

The Scottish Parliament Pàrlamaid na h-Alba

Liam McArthur MSP

20 May 2024

Clare Haughey MSP Convener Health, Social Care and Sport Committee c/o Clerk to the Committee

Dear Clare

Assisted Dying for Terminally III Adults (Scotland) Bill

I understand that the Assisted Dying for Terminally III Adults (Scotland) Bill, for which I am member-in-charge, has been referred to your Committee for Stage 1 scrutiny.

The Non-Government Bills Unit (NGBU) has provided support to me in the preparation and drafting of the Bill. As part of that role, NGBU has carried out an Equalities Impact Assessment (EQIA) for the Bill in order to ensure that best practice has been followed and that the Bill's impact has been appropriately identified and considered. I have added my comments to the EQIA.

The EQIA is attached at the Annex for the Committee's information.

Yours sincerely

Liam McArthur

Equality Impact Assessment

Assisted Dying for Terminally III Adults (Scotland) Bill	
(1) Aims of the Policy	
What is the purpose of the proposed policy?	The purpose of this Member's Bill (introduced by Liam McArthur MSP) is to allow eligible ¹ mentally competent adults in Scotland with an advanced and progressive terminal illness, from which they will not recover, to voluntarily choose to be provided with assistance by health professionals to end their own lives. The Bill establishes a lawful process for an eligible person to access assisted dying and, in doing so, will help address existing legal uncertainty ² .
What are the anticipated outcomes of the policy?	The outcome of the Bill will be that assisted dying as explained above will be lawful in Scotland for eligible adults. The Member anticipates that, as a result, if they choose, eligible adults will be able to avoid the pain, suffering and symptoms associated with terminal illness, which will in turn afford the person autonomy, dignity and control over the end of their life.
Who will be affected by the policy?	The Bill will affect eligible terminally ill adults in Scotland as the Bill would give them a choice of being provided with assistance by health professionals to end their own life – and would particularly affect any such person who decided to have an assisted death. The Bill would also affect those emotionally close to any such terminally ill adults (family and friends).
	The Bill will also affect health professionals (in particular, registered medical practitioners, registered nurses and registered pharmacists) that would facilitate, manage and deliver access to assisted dying.

¹ To be eligible, a terminally ill adult must: have capacity to make and understand the decision; have been ordinarily resident in Scotland for at least 12 months; and be registered with a medical practice in Scotland. A terminally ill adult must also make the decision of their own free and settled will, without being coerced or pressured.

² There is currently no specific legislation in Scotland which makes assisted dying a criminal offence, yet it is also possible to be prosecuted for murder or culpable homicide for assisting the death of another person.

(2) What is known abou policy	t the diverse needs of those who will be affected by the
Gender* (including transgender, maternity and pregnancy)	Any eligible terminally ill adult acting of their own free will would be able to request, and be provided with, assistance to end their own life, regardless of their gender.
programoy)	Data collected from jurisdictions where a form of assisted dying is in place shows that, on average, slightly more men access assisted dying than women (around a 52% - 48% split).
	Research has shown that the lack of choice at the end of life disproportionately and detrimentally affects women who continue to be the primary care givers at the end of life ³ . This is relevant in situations where a terminally ill adult would have wished to be provided with assistance for them to end their own life but is currently unable to do so – therefore also impacting on carers.
	In terms of transgender issues, Marie Curie published information for healthcare professionals in March 2022 ⁴ about palliative and end of life care for LGBTQ+ people. One of the key points noted is that "LGBTQ+ people access palliative and end of life care services late or not at all, due to fear of discrimination."
	The Member believes that, as with other aspects highlighted in this EQIA, this should be taken into account when considering how best to raise awareness of assisted dying and how the process works.
Religion and Belief	Any eligible terminally ill adult acting of their own free will would be able to request, and be provided with, assistance to end their own life, regardless of their religion or belief.
	Some health professionals who may be involved in managing and delivering assisted dying as provided for in the Bill may object to doing so because they consider it to be contrary to their particular religion or belief. Some health professionals that responded ⁵ to the Member's consultation on his draft proposal for a Bill expressed this view (this included some who said that they would object as well as others who said

