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Views of Disability Rights Organisations on Assisted Dying Legislation in England, Wales and Scotland: an analysis of position statements

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ABSTRACT

Assisted dying is a divisive and controversial topic and it is therefore desirable that a broad range of interests inform any proposed policy changes. The purpose of this study is to collect and synthesize the views of an important stakeholder group - namely people with disabilities (PwD) - as expressed by disability rights organisations (DROs) in Great Britain. Parliamentary consultations were reviewed, together with an examination of the contemporary positions of a wide range of DROs. Our analysis revealed that the vast majority do not have a clear public stance; those that do exhibit a significant diversity of opinion. DROs opposing legislation on assisted dying have argued that it would be premature, misguided, inequitable and culturally undesirable. Some specify conditions that would have to be satisfied before they could support legalisation, such as radical improvements in health and social care services (especially those relating to end of life care) and the elimination of discrimination against PwD. DROs supporting assisted dying maintain that a change in the law would promote autonomy, end intense suffering, can be delivered safely and is supported by the DRO's membership. The discussion considers the reasons why so many DROs adopt a neutral stance and the argument is made that, whatever their overarching stance on the issue, DROs need to be involved in the policy debate so that the crucial perspectives of PwD are heard and addressed. This is an important message for countries around the world that permit, or are considering legalising, assisted dying.

INTRODUCTION

Since 1997, several countries and US states have legalised assisted dying, using one or both of two different methods. *Euthanasia* is where a physician intentionally ends a patient's life, at their explicit request, by means of active drug administration. *Physician-assisted suicide* "is similar to euthanasia but involves the provision or prescribing of drugs by a physician for a patient to use to end their own life."^[1] Despite numerous legislative initiatives and judicial challenges, it remains unlawful to encourage or assist the suicide or attempted suicide of a person in England and Wales (as a result of section 2 of the Suicide Act 1961) while, in Scotland, it is illegal to do something knowing that it will be the immediate and direct cause of another person's death.^[2,3]

Leaving to one side the role of the judiciary, it is important to note that the law covering England and Wales (which is determined by the UK Parliament, comprising the elected House of Commons and the unelected House of Lords) is independent of Scottish law on assisted dying (which is determined by the Scottish Parliament). The Bill considered by the House of Commons, in 2015, would have allowed "competent adults who are terminally ill to choose to be provided with medically supervised assistance to end their own life."^[4] Similarly, the Assisted Suicide (Scotland) Bill, in the same year, sought to enable "people with terminal or life-shortening illnesses or progressive conditions which are terminal or life-shortening and who wish to end their lives to obtain assistance in doing so."^[5]

People living with disability have a key contribution to make to these Parliamentary debates. Some might be considered particularly vulnerable to abuse or pressure to end their lives prematurely. Yet many people with a disability support assisted dying and, indeed, have initiated landmark legal challenges to attempt to change, or at least clarify,

the law.[6] Disability rights organisations (DROs) therefore have an important and challenging task to represent these diverse views and interests to decision-makers. To date, however, there has been no overarching analysis of their positions on this fundamental moral issue. Nor has there been detailed inquiry into the types of arguments that DROs deploy when seeking to influence legislative debates and wider public policy. This research is relevant and important, therefore, in the light of the ongoing legal and societal debate.

The paper has two aims. First, to examine the distribution of public positions that DROs have adopted on the legalisation of assisted dying in Great Britain. Second, to present a thematic analysis of the arguments deployed by DROs in support of their positions. The study is focused on England, Wales and Scotland and therefore reflects the social and political arrangements in those countries. Nonetheless, the insights that it generates have international relevance and can inform the positions taken by DROs and policy makers globally, remembering that 15% of the world's population lives with a disability.[7]

METHODOLOGY

Defining the target population

In the UK context, disability is defined in the Equality Act 2010. Section 6 sets out the general test that it is a “physical or mental impairment which has a substantial and long term adverse effect on [a person’s] ability to carry out normal day to day activities.”[8] Schedule 1 includes a range of supplementary provisions, the most relevant of which (Paragraph 6) notes that Cancer, HIV and Multiple Sclerosis are disabilities. The Schedule also gives powers for the making of Regulations on the meaning of disability.[9]

For the purposes of this article, a DRO is defined as any organisation whose primary purpose is to support those with a disability (as defined above). Most DROs focus on providing support and information to people with a particular condition, such as the British Heart Foundation or Versus Arthritis. Others relate to a particular age group that will include some who are disabled (e.g. Age UK) and some provide generic support, including to people living with a disability (e.g. Scottish Independent Advocacy Alliance).

