



Disability Rights Commission

Assisted Dying Policy Statement October 2005

Introduction and background

The Disability Rights Commission (DRC) was set up by Act of Parliament in 1999 to work towards a society in which all disabled people are able to participate fully as equal citizens.

In considering sensitive, ethical issues like assisted dying, the DRC decides solely on the effect the issue would have on the lives of disabled people. We are not motivated by moral judgements or general ethical considerations about rights to live or die. We look at the debate through the very specific lens of equality for disabled people.

The DRC reached a policy position on assisted dying following Lord Joffe's introduction of a Bill in the House of Lords on the issue. People with terminal illnesses are likely to be classified as disabled people under the Disability Discrimination Act (DDA) definition. It was therefore necessary for the DRC to ensure that the views of disabled people were taken into account in the consideration of the Bill.

In reaching our position the DRC held seminars, took part in debates, ran an online poll, undertook research and consulted stakeholders and their organisations. Our conclusion is that views are deeply divided. What is clear is that most disabled people and their organisations think it is a much higher priority to legislate for rights to independent living and high quality health and social care – including palliative care – free of discrimination. Disabled people and their organisations currently view these issues more urgently than legislating for assisted dying. Without proper support it can be very difficult for some disabled people to achieve good quality of life. Many experience the fear that their lives will be put at greater risk if assisted dying were legalised before other priorities are settled and because without appropriate support achieving a good quality of life is much harder; others are opposed as long as discriminatory attitudes mean that disabled people's lives are viewed as being of lesser value than the lives of other citizens.

Given such significant reservations the DRC cannot support legalising assisted dying at this point in history.

The DRC provided written evidence to the Lords committee on the Assisted Dying (for the Terminally Ill) Bill¹ and we were called to give oral evidence, as was our Commissioner Jane Campbell who gave evidence in a personal capacity due to experience of medical professionals assuming she would rather die than be supported to live².

The DRC has faced criticism for our position on assisted dying. The issue is one of controversy and arouses strong emotions. However, no major national disability organisation supports the introduction of assisted dying legislation. The DRC takes very seriously its role as a Commission for **all** disabled people, working to further the rights and independent living of the broadest disability community. The DRC believes it would be a mistake to support assisted dying because of particularly complex individual cases in a society that does not recognise disabled people as equal citizens nor provide the services and support we believe are fundamental before assisted dying is legalised.

There are, of course, many issues involved in the debate around assisted dying. The DRC aims to cover the most important of those relating specifically to disability below.

Autonomy/choice

The DRC takes very seriously the principle of autonomy expressed by disabled people campaigning for a 'right' to die. The DRC believes that rights to live are equally important and are not currently being addressed. In the absence of rights and appropriate support to live it is likely that some disabled people would opt for an assisted death were this to be provided as an option through assisted dying legislation.

The DRC is a rights-based organisation and aims to uphold and further the rights of disabled people. We cannot conclude that legislating for a right to die would positively increase disabled people's autonomy or prevent disability discrimination. We believe it would result in the opposite – creating a 'false choice' given the lack of palliative care and support services in particular – and we believe it is likely to produce a further level of discrimination in the experiences of disabled people in the health service. It is plausible that a new assumption by medical professionals would be created in favour of ending life or emphasising the 'choice' of death in the absence of seemingly viable alternatives, due partly to prejudicial ideas on the quality of life and opportunities of disabled people.

¹ See <http://www.drc-gb.org/publicationsandreports/campaigndetails.asp?section=he&id=609>

² See page 5 for further information on the experience.

Evidence shows that assisted dying legislation in the Netherlands and Oregon has already produced the above, with physicians emphasising assisted dying over other choices relating to maintaining life. One physician in Oregon, for example, was recorded offering alternatives to an assisted death in just three sentences – which included derogatory comments on the value of the options³. All choice occurs in context. If someone believes they will be a ‘burden’ and have little or no access to services to enable them to live independently, or does not have the equipment that would enable communication, then any ‘choice’ they may make to die is not fully autonomous or balanced.

The DRC supports the rights of disabled people to make decisions relevant to all aspects of life and death. No one wishes to die in a state of distress or discomfort. The DRC calls for a more sensitive, in-depth understanding of the dying process, perhaps as part of curricula for schools. The DRC also believes that everyone should have the right to the care and support they need to die as comfortably as possible at home; the Government and Commons Health Committee have both stressed that this should be made more possible given that over half the people that would prefer to die at home are not currently enabled to do so⁴. We further believe that a better knowledge of living with disabilities is vital to produce a truer autonomy before assisted dying is legalised.