 ³ Dying in Scotland: A Feminist Issue at: <u>https://features.dignityindying.org.uk/dying-in-scotland</u>.
⁴ <u>Palliative and end of life care for LGBTQ+ people | For professionals (mariecurie.org.uk)</u>.
⁵ <u>Assisted Dying Consultation – Consultation on Assisted Dying for Terminally III Adults (Scotland) Bill</u>.

	they would not, and would participate, but believed it was important that not participating be an option and that health professionals should not be compelled to participate). The Bill does not compel anyone (including health professionals) to participate in the provision of assistance to a person to end their life if they have a conscientious objection to doing so. Such a conscientious objection may be because of a particular religion or belief – therefore any person who had a conscientious objection to participating in the provision of assisted dying rooted in religion or belief would not be compelled to do so.
Age*	Access to assisted dying as provided for in the Bill is restricted to adults – i.e. those aged 16 and over. The Member believes this is appropriate and consistent with many other age restricted activities and practices under Scots law. The Member believes that those aged under 16 are being protected by not being able to access assisted dying. Some terminally ill people under the age of 16, and their families, may feel that they should have access to assisted dying as provided for in the Bill.
	Evidence from jurisdictions where a model of assisted dying is legal indicates that a significant majority of those who request, and then have, an assisted death are aged 65 and over ⁶ .
	Some concern was expressed in the consultation run by the Member on his draft proposal for a Bill ⁷ that some eligible terminally ill older people may feel they are a burden on those around them making them more likely to choose to have an assisted death and stressed that the Bill must take steps to protect a person who is vulnerable due to their age.
	Regardless of age, a terminally ill adult will only be eligible to be provided with assistance to end their own life if two registered medical practitioners, acting independently of each other, consider that they have sufficient capacity to make and understand the decision, and are reassured that the adult is acting voluntarily, of their own free will, and not being coerced or pressured.

 ⁶ For example, in Oregon, from 1998- 2021, 75% of those who had an assisted death were aged 65 and over: <u>DWDA 2021 (oregon.gov)</u>.
⁷ <u>Assisted Dying Consultation 2021 - FINAL (parliament.scot)</u>.

Disability*	Any eligible terminally ill adult acting of their own free will would be able to request, and be provided with, assistance to end their own life, regardless of a person's disability. However, an adult is not eligible only because they have a disability of any kind.
	Concerns were expressed in the consultation run by the Member on his draft proposal for a Bill, by some disabled people and organisations representing people with a disability, that some eligible terminally ill adults with a disability may feel they are a burden on those around them, making them more likely to choose to have an assisted death, for reasons other than wanting to end their own life due to the pain, indignity and/or lack of control they are experiencing. Other concerns raised were that a lack of equality in the provision and availability of care could lead to disabled people being particularly and disproportionately vulnerable to being coerced/pressured into choosing to have an assisted death, and that the Bill could be the start of a "slippery slope" that would allow for assisted dying to be made available to a wider cohort of people than set out in the Bill, including not only those terminally ill, but extending to those with various disabilities.
	Some other people with a disability were supportive of the proposed legislation and believed it important that access to assisted dying was provided on an equal basis to those with and without a disability. The University of Glasgow School of Humanities published a briefing on the issue of disability and assisted dying laws in 2021 ⁸ and concluded that " assisted dying laws should not be opposed on the basis of the views, welfare, respect or healthcare of people with disabilities. Instead, respect for disabled people's autonomy gives some reason to legalize assisted dying, at least for people expected to die within six months. This conclusion is supported by four key findings: 1. People with disabilities are not generally opposed to assisted dying laws. 2. Assisted dying laws do not harm people with disabilities. 3. Assisted dying laws do not show disrespect for people with disabilities. 4. Assisted dying laws don't damage healthcare for people with disabilities."
	The Member believes that the Bill contains appropriate and proportionate safeguards to protect people with a disability. The Member considers it important to not deny access to the provision of assistance to a person to end their own life, if

⁸ PolicyBriefingDisabilityAndAssistedDyingLaws.pdf.