Note that hospices are not part of the study, even though they support people living with disability, since they have a unique perspective on assisted dying that deserves to be studied in its own right. Equally, lobby groups established specifically to influence the assisted dying debate are excluded. There are many of these, such as Care Not Killing, Dignity in Dying, Disabled Activists for Dignity in Dying, Friends at the End, Living and Dying Well, My Life, My Death My Choice and Not Dead Yet. They were formed, and exist, to articulate and defend a particular side of the argument. Our interest is in DROs whose focus is on people with disability and whose perspective on assisted dying is not their *raison d'être*.

Date Collection Procedure

The positions of DROs and their supporting arguments were identified and analysed using two methods.

Method 1: DROs were identified by searching the websites of (a) the Charity Commission for England and Wales and (b) the Scottish Charity Regulator (OSCR).[10,11] A total of 372 charities were identified that operated throughout England and Wales, with an income exceeding £1million, where “what the charity does” was selected as “disability” (code 104) and “who the charity helps” was selected as “people with disabilities” (code 203). A total of 403 charities were identified on the OSCR database, with an income exceeding £1million,

where the charity's purposes were defined as "the relief of those in need by reason of age, ill health, disability, financial hardship or other disadvantage" and the beneficiaries were classed as "people with disabilities or health problems".

These results were then filtered (by inspecting the charity websites) to exclude charities that were not thought appropriate for inclusion. For example, they were grant providers, housing bodies, animal rights organisations, entities operating internationally and hospices. Emails were then sent to the remaining 140 DROs asking if they have a current public position on assisted dying, which could include one of neutrality. If they had a public position, they were invited to send further details. If not, they were simply asked to confirm that they did not have a public stance on the issue. Reminder emails were sent roughly a month later. Where no reply was received, the charity's website was searched for any indication of a public position on assisted dying. In addition, the websites of DROs who did reply were reviewed to ensure that there were no inconsistencies in the information supplied. The research was carried out from December 2019 to June 2020.

Method 2: Written evidence was gathered that had been submitted by DROs (a) in 2004 as part of the consultation processes for the Assisted Dying Bill in the House of Lords and (b) to inform deliberations on the Assisted Suicide (Scotland) Bill 2015.[12,13] These are the two most recent public Parliamentary consultations to have taken place on this topic in the UK and Scottish legislatures respectively.

Data analysis

All of the relevant submissions that had been identified using **Method 2** were collated, together with any policy statements received using **Method 1**. Through multiple readings of the documents, an initial selection of themes was identified by GB. This was amended by KC and simplified, identifying major categories that could be combined from narrower themes. Following another comprehensive review by both authors, a further iteration restated those themes as arguments for and against the legalisation of assisted dying. The process also identified pre-conditions for supporting a change in the law and justifications for the adoption of a neutral stance by a DRO.

FINDINGS

The quantitative findings from **Method 1** are presented in Table 1. As noted earlier, the websites of non-respondents were searched for any indication of a public position on assisted dying. Not one such reference was identified. The majority of DROs covered by the study, at least 85%, do not have a public position on assisted dying.

DRO position/response	Frequency (%)
No reply and no mention of a position on assisted dying on their website	61 (44%)
Confirmed that it has no public position on assisted dying	57 (41%)
Adopts a neutral position	5 (4%)
Opposed to a change in the law on assisted dying	5 (4%)
Replied ambiguously and no mention of an assisted dying position on their website*	12 (9%)

* Ambiguous replies included phrases such as "this is not something we can help you with", "no comment" or

our position is “guided by the law”. The websites of organisations that provided ambiguous responses were searched in a bid to clarify their position on assisted dying but no formal public stances were identified. Percentages have been rounded and, as a result, do not sum to 100.

Table 2 identifies the ten DROs (applying Method One) that confirmed a clear public position on assisted dying, together with a brief summary of their justification, in their own words. They are evenly divided between neutrality and preferring the status quo.

