledge of the individual, and values the perspective provided by continuity of care in terms of evaluating capacity, and documenting decisions discussed and taken by the individual over time.

There are many problems associated with capacity for decision-making in legislation on assisted dying (Price et al., 2014). The application of any definition of capacity in clinical practice is unclear and a number of difficulties arise including assessing and operationalising how a person uses and weighs information and how affective states impact on capacity. Determining capacity, it has been argued, is value-laden, and there may be a broad range of opinions about whether or not a person has capacity to make the decisions. Setting thresholds for capacity is not straightforward. Price et al. (2014) found that experts contributing to the Commission on Assisted Dying in the UK, including those supportive of assisted dying, unanimously agreed that mental capacity should be included as a safeguard in any legislation on assisted dying. Nevertheless, the authors found that, as capacity occurs along a spectrum, there are different conceptualisations of capacity. The boundaries between mental state and mental capacity can be blurred and it is not clear how depression might impact on decision-making capacity. The interface of capacity with other areas that might have a bearing upon its determination, particularly motivation, voluntariness, autonomy, rationality, was also blurred (Price et al., 2014). As Price et al. (2014) point out, such challenges are not unique to the Assisted Dying situation. These complex issues have not been teased out in the Irish context.

Assistance in dying: Under Section 11(3)(c) of the 2020 Bill, patients only have to request Assisted Dying once before being granted access to the necessary drugs; the drugs can be delivered after a period of not less than 14 days has elapsed since the day on which the declaration took effect. This proposition is much laxer than in any other jurisdiction.

The processes set out under the proposed Bill for assistance in dying are weak and lack detail. Furthermore, there has been no discussion or debate about the implications for medical practitioners, nurses or other health and social care professionals who will be tasked with implementing the Bill. These implications require to be considered as part of developing the

proposed legislation, in a manner similar to that evident in establishing Termination of Pregnancy services, where the right to conscientious objection in actively participating in termination of pregnancy is respected, concurrent with a universal professional obligation to signpost the patient to practitioners or services where they can be supported in accessing service. These principals are clearly communicated and upheld by the Medical Council of Ireland and are applicable to all registered medical practitioners as a condition of their practice.

Conscientious objection: Under the proposed Bill, there is no obligation for any medical practitioner or assisting healthcare professional to participate in anything authorised by the legislation on Assisted Dying to which he or she has a conscientious objection. However, there is a condition that a person who has a conscientious objection ‘shall make such arrangements for the transfer of care of the qualifying person concerned as may be necessary to enable the qualifying person to avail of assistance in ending his or her life in accordance with this Act’. Legislative conditions attached to conscientious objection to Assisted Dying vary by jurisdiction. For example, in the Australian State of Victoria, there is strong protection in the legislation for health practitioners with a conscientious objection to voluntary assisted dying, and there is no requirement for health professionals with a conscientious objection to voluntary Assisted Dying to refer patients on to a willing practitioner (McDougall and Pratt, 2020). In Western Australia, the objector has an obligation to give patients some basic information about their options. In Ireland, there has been no debate as to whether or not conditions should be attached or what these conditions should be.

Obligation to keep and provide records: Under the proposed Bill, there is an obligation to keep and provide records. However, there are no details on what information will be in the records and there doesn't seem to be a provision for the establishment of a register. Across different jurisdictions, it is most common for reporting to take place after the final act has taken place, as in the proposed Bill. However, in some jurisdictions, reporting must take place at various specified points, e.g., when a formal, written request is made; after the first/second assessment; when medication is dispensed. For example, in Canada, under the Regulations for the Monitoring of MAID, physicians and nurse practitioners are required to report on all written requests for MAID, even if the request does not result in the administration of MAID. Pharmacists are required to report on the preparation and dispensing of substances in connection with the provision of MAID. Practitioners are required to provide other information such as basic sociodemographic information about the person requesting MAID; on the assessment of the request and whether eligibility requirements were met; information about procedural safeguards if MAID was provided; and information as to why a request may have gone unfulfilled (Health Canada, 2020). Some jurisdictions have an extremely detailed notification process. For example, in some US states and Victoria, reporting forms are set out in the legislation.