	they are eligible, solely on the basis that they have a disability. Neither does the Member consider it appropriate to make access to assisted dying for eligible adults who have a disability more stringent than that for people without a disability.
Ethnicity and Race	Any eligible terminally ill adult acting of their own free will would be able to request, and be provided with, assistance to end their own life, regardless of a person's ethnicity or race. A study ⁹ based on evidence from parts of the United States
	of America where a form of assisted dying is legal shows that the rates of use of assisted dying are much higher for people identifying as white. The study believed there were cultural, structural, and interactional explanations for racial and ethnic variability in the use of assisted dying in the US: that cultural and religious differences across racial and ethnic groups affect preferences for end of life care and assisted dying; that people of colour are not given equal access to information and quality care and therefore may not be aware of the option of assisted dying; and that interactions with health professionals may vary for different racial and ethnic groups. The Member believes that this should be taken into account when considering how best to raise awareness of assisted dying and how the process works.
Sexual Orientation	Any eligible terminally ill adult acting of their own free will would be able to request, and be provided with, assistance to end their own life, regardless of a person's sexual orientation. As noted in the section on gender, Marie Curie published information for healthcare professionals in March 2022 ¹⁰ about palliative and end of life care for LGBTQ+ people. One of the key points noted is that "LGBTQ+ people access palliative and end of life care services late or not at all, due to fear of discrimination."
	The Member believes that this should be taken into account when considering how best to raise awareness of assisted dying and how the process works.

 ⁹ Cain CL, McCleskey S. Expanded definitions of the 'good death'? Race, ethnicity and medical aid in dying. Sociol Health Illn. 2019;41(6):1175-1191. doi:10.1111/1467-9566.12903. Available at: Expanded definitions of the "good death"? Race, ethnicity, and medical aid in dying - PMC (nih.gov).
¹⁰ Palliative and end of life care for LGBTQ+ people | For professionals (mariecurie.org.uk).

Marriage and Civil Partnership	Any eligible terminally ill adult acting of their own free will would be able to request, and be provided with, assistance to end their own life, regardless of a person's marital or civil partnership status. There are no known needs specific to a person's marriage or civil partnership status.
(3) Is there enough info of those affected by the	rmation to help understand the needs and/or experiences policy
Gender* (including transgender, maternity and pregnancy)	It is considered that the Bill does not significantly engage the gender characteristic, and that the information referred to above is sufficient to understand, and be able to respond to, the needs and/or experiences of people with different genders who wish to be provided with assistance to end their own life as provided for in the Bill or may be otherwise affected.
Religion and Belief	It is considered that the information referred to above is sufficient to understand, and be able to respond to, the needs and/or experiences of people with a religion or belief who wish to be provided with assistance to end their own life as provided for in the Bill or may be otherwise affected. This includes any person (including health professionals) who does not wish to participate in the provision of assistance due to a conscientious objection founded in religion or belief.
Age*	It is considered that sufficient information is available to understand, and be able to respond to, the needs and/or experiences of people within different age groups who wish to be provided with assistance to end their own life as provided for in the Bill or may be otherwise affected.
Disability*	It is considered that the information referred to above is sufficient to understand, and be able to respond to, the needs and/or experiences of people with a disability who wish to be provided with assistance to end their own life as provided for in the Bill or may be otherwise affected.

Ethnicity and Race	It is considered that the information referred to above is sufficient to understand, and be able to respond to, the needs and/or experiences of people of a particular ethnicity and race who wish to be provided with assistance to end their own life as provided for in the Bill or may be otherwise affected.	
Sexual Orientation	It is considered that the information referred to above is sufficient to understand, and be able to respond to, the needs and/or experiences of LGBTQ+ people who wish to be provided with assistance to end their own life as provided for in the Bill or may be otherwise affected.	
Marriage and Civil Partnership	It is considered that the Bill does not engage the marriage and civil partnership characteristic.	
If not, what other information is required	N/A.	
(4) What does the inform	(4) What does the information given say about how the policy might impact positively and negatively on different groups	
Gender* (including transgender, maternity and pregnancy)	The information available indicates that slightly more eligible terminally ill men may decide to have an assisted death, and that the Bill will have a positive impact (in situations where a terminally ill eligible adult wished to be provided with assistance to end their own life) on addressing the current lack of choice at the end of life, which disproportionately and detrimentally affects women who are often the primary care givers. Note that the provision of assistance to eligible terminally ill adults to end their own life must be chosen by the adult in question, voluntarily, of their own free will, without being coerced or pressured. The information available indicates there could be some terminally ill eligible transgender adults who experience a negative impact due to wishing to choose assisted dying but deciding not to access assisted dying due to fear of discrimination. The Member does not consider this to be a potentially direct negative impact of the Bill, and believes it is important that health professionals are aware of the possibility of this issue, as highlighted by Marie Curie, so they can respond appropriately. The overall information suggests that the Bill is likely to have	
	i ne overall information suggests that the Bill is likely to have	

