End of Life Assistance (Scotland) Bill

Equality and Human Rights Commission Scotland

As part of our submission I have also posted you 7 copies of a written report and DVD from our “Equal to the End?” debate.

End of Life Assistance (Scotland) Bill: Written Evidence at Stage 1

1. The Equality and Human Rights Commission (the Commission) has a statutory duty to promote equality and diversity, work towards the elimination of discrimination, promote human rights and build good relations between and among groups. The Commission is a non-departmental public body established under the Equality Act 2006 – accountable for the use of its funds, but independent of Government. The Commission has responsibilities in seven areas of equality: age, disability, gender, gender identity, race, religion or belief and sexual orientation, as well as human rights. It has a statutory Disability Committee, established under Schedule 1 Equality Act 2006, with a decision-making role in relation to certain disability matters.

2. The Commission welcomes the opportunity to provide written evidence in response to the End of Life Assistance (Scotland) Bill. The subject matter of this bill is one that arouses significant individual and public passions. We are aware that this is a complex medical, legal and ethical issue which will benefit from public debate and parliamentary scrutiny.

3. It is important to note that the Commission does not, as yet, have an agreed policy position on the issues raised by the Bill, and nothing in this response should be taken as indicating a settled view. The Commission has recently responded to the Department of Public Prosecution’s consultation in England and Wales on an interim policy for prosecutors in assisted suicide cases1 which touches on some of issues considered by the End of Life Assistance Bill. As we do not have a concluded policy position on assisted suicide, this response will focus on our good relations work in this field and will consider some of the disability equality issues raised.

Good Relations Remit

4. In anticipation of the introduction of this bill the Commission hosted a debate, “Equal to the End?”, in March 2009. The Commission approached the debate in a neutral role, using our statutory good relations remit to bring together divergent views to debate end of life choices and facilitating public engagement with complex ethical subject matter. The ‘Question

1 Available from: http://www.equalityhumanrights.com/legislative-framework/consultation-responses/
Time’ style event focused on the main issues surrounding voluntary euthanasia and assisted suicide. The four speakers on the panel represented contrasting views on this issue, as did participants in the discussion that followed with contributions from, among others, religious bodies, disability groups and medical ethicists. The event allowed a wide range of concerns to be aired, analysed, and countered by opposing responses. A discussion paper based on this event and the DVD of the debate is included as part of this evidence.

Disability Discrimination

5. The Commission recognises that the debate about assisted suicide in part turns on the question of personal autonomy. Individual autonomy is recognised under Article 3(a) of the UN Convention on the Rights of Persons with Disabilities as one of its general principles.

6. However the principle of autonomy and the right to make choices about one’s own body must be reconciled with the need to protect individuals who may be coerced into ending their life prematurely. The danger of people internalising negative constructs of disability, hence feeling under pressure to choose death to avoid becoming a burden on family, friends or society in general, was recognised by participants in our “Equal to the End?” debate. Participants expressed concern that allowing disabled people assistance to commit suicide would further devalue the life of disabled people as it could reinforce the view that some lives may be seen to be worth living and some not. This would further perpetuate assumptions about disabled people’s quality of life and negative attitudes towards disabled people across society. Many disabled people have spoken about their experience of ‘diagnostic overshadowing’: the tendency of some medical professionals to medicalise disability and to therefore allow diagnosis and prognosis to be tainted by unwarranted assumptions about a disabled person’s life:

“There’s plenty of evidence...that disabled people who have conditions which cannot be cured or treated are scared to go into hospital because they’re scared that their treatment would be worse. Even Baroness Campbell had a No Resuscitation order slapped on her without her consent, without her knowledge.”

2 The Offences (Aggravation by Prejudice) (Scotland) Act 2009 demonstrates the recognition of the Scottish Parliament of the existence and impact of negative attitudes towards disability within society and represents a challenge to these attitudes. The Commission is currently undertaking a formal inquiry into Disability related harassment and its causes. For more information visit: http://www.equalityhumanrights.com/legislative-framework/formal-inquiries/


7. One of the Commission’s concerns therefore with the draft legislation is the criterion at section 4(2)(b) which sets out that a person is able to request suicide under the provisions of this bill if the person is:

“Permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable”.

We would argue that the legislation has been too broadly drawn with the inclusion of this provision. To include the ‘permanently physically incapacitated’ in this legislation suggests that the life of a disabled person who is not terminally ill is worth less than the life of a person who is not disabled. This was illustrated by the public and media perceptions of the case of Daniel James, a severely depressed tetraplegic who persuaded his mother to facilitate his suicide in Switzerland:

“…. his wish to die was considered acceptable because he was a disabled man. The same desire to die in a non-disabled person of either sex or any age would be considered to be unreasonable and a sign of mental illness”.\(^5\)

8. Additionally, we anticipate difficulty with the use of the phrase ‘to live independently’ in the legislation. The Independent Living Movement in Scotland has gained a great deal of momentum over the past four decades. The central tenet of the movement is:

“ … disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. 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”.\(^6\)

9. Those within the movement have successfully created a positive image of disability that challenges societal stereotypes about the lives of disabled people being so ‘tragic, burdensome and insufferable that [they] must want to die.’\(^7\) Utilising ‘independence’ in this context may risk reversing hard-won gains achieved by the Independent Living movement. Some individual activists within the movement have already made clear how

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\(^6\) For more information about Independent Living in Scotland please visit: [www.iwis.co.uk](http://www.iwis.co.uk)

uncomfortable they are with the term being ‘appropriated’ for use in this legislation.\(^8\)

10. We would also suggest that the inclusion of those defined as being ‘permanently physically incapacitated’ in this legislation should be considered in light of the anticipated cuts to public sector spending across Scotland. Such cuts may be the difference between what makes life tolerable or intolerable for disabled people.\(^9\)

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\(^9\) In light of political and economic developments the Commission is currently undertaking research called ‘Counting the Cost’ which seeks to: analyse funding and organisational decisions made by local authorities; to examine the impact of these decisions on particular equality groups; and to identify the extent to which local authorities have taken their public sector duties into account when making such decisions. The research will be looking at the race, gender and disability duties and where authorities are being reviewed in terms of the Disability Equality Duty the research will focus on the provision of non-statutory services to disabled people, and the impact of decisions on the lives of disabled people. The research will be published by late Summer 2010.