Establishment of Assisted Dying Act Review Committee: We have specific concerns that the review process as outlined in the proposed Bill is weak. The 2020 Bill proposes a Review Committee but does not give it any statutory powers beyond receipt of notifications of assisted dying. It has no powers in terms of scrutiny, oversight or investigation.

As far as we are aware, an impact assessment (social, legal, ethical, cultural, economic) has not as yet been published by Government or a third party in respect of each proposal contained within the Bill.

8. Could the Bill, as drafted, have unintended policy consequences, if enacted?

The proposed Bill will have unintended policy consequences, if enacted. However, without a detailed examination of all of the issues that arise, and until there is a full and informed debate and thorough exploration of the Bill, it is difficult to provide a full list of the unintended policy consequences. Specific concerns we have are as follows:

In jurisdictions where some form of Assisted Dying is permitted, there has been a steady increase in the number of people availing of the option over time, and it can be expected that this will be the trend in Ireland, if the Bill is enacted. Factors contributing to the growth in numbers include greater acceptability among the public, greater awareness, greater demand, less reluctance among physicians, and population ageing.

If enacted, the proposed Bill will shift the boundaries of what is permissible in Ireland. It is possible that the boundaries will shift again in the future, as jurisdictions that have introduced Assisted Dying show that legislation in this area, as in many others, does not always remain constant over time. Eligibility criteria are subject to extensive debate and have proven to be controversial and may change over time, e.g. – extension of eligibility to different age groups, illness and other conditions.

The Bill does not contain meaningful or adequate safeguards. The Oireachtas Joint Committee report (2018) made clear that any legislation for Assisted Dying would require adequate safeguards to ensure requests were not being made out of compulsion or reduced decision-making capacity. Safeguards, like eligibility criteria, are subject to extensive debate and have proven to be controversial. It has been argued that some provisions framed as ‘safeguards’ in legislation on Assisted Dying have substantial consequences for equal access (McDougall and Pratt, 2020) and the law may be challenged on this in the future.

Opponents of Assisted Dying argue vigorously that extension of Assisted Dying to non-terminally ill people would expose vulnerable populations. As well as people with chronic rather than terminal illnesses, vulnerable groups frequently referred to include older people; children; people with disabilities; people with dementia; people with illnesses that are stigmatised e.g., AIDS; people who are disadvantaged and/or do not have access to good medical care; and people in minority groups who have experienced discrimination. The consequences for vulnerable groups such as these are a major concern and adequate safeguards are required.

The concept of conscientious objection is commonly built into legislation as a safeguard for health professionals and is provided for under the proposed Bill. However, the law to protect physicians could be challenged and leave practitioners exposed, especially those with a conscientious objection to assisted dying.

Concerns exist that enactment of the proposed Bill will pose challenges for palliative care at the policy level, with regard to the development of guidelines and at a practice level. The limited evidence from other countries suggests that subtle dilemmas, uncertainties and variable practices are likely to emerge. The proposed Bill, if enacted, raises many questions. Gerson et al. (2020) have identified the following questions: How does a person-centred multidisciplinary palliative care team-work with patients who have voiced an interest in opting for assisted dying? What happens when a palliative care team wants to support a patient in their decision to choose an assisted death and then come into conflict with an institutional policy or practice that objects to Assisted Dying as an option? What happens if evidence emerges suggesting that palliative care does work in conjunction with Assisted Dying once legislation has shifted the boundaries of what is permissible? What happens in a practical sense when a patient who is receiving palliative care then opts for assisted dying, or alternatively, how might those choosing Assisted Dying then receive palliative care?

9. Has the Committee taken due consideration of the opinion of the European Central Bank (ECB) on the Bill, if applicable?

Not applicable

10. How would the Bill, if enacted, be implemented?

The Dignity with Dying Bill 2020 is lacking on detail with respect to implementation. This is of great concern. There are no details in the Bill with respect to who is responsible for implementing the Bill. The proposed Bill provides for the establishment of an Assisted Dying Review Committee. However, there are no further details in the proposed Bill about the composition, role or responsibilities of the Assisted Dying Review Committee. The lack of detail in the proposed Bill contrasts greatly with legislation proposed or enacted in other jurisdictions such as the Australian States of Western Australia and Victoria.