	a positive impact on eligible terminally ill adults, and their carers, regardless of gender, and that health professional should be aware of the potential for some transgender adults to not engage in end of life care (including assisted dying) due to fear of discrimination.
Religion and Belief	The information available indicates that some health professionals that have a particular religion or belief are concerned that they should not be compelled to participate in the provision of assistance to a person to end their own life as it is contrary to that religion or belief.
	With that in mind, by not compelling anyone to participate in the provision of assistance if they have a conscientious objection to doing so, the Bill is likely to have a neutral or positive impact on any health professional with a religious or belief-based objection to participating in delivering assisted dying.
Age*	The information available indicates that it is considered important to ensure that a person who may lack capacity to make and understand a decision to request assistance to end their own life as a result of their age is suitably protected and that any age-related capacity issues taken into consideration. As the Bill only allows the provision of assistance to end life to adults (those aged 16 and over) and also limits eligibility to terminally ill adults who have sufficient capacity to make and understand the decision it is considered that it will not impact negatively on a person because of their age.
	The available information also shows that a significant majority of people who request an assisted death are likely to be aged 65 and over, which reflects the greater number of older people suffering from terminal illness and shows the positive impact the policy may have on those older people who have a terminal illness, are experiencing pain and distress, are eligible, and choose to request the provision of assistance for them to take to end their own lives. The Bill may also provide comfort to some of those people by providing an option they would know was available, but which they may not decide to use, rather than feeling that they have no option.
Disability*	The information available indicates that some people with a disability consider that the Bill may have a negative impact on

	them, as they believe a terminally ill eligible adult with a disability may choose to have an assisted death for reasons connected to their disability, and society's resulting treatment of, and perception of them. However, the information also indicates other disabled people believe the Bill will have a positive impact, as access to assisted dying is not restricted on the basis of disability, and also does not allow a person to access assisted dying only due to a disability. Rather a person with a disability would have to meet the various eligibility criteria (which includes having capacity to make and understand the decision) and be assessed as making the decision of their own free will without being coerced or pressured to be eligible for the provision of assistance.
Ethnicity and Race	The information available indicates that there could be differential impacts on people of certain ethnicities and races due to established institutional and/or cultural barriers to accessing information – in this case about assisted dying. However, note that the evidence is specific to parts of the USA and that the situation may be different in Scotland. The Bill allows Scottish Ministers to issue guidance on the practical operation of the Bill, which includes the provision of information about assisted dying to the general public. It therefore provides an opportunity for any issues which do exist, or which are identified, to be addressed.
Sexual Orientation	The information available indicates there could be some terminally ill eligible LGBTQ+ adults who experience a negative impact due to wishing to choose assisted dying but deciding not to access assisted dying due to fear of discrimination. The Member does not consider this to be a potentially direct negative impact of the Bill, and believes it is important that health professionals are aware of the possibility of this issue, as highlighted by Marie Curie, so they can response appropriately. The Member believes that the Bill will have a
Marriage and Civil	positive impact on terminally ill eligible adults, regardless of their sexual orientation, who wish to choose to be provided with assistance for them to end their own life. No particular impacts identified.
Partnership	
Completed by the Non-	Government Bills Unit: [insert date]

*Although not a protected characteristic, carers should be given specific consideration in this category (e.g. the potential impact on those who care for older people)

Member's Comment on NGBU's Equalities Impact Assessment

Evidence gaps identified	No evidence gaps were identified.
Member's comment: a	am content with the commentary and information set out in this
document.	, ,
Adverse impacts	No adverse impacts of the Bill were identified. Some existing
identified	potential adverse impacts which the Bill should be mindful of were identified.
Member's comment: I am content with the commentary and information set out in this	
document.	-
Completed by Liam McArthur MSP	