Table 2 – DROs identified as having a clear public position on assisted dying	
NEUTRAL	
Disability Rights UK	“This is a complex issue on which people hold different passionately held views. Disability Rights UK respects those different views.” (Website statement 10 th September 2015)[14] and neutral position confirmed in email correspondence (January 2020)
Motor Neurone Disease Association	“The Motor Neurone Disease (MND) Association supports all people with MND, their families and carers. We are a membership organisation and our members hold a wide range of views on assisted dying. We take a position of neutrality towards any change in the law.” (Policy Statement December 2019)[15]
Motor Neurone Disease Scotland	“As an organisation we neither support nor oppose any attempt to change the law regarding euthanasia or assisted suicide because we believe it is a matter of individual conscience and it is not for the organisation to make judgements.” (General Statement on Euthanasia – Assisted Suicide: undated and not available on website)
Parkinson’s UK	“Parkinson’s UK neither supports nor opposes a change in the law to allow assisted suicide. Our position is neutral because we recognise that people affected by Parkinson’s have a wide range of personal beliefs on this issue.” (Current website policy statement)[16]
Spinal Injuries Association	“Individuals must have the right support, advocacy and safeguards - particularly at vulnerable times - to enable them to make an informed decision that takes account, not just of their present circumstances but of their potential future.” (Press Release 11 th September 2015 – not available online) and neutral position confirmed in email correspondence (May 2020)
OPPOSED	
Alzheimer Scotland	“Against legislation to legalise assisted suicide at this time because service provision to provide high quality palliative care throughout the illness is inconsistent and often poor for people with dementia.” (Evidence submitted to consultation on Assisted Suicide (Scotland) Bill 2015)[17]
Inclusion Scotland	“Inclusion Scotland acknowledges that disabled people are divided on the issue of assisted suicide. We accept that there are disabled people with sincerely held contrary views. However, when we last consulted on this issue our membership overall remained against the principle of assisted dying/suicide.” (Evidence submitted to consultation on Assisted Suicide (Scotland) Bill 2015)[18]
Livability	“As the largest Christian disability charity in the UK, Livability recognise and uphold the sanctity of human life and support the decision reached in Parliament.” (Online Blog September 2015)[19]
Marie Curie Cancer Care	“Our clinical services are focused on helping terminally ill people and their families to live as well as possible...As an organisation providing care, we are not seeking a change in the law to permit euthanasia or physician assisted suicide.” (Current ethical statement on charity website)[20]

Table 2 – DROs identified as having a clear public position on assisted dying

Scope	“If you are disabled, you all too often face the view that it’s not worth being alive, and that you’re a burden. The ban on assisted suicide sends a really powerful message countering this view.” (Press Release 20 th January 2018)[21]
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The policy statements collated using **Method 1** were qualitatively analysed together with the responses of DROs to the two Parliamentary consultations covered by **Method 2** (Appendix One provides an overview of the DROs who contributed to the thematic analysis, and Appendix Two lists the DROs who made written submissions to the two consultations).[22,23] Collectively, these documents articulate a broad range of arguments that have been deployed by twenty DROs with respect to assisted dying. This thematic analysis is organized in four sections, namely (a) DRO arguments against assisted dying (b) DRO arguments supporting assisted dying (c) DRO justifications for adopting a neutral stance, and (d) DRO conditions or requirements to support assisted dying.

Arguments against the legalisation of assisted dying

Table 3 identifies overarching argument ‘categories’ opposing assisted dying which, where appropriate, are sub-divided into more concrete claims. Supporting examples and quotations are provided to illustrate or clarify the points made by DROs. DROs have argued that legislation on assisted dying would be premature, misguided, inequitable and/or culturally undesirable. It is also argued that there is a risk of coercion and other abuses, a lack of support among key stakeholders and may damage the public trust that is essential to good health care. The number of DROs articulating each argument ‘category’ is provided in parentheses.