Government targets to reduce suicide

When people state they want to die the usual response from society is to offer support to try to enable them to see that life is worth living. The Government has set targets to reduce suicide to achieve exactly this. The DRC believes this should be no different in the case of disabled people who are terminally ill. If a terminally ill disabled person expresses the wish to die the first task should be the same as for a non-disabled person; to try to enable them to make the choice to live. Introducing the legal support for an assisted death before introducing the practical support some people need to live would be a negative step for a Government committed to reducing suicide rates.

Equality

Until disabled people are treated equally – their lives accorded the same value as the lives of non-disabled people, their access to necessary services guaranteed, their social and economic opportunities equal to those of non-disabled people – then the ‘right to die’ may jeopardise many

³ Hendin, 2004.

⁴ Commons Health Committee report, 2004. Stephen Ladyman MP, Parliamentary Under-Secretary of State, Department of Health, 2004.

disabled people's rights and opportunities to live and participate as equal citizens.

The likely effect of assisted dying legislation is that many disabled people would experience further negative assumptions about their position in society. Although assisted dying legislation would provide a legal definition of who qualifies to opt for an assisted death, the day-to-day reality will be assumptions made by the general populace about disabled people more widely, given the misconceptions of living with disabilities and a societal lack of understanding about disability.

Disabled people experience daily discrimination from others in society about their standard of living and quality of life. It is far from uncommon for a disabled person to hear someone say 'I couldn't live like that'. Assisted dying legislation will further such prejudice and misunderstanding of the fact that disabled people enjoy the same opportunities, standard of living and quality of life as non-disabled people.

There is also evidence showing how opinions alter towards impairments and disabilities through experience. Many non-disabled people make assumptions about what they could or could not live with/without. Direct knowledge through individual, family or friends' experiences changes discriminatory perceptions. Perhaps the clearest examples of this are around HIV/AIDS or cancer; knowledge of these conditions is at a much more advanced stage now than ever before. This is becoming truer for other conditions and disabilities as knowledge rises and disabled people become gradually more equal⁵.

Culture and society

Disabled people also describe more subtle pressures that can make life seem unbearable. In a culture that still views disability as a tragedy and disabled people as victims many people who become disabled assume initially that their life is over. This view is most apparent in the media and is worrying given that more than 80 per cent of disabled people become disabled as adults.

Dr Ian Basnett states:

"I became quadriplegic following a sporting accident 17 years ago. I was ventilator dependent for a while and said to people "I wish I was dead!" I am now extraordinarily glad that assisted dying was not legal. I think the first difficulty I faced was that, like many people, I

⁵ For further evidence on direct experience altering perceptions of living with disabilities please see Oliver, M et al, 1998 and Whiteneck, G and Menter, R et al, 1992.

had a terribly negative image of disability. When you suddenly become severely disabled you still have that viewpoint”.

For many newly disabled people, the lack of employment and social opportunities reinforces all too graphically the idea that ‘life is now not worth living’. The DRC has substantial evidence surrounding the lack of access disabled people have to work and social opportunities. Society is improving gradually but the DRC believes legalising assisted dying would be a step in the wrong direction and could undermine the advances in rights and opportunities that disabled people have spent decades securing – and others still being fought for.

Disabled people continue to challenge the lack of value placed on their lives. DRC Commissioner and Chair of the Social Care Institute for Excellence, Jane Campbell, went into hospital and was asked by more than one doctor the leading question ‘you won’t be wanting resuscitation, will you?’ They explained it would mean being on a ventilator and that she wouldn’t want that either, would she? After that she describes being too afraid to sleep as her life was in danger.

If assisted dying were legalised we do not know how many disabled and terminally ill people would succumb to subtle pressures or leading questions. There is no provision in the Bill for independent review of trends in practice; we would have to rely on doctors’ reports. Evidence from where assisted dying is legal shows that medical professionals do not accurately report their use of assisted dying legislation; only half of the assisted deaths in the Netherlands go reported for example⁶. The DRC is not aware of anywhere that has framed legislation that would provide adequate safeguards. The proposed legislation in the House of Lords does not assuage our fears in this area.