No guidance has been developed for the implementation of Assisted Dying in Ireland.

11. Are there appropriate performance indicators which the Department, or whoever is ultimately charged with implementing the Bill, can use to assess the extent to which it meets its objective? Does it include formal review mechanisms?

There are no details in the Bill with respect to who is responsible for implementing the Bill. The proposed Dying with Dignity Bill, 2020, provides for the establishment of an Assisted Dying Review Committee. Details in the proposed Bill about the Assisted Dying Review Committee, regarding its composition, functions and what responsibilities it will have with respect to monitoring Assisted Dying in Ireland are absent. The proposed Bill does not yet include details with respect to a review process or review mechanisms, or indeed what other authorities will need to be involved. Under Section 14 of the proposed Bill, the attending medical practitioner is obliged to keep and provide records, there is yet no reference to health services and the collection of data and information to measure performance in relation to assisted dying.

Review committees have been established in many jurisdictions that permit Assisted Dying and other authorities are also often involved in the process. For example, in the Netherlands, as well as the medical practitioner who performs assisted dying, the review process involves the municipal pathologist and regional euthanasia review committees. Where due care criteria are not complied with, the Board of Procurators General and the Health Care Inspectorate will become involved and the Regional Healthcare Disciplinary Boards or the Public Prosecutors and the Criminal Court may become involved.¹ A Euthanasia Code outlining how the review process works in practice was first published in 2015 and was updated in 2018. It is primarily targeted at physicians who perform Assisted Dying and independent physicians (RTE, 2018). In Canada, oversight varies by provinces, and includes review committees, the Chief Coroner's Office and professional regulatory bodies. In Victoria, the Voluntary Assisted Dying Review Board has been established as the oversight committee. Its functions, powers, memberships, and procedures are set down in the legislation on VAD, as well as requests by the Board for information, referrals of information etc.

Cost evaluation

12. Will there be enforcement or compliance costs?

Yes, there will be enforcement and compliance costs.

There would need to be assurance that progressive funding for homecare, older person's care or indeed the national palliative care budget are separate from this funding. Funding for palliative care services should not be contingent on providing this service.

13. What are the likely financial costs of implementing the proposals in the Bill, and what is the likely overall fiscal impact on the exchequer?

Section 4 of the proposed Bill states that: 'The expenses incurred by the Minister in the administration of this Act shall, to such extent as may be sanctioned by the Minister for Public Expenditure and Reform, be paid out of moneys provided by the Oireachtas'. However, it is beyond our scope or expertise to estimate the likely financial costs of implementing the proposals in the Bill, or the likely overall fiscal impact on the exchequer.

14. Have cost-benefit analyses (CBA) been provided/published (by Government or a third party) in respect of each proposal contained within the Bill? Will benefits/costs impact on some groups/stakeholders more than others?

As far as we are aware, a CBA has not been provided/published (by Government or a third party) in respect of each proposal contained within the Bill.

¹ <https://english.euthanasiecommissie.nl/review-procedure>

PART B - Legal Analysis

Please note: Irish Hospice foundation is not expert in legal matters and our commentary is provided in good faith.

15. Is the draft PMB compatible with the Constitution (including the ‘principles and policies’ test)?

We advise that the Committee seeks advice from constitutional law experts.

16. Is the draft PMB compatible with EU legislation and human rights legislation (ECHR)?

We advise that the Committee seeks advice from human rights / EDHR law experts.

17. Is there ambiguity in the drafting which could lead to the legislation not achieving its objectives and/or to case law down the line?