Table 3 – DRO arguments opposing the legalisation of assisted dying

LEGALISATION IS PREMATURE (mentioned by 9 DROs)	
Services are currently inadequate	In their written submission to the House of Lords, the Disability Rights Commission (DRC) contended that “it is essential to improve palliative care...before assisted dying is offered to patients”[24] More broadly, the social and material pre-conditions for assisted dying to be legalised have yet to be fulfilled.
Genuinely autonomous choices are not currently possible	According to Alzheimer Scotland, “people with dementia may not have a balanced view of the options; end of life choices do not exist.”[17] The autonomy-based arguments in favour of assisted dying fail to understand the current realities, and the stark denial of autonomy, for disabled people.
Issue requires further research and debate	Marie Curie Cancer Care, writing in 2004, strongly supported the call “for a delay in legislation until the results of robust research into all aspects of euthanasia and PAD [physician assisted dying] are available and have been widely debated in society.” The issue should be addressed as part of a wider discussion of “how society cares for those who are approaching the end of life.”[22]
LEGALISATION WOULD LEAD TO DIRECT OR INDIRECT COERCION (mentioned by 6 DROs)	
Disabled people may be directly pressured into opting for assisted dying	This pressure might come from friends, family or professionals who judge that someone would be better off dead. It may be motivated by self-interest but also as a result of the “extreme difficulties that so often arise out of the ‘caring’ role because of lack of appropriate service provision and palliative care.” (Disability Awareness in Action)[22]
Disabled people may be indirectly pressured into assisted dying	The DRC argues that some will opt for assisted dying as they feel that “they are an unacceptable burden on loves ones” [22] while Livability suggests that, at its most extreme, “the ‘right to die’ may become a ‘duty’ for the most vulnerable people.”[19]
LEGALISATION CANNOT GUARANTEE EFFECTIVE SAFEGUARDS (mentioned by 5 DROs)	
Any safeguarding measures will be	DROs expressed concerns about the safeguards, including monitoring and policing, included within the proposed legislation. Help the Aged stated that their “principal

ineffective or open to abuse	objection" to the proposed legislation "related to the absence of robust and effective protective mechanisms against potential abuse." [22]
Medical decisions are unreliable and often inconsistent	Judgments about the timing of an illness becoming terminal can be unreliable. <i>Together for Short Lives</i> , for example, note that "it is much more difficult to identify when a young person is moving into their end of life phase." [25]
A 'slippery slope', with result with widening of coverage	In a joint letter relating to Lord Falconer's Assisted Dying Bill in 2014, Scope (and others) affirmed that "where assisted suicide or euthanasia have been legalised, there has been significant expansion of the groups who qualify - whether through broadening of the definition by statute or through evolution of the way the law is interpreted..." [26]
LEGALISATION IS MISGUIDED (mentioned by 3 DROs)	
The policy focus should be on care and support rather than assisted dying	Requests for help to die are often driven by poor quality of life which, according to Inclusion Scotland, "results from public attitudes towards disability, poor services, poverty and inaccessible public spaces." Rather than giving "priority to enabling people who have impairments to have a (debatably) good death" the government should be "supporting them to have the best possible life". [18]
Assisted dying values profit more than people	Inclusion Scotland also recommended safeguards to avoid institutional gains that might result from assisted dying, highlighting "governments who wish to save money to fund tax cuts" and "local authorities/health authorities who could save expenditure on expensive care provision." [18]
It is never right to help someone to die	Disability Awareness in Action maintain that "in the situation of someone wishing to commit suicide because of pain and suffering, it is the duty of society not to help them to die but to alleviate their pain and suffering." [22]
Assisted dying is unnecessary	The DRC refers to palliative care professionals who state that "drugs can control most pain for most people - the ability to control physical pain is limited to a slight degree in just five percent of people." [22]
LEGALISATION PERPETUATES AN UNDESIRABLE CULTURE (mentioned by 3 DROs)	
Assisted dying reflects the prejudices disabled people face	Negative perceptions of life as a disabled person are widespread and regularly reinforced by the media. The prevailing culture values human life only in financial terms and disabled people are viewed as 'scroungers', 'cheats' and 'skivers' who impose a burden on the economy (Inclusion Scotland). [18]
Assisted dying would further devalue the lives of disabled people	In a 2011 article in a national newspaper, the Scope Chief Executive cited a ComRes poll which indicated that 56% of disabled people felt "the legalisation of assisted suicide would be detrimental to the way that they are viewed by society as a whole." [27]
Disabled people are encouraged to give up	Assisted dying encourages a perception that ending lives can be merciful and that it is "of course, 'naturally' a "kindness to help people who are terminally ill or significantly disabled (or both) to die." [18]
LEGALISATION WOULD DAMAGE THE HEALTH CARE SYSTEM (mentioned by 3 DROs)	
Assisted dying would undermine trust health care	The DRC shares the fears of the British Medical Association (BMA) that "it could undermine the trust the vulnerable, elderly, disabled or very ill patients have in the health care system." [18]
The doctor-patient relationship would be harmed	Inclusion Scotland asserts that "everyone must be able to trust that their doctor is there to promote their good health...the National Health Service should not be transformed into a National Death Service." [22]
MISCELLANEOUS ARGUMENTS (mentioned by 3 DROs)	
Legalisation is widely opposed	The DRC stated that "there is a body of opinion among not only disabled people, but also ethicists and the legal and medical professionals that believes there is such a significant risk that they have recommended euthanasia is not legalised." [22]
Legalisation fails to respect the sanctity of life and suicide should not be aided	In 2015, Livability argued that suicide should never be facilitated. "While people who attempt to take their own lives are, rightly, treated with understanding, suicide itself is not regarded as something to be encouraged, much less assisted..." [18]
Legalisation introduces inequity among disabled people	With respect to Lord Joffe's 2005 Bill, the DRC objected that the exclusion of people with learning disabilities and mental health service users is discriminatory since it prevents "some disabled people from being able to make decisions freely available to other sections of society." [22]