Legalisation of assisted dying in any country reflects and impacts upon its view of disability, impairment and terminal illness. The DRC strongly believes that the UK does not yet hold a mature enough attitude towards disability, terminal illness and disabled people’s lives. The media and medical profession in particular still portray disabled people as weak, passive recipients of society rather than as active contributors to it. Societal attitudes are changing slowly and the DRC supports the establishment of a single equality commission representing race, faith and religion, gender, sexuality, age and disability to progress attitudes further and sustain the pressure of disability as a rights issue, rather than a concern only for charity or pity. Until the DRC believes all disabled people

⁶ Hendin, 2004.

have the opportunity to participate fully as equal citizens we do not believe our society is ready to legalise assisted dying.

The DRC does not believe disabled people are yet accepted as equal citizens in the UK. We believe equal citizenship to be a set of basic rights and the means to exercise those rights effectively⁷. Until disabled people have the rights to live independently a culture of dependency will exist that encourages the medical and media portrayal of disabled people as somehow inferior and in need of charity or pity. Legalising assisted dying in a culture of this kind would encourage it still further.

Legalised assisted dying outside the UK

The DRC is not aware of a country/state that has managed to frame a law that allows assisted dying for people with terminal illnesses whilst ensuring that disabled people are protected from coercion, pressure, and involuntary euthanasia.

The belief that legalising assisted dying in the UK would create a stricter and safer structure for what already occurs is erroneous; in the Netherlands just half of the instances of assisted dying are reported and a quarter of all assisted deaths take place where there has been no explicit request from the patient. In one case a physician took the decision to assist a female patient to die as it was thought her religious beliefs would prevent her from requesting the assistance; she was a nun⁸.

The DRC does not believe it is suitable to legalise assisted dying and then establish reasons for its usage; this would be putting the cart before the horse. Thorough research is required on why assisted deaths are occurring illegally in the UK now. This could be useful in addressing the current situation and possibly assist in the formation of future, safer legislation.

Until the DRC is convinced that sufficient regulation and safeguards can and will be put in place to ensure the rights to life of disabled people we can not support the legalisation of assisted dying in the UK.

Living with disabilities/terminal illnesses in the UK

For the DRC, assisted dying – which could be offered in cases of ‘unbearable suffering’ – raises huge issues about how ‘unbearable’ it is for some people to live with disability or terminal illness in Britain today – and the reasons for this.

⁷ See Miller, 2005.

⁸ Hendin, 2004. One physician took the decision for a female patient as it was thought her religious beliefs would prevent her from requesting the assistance. She was a nun.

Unbearable suffering is not just a matter of physical pain. For example, someone may find life ‘unbearable’ when they have become physically unable to communicate and no one can afford the equipment that would enable them to have a vital connection with their family/the people around them. In one US case a man fought vigorously for the right to die via the courts and media coverage mentioned his communication impairment. A software company provided specialist equipment and others raised funds to provide him with home-based support. With this support and equipment he regained the dignity and independence he thought was lost forever and decided that he no longer wished to die. Life was ‘bearable’ again.

Our concern about some of the language used in Lord Joffe’s Bill was also recognised by the Lords committee that examined the Assisted Dying (for the Terminally Ill) Bill, which stressed:

‘The need for qualifying conditions for assisted suicide or voluntary euthanasia to be set which reflect the realities of clinical practice as regards the prognosis of terminal illness and which define a patient’s suffering in as objective a manner as possible – eg ‘unrelievable’ rather than ‘unbearable’ suffering.’

The committee believes that the Bill needs redrafting in this respect and the DRC supports that call.

The DRC believes that we should legislate to give people rights to essential support, to provide dignity and independence, before we consider legalising death as an alternative. This is particularly important with regards to palliative care provision for example – which is not available to many people with terminal illnesses and tends to be restricted to people with cancer even where it is available.

The current Bill states that a terminally ill person must be **offered** palliative care treatment. This does not account for the patchy existence of palliative care services across the country that the House of Commons Health Committee recently reported on⁹. Nor does it account for the fact demand for the service currently outstrips supply.

The DRC would like reassurance that palliative care would not just be offered, but be routinely **available** to all disabled people with terminal illnesses before assisted dying were legalised. Given who the Bill is targeted at, being offered palliative care is not a ‘real’ option if there is a six month waiting list for treatment. To legalise assisted dying before the

⁹ See <http://www.publications.parliament.uk/pa/cm200304/cmselect/cmhealth/454/454.pdf>

service is available nationally and to the same standards could create a postcode lottery false choice between palliative care and assisted dying – and would undermine current Government initiatives to roll-out coverage and double palliative care staff by 2015, as well as introducing another layer of health inequality.