Yes, there is ambiguity in the drafting. We have several examples:

Terminology

If enacted, the Bill will be cited as the Dying with Dignity Act, 2020. This title implies that Assisted Dying is the only or a better way to die with dignity. It implies that certain terminal illness conditions are such that palliative treatment is not sufficient to ensure a death with dignity and that therefore voluntary euthanasia and assisted suicide should be used. The title of the Bill undermines the work of IHF (and many others) over the past 35 years in developing services across all settings to ensure people can die with dignity, whether at home, Hospice or in hospital. Moreover, the Bill advocates both assisted suicide and voluntary euthanasia, but neither of these terms are referred to anywhere in the Bill. The title of the Bill should accurately reflect what is proposed in the Bill. It should be called “The Assisted Dying Bill”.

The key voluntary euthanasia and assisted suicide are explained here.

The term *Euthanasia* is used when steps are deliberately taken with the intention of ending a person’s life. A distinction can be made between voluntary and non-voluntary euthanasia. *Voluntary euthanasia* describes a situation where a lethal substance is directly administered to an individual at that person’s request (Campbell et al., 2018; Dyer et al., 2015). *Assisted suicide* is ‘the act of intentionally providing another person with the knowledge or means to end his or her life, at his or her request’ (Campbell, 2018). The main distinction that is usually made between euthanasia and assisted suicide is with regard to who performs the final, fatal act, the individual themselves or someone other than the individual. In euthanasia, the final act is undertaken by someone other than the individual, e.g., a doctor who administers a lethal substance intended to end the person’s life. In assisted suicide, a lethal substance is prescribed to be voluntarily ingested by the person. The Bill allows for both voluntary euthanasia (PAS) and assisted suicide (self-administered, requiring capacity to take medication). Most countries differentiate between these

two methodologies as one is self-administered and the other (euthanasia) is administered by an external professional (usually a doctor). By necessity, both require different controls and administration.

The terms *Assisted Dying* or *assisted death* are also commonly used. They are used to refer to both kinds of action, i.e., euthanasia (usually voluntary euthanasia), and assisted suicide. According to Campbell (2018), the use of terms such as Assisted Dying or assisted death is usually driven by a concern to avoid the negative connotations associated with terms such as euthanasia and suicide. A similar argument can be made for the term ‘dying with dignity’.

Section 6 of the proposed Bill does not differentiate between voluntary euthanasia and assisted suicide. It is critical that the legal, medical and other requirements for both voluntary euthanasia and assisted suicide are outlined.

IHF raises concern regarding other areas to include eligibility criteria, record keeping, review function, access to palliative & hospice care. These are detailed below.

18. Are there serious drafting deficiencies or technical drafting errors (e.g. incorrect referencing to Acts etc.)?

Whilst not expert in law, IHF is familiar with the depth of detail contained in comparative Bills. The Bill appears very light on detail and, even if it is accepted that some such legislation is needed, it would be preferable to begin with a much more comprehensive and robust Bill.

IHF have concerns regarding the following;

- (1) **Eligibility Criteria.** The proposed Bill lacks definition regarding eligibility requirements and is sparse on detail in particular regarding criteria for terminal illness. Section 7 of the Bill notes qualifying persons as “a qualifying person if he or she— (a) is terminally ill, (b) has a clear and settled intention to end his or her own life and has made a declaration to that effect in accordance with section 9, and (c) on the day the declaration is made— (i) the individual is aged 18 or over, and (ii) is a resident on the island of Ireland and has been for not less than one year.

Unlike some other countries, there is no time limit on this. IHF would expect that any proposed Bill would contain fairly strict safeguards, requiring that the patient have a terminal illness – for example is likely to die within 6 months, or other anticipated timeframe). For example, in Canada, ‘natural death has been reasonably foreseeable’, and in New Zealand a person must suffer from a terminal illness that is likely to end their life in 6 months. We would strongly recommend that if such legislation were to be introduced that serious consideration is given to eligibility criteria relating to terminally ill.

- (2) **Record Keeping** While there is an obligation to keep and provide records, there are no details on what information will be in the records and there doesn’t seem to be a provision for the establishment of a register

(3) **Review functions:** There are no details on the composition or functions of the review committee. See note under section 20.

Legal advice should come from an expert in criminal law, experts in medical law in addition to human rights lawyers.

We advise that comparative Bills on Assisted Dying which have been subject to thorough testing in other jurisdictions are used to test this current Bill.