DRO arguments in favour of the legalisation of assisted dying

Notably fewer arguments were identified in favour of assisted dying. These maintained that a change in the law would promote autonomy, end intense suffering, can be delivered safely and is supported by the DRO's membership.

The legislation respects individual autonomy	The Terence Higgins Trust notes that people are often obliged to take difficult and complex decisions about their care. "The provision of a safe and regulated option of assisted dying for competent, terminally ill adults would extend their choice to be able to make decisions throughout their life with HIV." [22]
Some lives are no longer worth living and can be unbearably distressing.	Macmillan Cancer Relief maintains that "a small number of people who are terminally ill have symptoms that cannot be relieved by palliative measures" [22] (House of Lords page 708) while the Scottish Disability Equality Forum (SDEF) states that "life should be about quality not just length." [28]
The legislation is supported by the membership	The SDEF further notes that its members agree with the principle of making assisted suicide "legally allowable." [28]
The legislation can provide suitable safeguards	In its 2004 submission, the Terence Higgins Trust expressed confidence that the proposed Bill would provide "careful safeguards, including the obligatory consideration of all the alternatives, in particular the option of palliative care, the provision of pain control and the revocation of decision at any time." [22]

Arguments underpinning the neutral stance adopted by some DROs

Several DROs espouse a neutral stance with respect to the legalisation of assisted dying. Parkinson's UK, for example, neither support nor oppose a change in the law because they "recognise that people affected by Parkinson's have a wide range of personal beliefs on this issue." [16] The stance of the Motor Neurone Disease Association is similar. In their 2018 policy review, they explained that their neutral position allows them to represent all of their members - "a move away from this would run the risk of losing significant and valued support." [29]

Two further findings are worth noting. First, DROs may feel that they are not yet in a position to commit to a position on this issue. In 2004, for example, Macmillan Cancer Relief, felt unable to take a stance "given our present state of knowledge and the existing legal situation." [22] Second, the lack of a clear, overarching stance does not prevent DROs from contributing to policy development in this area. Together (Scottish Alliance for Children's Rights) took no position on assisted suicide but was still able to make the argument that "the rights of children should be taken into account" and "the views of a child must be given due weight in accordance with their age and maturity." [30]

Necessary conditions for the legislation to be acceptable

Although not initially intended, our thematic analysis identified explicit or implicit stances from DROs on the conditions that would need to be satisfied before assisted dying could be safely adopted. The Disability Rights Commission (DRC) submission, for example, listed "the substantial systemic changes and support services necessary to support the opportunity of all people with terminal illnesses to live as full lives as possible...and to have genuine choices about the nature of their lives and deaths." [22] Other DROs highlighted considerations of particular importance for their members, such as access to speech and language therapy or to mental health specialists. These pre-conditions are

summarised in Table 5 which highlights the importance of improved care services (especially for end of life care), appropriate support throughout the processes of assisted dying and comprehensive, rigorously monitored safeguards.