Services inevitably involve costs and although in Britain we have a National Health Service choices offered to service users are resource-based. Assisted dying could become an insidiously ‘attractive’ and inexpensive option in comparison to funding the treatment and support people need. This is of particular concern given that a survey by the Nuffield Trust and the Nursing Times found that the NHS is already failing to care adequately for hundreds of thousands of patients who die each year, many without proper pain relief¹⁰.

Someone near death may find life ‘unbearable’ without good palliative care and someone who is disabled long-term may find life ‘unbearable’ if there is inadequate home-based support, eg if they have to live in an institution or in undignified circumstances at home. The DRC believes that disabled people should have the right not to be institutionalised against their will. A local newspaper reported an elderly mother having to wash her disabled adult daughter with a bucket and flannel because support services were unable to fund a level-floor shower they had been assessed as needing¹¹. This could be deemed unbearable and is exactly the kind of situation the DRC would like to see resolved before the passage of assisted dying legislation.

The concern of many disabled people and their organisations is not just that assisted dying legislation would be problematic enough, but that although it would initially be enacted for disabled people with terminal illnesses, it could at a later stage be rolled out further to include more disabled people. This has been the case in the Netherlands.

It may also be ‘unbearable’ to witness your partner becoming exhausted and to feel you are now nothing but a ‘burden’. Studies in Oregon and Holland find that a substantial proportion of people seeking assisted deaths give ‘not wanting to be a burden’ as their reason. We believe the policy imperative is to introduce an agreed entitlement to essential services for independent living and palliative care when needed so that people do not feel a burden – this could possibly cover support for family members and carers also. That way ‘unbearable’ suffering can be turned into a bearable life – and possibly a more bearable death.

¹⁰ ‘How do you deal with death?’ Nursing Times 1st February 2001.

¹¹ East Anglian Daily Times.

Given that evidence consistently shows that disabled people do not have access to adequate support or health services, the DRC believes that in order to offer 'real' alternatives to opting for an assisted death, it is imperative that service provision is improved before legalisation of assisted dying takes place.

Next steps

The DRC believes it is fundamental to create a society in which disabled people can participate fully as equal citizens. We believe there are a number of steps that need to be taken before assisted dying legislation is progressed further. The most important items are:

- Abolishing discriminatory guidelines and practice on withholding and/or withdrawing life-saving treatment for disabled people¹²;
- Producing demonstrable reductions in discrimination and inequalities in health services;
- Improving the quality and capacity of palliative care provision equally across the country and ensuring supply does not lag behind demand (as is currently the case);
- Implementing effective rights to independent advocacy and communication support; and
- Implementing rights to independent living to create a society where all disabled people are able to participate fully as equal citizens¹³.

The DRC believes that legislating for assisted dying would set disability rights back and be a negative step until the issues above have been addressed. We regret the demand for rapid action on assisted dying legislation given the inaction on providing the support, services and independence for disabled people to participate fully and without discrimination as outlined above.

Conclusion

The DRC believes that the legalisation of assisted dying would not be safe for disabled people at the current time and until effective rights to independent living and equal citizenship are established. The DRC believes assisted dying could create an additional and discriminatory pressure on some disabled people to choose death in a society where they are made to feel inferior and a burden on relatives, carers and public resources, where there is a lack of social support and appropriate health services to aid dignity and independence and often a lack of palliative care.

¹² As supported in the High Court by Lord Justice Munby in the *Burke v GMC* case backed by the DRC.

¹³ For further information on DRC Independent Living work visit the DRC website at www.drc.org.uk

These pressures could add to the sense amongst some disabled people that the 'right' thing to do may be to opt for death. British society needs to achieve greater equality for disabled people before it is safe to legislate for assisted dying.

The DRC is working towards a society in which disabled people can participate fully as equal citizens. Society is moving towards our objectives but there is still some way to go before they are realised. We believe legalising assisted dying now would set back disability rights considerably; undermining the progress made over the last two decades by disabled people, and we believe that legalisation of assisted dying at the current time would create the potential for heightening discrimination against disabled people.

Further information

For more information please contact Neil Coyle, DRC Parliamentary Officer, on 020 7543 7039 or email Neil.Coyle@drc-gb.org