End of Life Assistance (Scotland) Bill

Lothian Centre for Inclusive Living (LCiL)

The Lothian Centre for Inclusive Living (LCiL) is a user-led Disabled People's Organisation which supports the right of disabled people to live independently in the community of their choice. LCiL is managed by a Board of Directors, over 50% of whom are disabled people. LCiL is part of the worldwide Independent Living Movement and the Disabled People's Movement which work for social justice and full equality for all disabled people. Our mission statement is: ‘LCiL works with disabled people to take control of their own lives, support their choice to take up their rights and enable their full participation in society.’

**Question:** Do you agree that a person should be able to request end of life assistance from a registered medical practitioner?

As an organisation of disabled people we recognise that even amongst disabled people there is divided opinion on these proposals. However, as an organisation controlled and led by disabled people, we have a number of serious concerns and objections to the proposed End of Life Assistance Bill as outlined in our response below.

**Rights, Autonomy and Choice**

LCiL works to promote Independent Living and equality for disabled people within society. Independent Living is about disabled people having the same rights and choices as non-disabled people. The End of Life Assistance Bill proposes to offer ‘choice’ to disabled people for assistance to die, and whilst we fully respect the individual’s right to choose, we do not believe that this can ever be a truly independent or free choice while disabled people continue to face significant discrimination and disabling attitudes in society. As one LCiL member recently stated on the issue of choice and assisted dying:

‘We need to be clear about what we mean by ‘choice’. There is a kind of choice associated with a ‘life’ politics (to do with justice, equality and participation) and a kind of choice associated with ‘lifestyle’ politics (to do with consumerism, promoted relentlessly by the media). The first presumes a certain level of emancipation from the fixities of tradition and from conditions of hierarchical domination. In terms of the Disabled People’s Movement, this means emancipation from institutionalised relationships of dependency, whether within the ‘care’ industry or the family, and from representations of impairment/disability as a personal tragedy which embed these oppressive relationships. What is required for full and free choices to be made are the conditions of life which make it possible for disabled people to be able to respect and value themselves for who they are without having their whole experience of life framed and distorted by the dominant (non-disabled) culture’s view of impairment/disability as a lamentable deficiency and tragedy.’
Question: Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

- We disagree with the eligibility criteria of the first category ‘anyone who has been diagnosed as being terminally ill and finds life intolerable’.

We are deeply concerned that the first category could cover a very large number of disabled people with progressive and life limiting conditions like Multiple Sclerosis, Muscular Dystrophy, Motor Neurone Disease, Cancer, Parkinson’s Disease, etc. LCiL has 20 years of experience of working with disabled people with progressive conditions and people diagnosed with life limiting conditions in supporting them to access Independent Living. In our experience, disabled people with life limiting conditions can live full and valued lives as long as they have the right practical and emotional support.

Emotional Support and Counselling
LCiL runs a national telephone counselling service, Your Call, for disabled people across Scotland. This is staffed by professionally trained counsellors, who are all disabled people themselves and therefore have an understanding of what it means to live as a disabled person. This service often provides emotional support to disabled people with life limiting conditions who are feeling depressed and suicidal. On the issue of assisted suicide, the Scottish Government is currently investing money in the prevention of suicide and in the ASSIST training programme, and yet at the same time the End of Life Assistance Bill is proposing a policy of assisted suicide for disabled people. We recommend that rather than support to end life, there should be further investment in counselling and suicide prevention services, in palliative care services, health and social care services.

Investment in Palliative Care
There is much evidence that continued investment in palliative care services can ensure good end of life care for people with terminal illnesses. Currently, lack of palliative care services and negative or discriminatory attitudes from medical professionals often mean that some disabled people literally have to fight for their right to life. For example, we are aware of several disabled people in Lothian, who have had Do Not Attempt Resuscitation Notices (DNAR) placed on them against their wishes, simply because doctors have made false value judgements about someone’s quality of life. There is a real fear amongst disabled people that legalising assisted dying would only perpetuate these discriminatory attitudes. And whilst the media and the rest of society continues to portray disabled people as living tragic and burdensome lives, disabled people will continue to encounter disabling attitudes, institutional discrimination and multiple barriers on a daily basis from public services such as the NHS.

- We strongly object to the eligibility criteria of the second category in the proposed Bill - ‘those who are permanently physically incapacitated to such an extent as to not be able to live independently and who find life intolerable...’
Many disabled people require support and assistance to live independently. To those in the Independent Living Movement, independent living means ‘disabled people of all ages having the same freedom, choice, dignity and control as other citizens. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life’.

The Right to Independent Living
LCIL is a member of Independent Living in Scotland (ILIS) and is actively working in partnership with the Scottish Government to promote Independent Living in terms of access to housing, transport, health and social work services, equipment, Direct Payments, employment and education. The Scottish Government and COSLA recently signed an agreement ‘A Shared Vision of Independent Living’ to promote equality of opportunity for disabled people at home, at work, in education and in the social and civic life of the community. We would like to see continued support for this vision from all sectors of society and the government, rather than continually focusing on promoting assisted dying.

The second category of eligibility criteria could be applied to any disabled person who is in receipt of social care services or disability benefits such as Disability Living Allowance or Attendance Allowance. In fact any individual with an impairment, who could demonstrate they needed assistance in their daily lives, would become eligible for assistance to die. Given that it is estimated that one in five of the population is disabled, the eligibility criteria could potentially cover hundreds of thousands of people in Scotland.

Disabled people currently have to fight very hard to access the support that they need, support to live independently and to be included in the mainstream of society. Disabled people face a continual battle for social work services, accessible housing, health services, transport, access to leisure activities, social activities and family life. It is felt amongst many disabled people in the Independent Living Movement that there is not enough discussion or debate around resources for social care services and assistance to live.

The Disabled People’s Movement
According to the Disabled People’s Movement, Independent Living is about achieving full equality and social justice for disabled people; it is not about disabled people being ‘dependent’ or ‘life being intolerable’. Under the Social Model of Disability, it is the barriers within society – physical, political, economic and attitudinal barriers which disable people, rather than their individual impairments. We are concerned that the End of Life Assistance Bill makes no mention of the Social Model of Disability, the Disability Rights Movement or the Independent Living Movement. Furthermore, as far as we are aware, not one disability organisation in the UK has come out in support of legalising assisted suicide for disabled people. In fact many disability rights organisations have strongly opposed the legalisation of assisted dying including: the National Centre for Independent Living (NCIL), RADAR, the former Disability Rights Commission (DRC), the Not Dead Yet campaign.
The former Disability Rights Commission (DRC) previously issued the following statement on assisted dying:

‘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. 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. 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.’

As a user-led organisation of disabled people, the Lothian Centre for Inclusive Living (LCiL) fully supports the statement from the former DRC and would urge you to invest in support for assisted living rather than assisted dying.

Catherine Garrod
Information Co-ordinator
Lothian Centre for Inclusive Living
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