Table 5 – DRO pre-conditions for supporting assisted dying	
Health and care services for disabled people need to be radically improved	Discrimination against disabled people must not be tolerated, inequalities (including geographical differences in care) should be eliminated and there should be a right to independent living with comprehensive support services.
Assisted dying debate must be part of a wider commitment to improve end of life care	Specialist palliative care and hospice services must be accessible to all who need it. Any discussion of assisted dying should take place in the context of the support available to those who are terminally ill, with full discussion of alternative approaches that might be taken
Those considering assisted dying must be fully supported throughout the process	There should be a right to comprehensive information, independent advocacy, specialist input and access to communication aids (such as Speech and Language Therapy). The needs of families and carers should be addressed and disabled people must be empowered to make their own decisions.
Effective safeguards must be put in place	These include mental health assessments, psychological support, elimination of all forms of coercion, provisions to change one's mind without time pressures, competent doctors who know their patients and their conditions, and rigorous monitoring processes

DISCUSSION

SUMMARY OF THE FINDINGS

The research revealed that the vast majority of DROs in England, Scotland and Wales do not currently have a position on assisted dying. Contrary to often-made claims affirming a consensus of DROs against assisted dying,[31,32] it has been shown that only 8% of the 140 organisations included in the email survey had a clear public commitment on the issue: those with a public stance are evenly divided between neutrality and opposition with respect to legalisation. The qualitative analysis classified the range of arguments deployed by DROs with respect to assisted dying. While supporters focused on autonomy and the avoidance of unnecessary suffering, opponents of assisted dying identified a range of concerns relating (among other things) to the paucity of existing care services, the lack of genuine choices, the coercion of vulnerable individuals and the reinforcement of a culture that devalues and prejudices the lives of disabled people. The thematic review also captured the conditions that must be satisfied before certain DROs could support assisted dying, as well as the reasons why some currently maintain a neutral stance.

STRENGTHS & LIMITATIONS

This study provides important insights into the attitudes of a key stakeholder group on assisted dying in Great Britain. It combines breadth and depth, both clarifying the distribution of DRO positions and revealing their underlying reasoning. The range of arguments was limited, however, by our decision to exclude contributions made by DROs to the 2012 Commission on Assisted Dying (a supposedly independent body whose objectivity was strongly contested by some critics within the disability movement).[33] The breadth of coverage was narrowed further by excluding the contributions of organisations dedicated to lobbying in this area. As a result, the thematic analysis is less rich than it might otherwise have been. We were also conscious throughout of the potential disadvantages of combining data from a range of years in our thematic review but

concluded that the arguments that we analysed remain relevant to contemporary debates (even if the views of some DROs have changed over time).

INTERPRETATION OF THE FINDINGS

Several factors might explain the low proportion of DROs with a firm public position. Some may feel that their views carry little weight relative to other stakeholders, such as the media or medical organisations, making it irrational to spend time (and political capital) on the issue. Others may find silence on the topic to be a prudent approach (given its divisiveness) or will view it as a marginal issue that would only touch a small proportion of their membership. There may also be a reluctance to adopt a position without a clear process to understand the views of their membership. One consequence of these (entirely legitimate) considerations is to weaken the validity of generalisations about the views of DROs, as a class, on assisted dying. With so many DROs silent on the issue, we simply don't know what the majority feels.

It is equally worth reflecting on the reasons why DROs have adopted a position of neutrality. For some, this follows from an overarching principle that it is not for the DRO to take a stance on matters of personal conscience. Indeed, DROs with a passion to help those with a particular condition may fear that 'taking a side' would deter some people from accessing information and services from which they might greatly benefit. Other DROs, such as the Motor Neurone Disease Association (MNDA) recognise that "there are a number of very active organisations on both sides of the debate which our members and supporters are free to join."^[29] This is an interesting approach, hinting at the delegation of representation on a key moral issue to specialist, cross-condition, lobby groups.