19. Are there potential unintended legal consequences which may stem from the PMB as drafted?

Yes – IHF has concerns regarding the following;

Section 11. Assistance in dying. The Bill allows for both Assisted Dying and voluntary euthanasia. Please see our note regarding terminology earlier. Both routes require different administration, training and support. In addition, IHF would expect reference to codes of practice and regulation of medicines be referenced within this section (as outlined very briefly in 11. (7)).

We would have concern that this section of the Bill lacks sufficient detail and guidance. Legal advice should come from experts in criminal and medical law for this section. IHF also recommends that an impact assessment of this process on medical practitioners, nurses and other health professionals be completed; with particular reference to those medical practitioners anticipated to be those administering lethal medication.

Concern over appeal mechanism.

20. Are appropriate administrative and legal arrangements necessary for compliance and enforcement of the provisions of the Bill included? (e.g. if draft Bill contains a prohibition, whether the necessary criminal sanctions - including the class of fine - are included).

No, we do not believe that appropriate administrative and legal arrangements necessary for compliance and enforcement of the provisions of the Bill are included. IHF has concerns regarding the following;

Access to palliative and hospice care: Section 9(4) of the Bill states:

In deciding whether to countersign a declaration under subsection (3), the attending medical practitioner and the independent medical practitioner must be satisfied that the person making it has been fully informed of the palliative, hospice and other care which is available to that person.

Please note the full range of palliative, hospice and other care services are not yet available on an equitable basis across Ireland. The Midlands and North East in particular, lack access to a regional inpatient unit (Hospice) which is available to all other regions, as stipulated under national policy from 2001. These inpatient units provide expert care to complex end-of-life cases -

those which this Bill is designed to support. This Bill will cause healthcare administration challenges as these services are not available in those regions.

The context and practicalities of how Assisted Dying would be implemented alongside access to palliative care need to be considered to inform future Bill.

Assessment of Capacity: Under Section 10, the Bill details arrangements for assessment of capacity. IHF would expect that the Bill would specify the requirement for intact decisional capacity, or, make reference to existing legislation regarding capacity. Current legislation dates from 1871. The Oireachtas has made provision for determining capacity as detailed in the, yet to be fully commenced, Assisted Decision Making (Capacity) Act, 2015. The Bill makes no cross reference to this Act. It is IHF opinion that the ADMA would need to be commenced and implemented in full before this Bill can be enacted.

Ensuring no Coercion or Duress: There should be no evidence of coercion from family or others, or evidence of depression or other psychiatric disease (and this can be ascertained). The Bill lacks detail in this regard. IHF would expect that the Bill would specify the requirement for “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.” Impact of mind-altering substances may also need to be considered.

Appeal & Review: The draft Bill notes “*Establishment of Assisted Dying Act Review Committee 15.* (1) *The Minister shall, by order, appoint a day to be the establishment day for the purposes of this Act.* (2) *On the establishment day there shall stand established a body to be known as the Assisted Dying Act Review Committee.*”

IHF notes that other countries that have legislated for Assisted Dying have thorough and robust review and appeal mechanisms. This Bill makes no reference to appeal structures. IHF questions whether one national Assisted Dying Act Review Committee will be a robust enough structure to monitor the Bill, review contested processes (or deaths) and act as an appeal mechanism. The Bill contains no reference to appeal nor to processes whereby a healthcare professional (or whistleblower) would be able to voice/raise concerns.

Access to medical professionals to support enactment. The draft Bill affords some protection to medical practitioner to some extent, but it assumes there is a bank of trained and willing doctors out there – at this point in time, we cannot assume there is a bank of such professionals. We are aware that the palliative care professionals remain largely opposed to Assisted Dying and that this group of professionals would be conscientiously objecting to playing a role in implementation. There is some evidence from other countries that a limited number of doctors are willing to be involved in assisted dying, but that this can become overwhelming if and as numbers requesting Assisted Dying rise. IHF advises further consultation with medical professionals (GPS, palliative care and other specialities), medical bodies and professional associations in this regard.