Of course, the adoption of a neutral stance does not require a DRO to remain silent on assisted dying. They have been able, together with DROs who support or oppose assisted dying, to propose necessary measures, such as those presented in Table 5. Given the polarized nature of the debate, this could even be considered their 'ideal' function. DROs can deploy their expertise to help governments and legislators to tailor assisted dying provisions so that they are safe and effective for people with vastly different underlying health problems. These might be sensitive to, for example, fluctuating or degenerative health conditions, clinical depression, the needs of carers or children and young adults. Equally, DROs who oppose assisted dying, as things stand, can use the issue as leverage to push for change in other areas, notably improved palliative care provision and better support for independent living.

The thematic review identified a far broader range of arguments employed by DROs against assisted dying than in support of its legalization. It is noteworthy that opponents often focused on protecting the interests of disabled people as a class with shared interests that might be damaged by the introduction of assisted dying. The arguments in favour of assisted dying, on the other hand, were more individualistic: disabled people are suffering needlessly, some want to be able to end their lives and they should be able to choose to do so. The 'group interests versus individual autonomy' division is central to understanding the disagreements between DROs. It is worth adding that, in many cases, DROs were not opposed to assisted dying in principle but were willing to support it if certain conditions were satisfied. Some of these pre-conditions, however, would require radical redistributions of resources and substantial cultural changes that will not easily be delivered.

RECOMMENDATIONS

Wherever the legalisation of assisted dying is contemplated, we would recommend that the consultation process included the following measures. First, capture the views of people living with disability directly using robust polling methods. Second, reach out to DROs and welcome their input into the debate, reassuring them that their insights add value even if they don't wish to commit to supporting either side of the issue. Third, DROs should be more willing to engage with this issue: cancer charities, for example, are notably silent given that cancer sufferers make up a substantial proportion of those opting for assisted dying.^[1] Fourth, learn from the experience of disabled people and DROs in countries where assisted dying has been introduced. Through this combination of strategies, the views of a key stakeholder group can be given the prominence that it merits.

CONCLUSIONS

The vast majority of people who would opt for assisted dying will have a disability. It is important therefore that the views of those living with disability are understood by legislators and policy-makers when considering legislative reform. DROs should have an important role to play in representing their members but our research shows that most are not engaged in that process. As a consequence, there is a risk that the voices of disabled people may carry less weight than they should and that the quality of policy-making on this critically important issue is thereby impoverished.

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Appendix One – Positions of DROs included in the thematic analysis

Positions of DROs included in thematic analysis <u>at the time</u> of their statement		
Opposed	Neutral	In favour
Alzheimer Scotland	Disability Rights UK	Scottish Disability Equality Forum
Disability Awareness in Action	Macmillan Cancer Relief	Scottish Independent Advocacy Alliance
Disability Rights Commission	MNDA	Terence Higgins Trust
Help the Aged	MND Scotland	
Inclusion Scotland	Parkinson's UK	
Livability	Scottish Association for Mental Health	
Marie Curie Cancer Care	Together (Scottish Alliance for Children's Rights)	
Scope	Spinal Injuries Association	
Together for Short Lives		

Appendix Two – Positions of DROs who contributed to UK (2004/5) and Scottish (2014/5) Parliamentary consultations on Assisted Dying/Assisted Suicide

Name of DRO	Consultation Date	Position at that time
Disability Awareness in Action	2004	Opposed
Disability Rights Commission (1)	2004	Opposed
Help the Aged (2)	2004	Opposed
Macmillan Cancer Relief (3)	2004	No position
Marie Curie Cancer Care	2004 & 2014/15	Opposed
Motor Neurone Disease Association	2004	Neutral
Terrence Higgins Trust	2004	In favour
Alzheimer Scotland	2014/15	Opposed
Inclusion Scotland	2014/15	Opposed
Parkinson's UK	2014/15	Neutral
Scottish Association for Mental Health	2014/15	"No view"
Scottish Disability Equality Forum	2014/15	In favour
Scottish Independent Advocacy Alliance	2014/15	In favour

(1) Now part of the Equalities and Human Rights Commission which discussed assisted dying at its March 2019 Board meeting and no agreement was reached on the issue. See <https://www.equalityhumanrights.com/en/corporate-reporting/board-meetings> (accessed on May 7 2020)

(2) Help the Aged has subsequently merged with Age Concern to form Age UK

(3) Now called Macmillan Cancer Support