End of Life Assistance (Scotland) Bill
Independent Living in Scotland (ILiS)

Contents
1. The Independent Living in Scotland Project
2. Independent Living
3. Eligibility for assisted death within the Bill
4. Appendix 1: Vision for Independent Living in Scotland
5. Link to ILiS DVD on YouTube

1.0 The Independent Living in Scotland project

1.1 The Independent Living in Scotland (ILiS) project is funded by the Scottish Government, hosted by the Equality and Human Rights Commission (EHRC) and led by a group of disabled people. It aims to support disabled people to have their voices heard and to build the disabled people’s Independent Living Movement (ILM) in Scotland.

This response has been prepared by the ILiS project team on behalf of the ILiS Steering Group. It is intended only to respond to the specific question posed in the consultation: Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

2.0 Independent Living

2.1 Independent living means:

‘Independent living means 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.’

2.2 For disabled people to live their life in the way they choose, the following rights must be in place:

• inclusive education and training
• equal opportunities for employment
• full access to our environment
• fully accessible public transport
• technical aids and equipment
• accessible and adapted housing
• an income including income from benefits
• accessible and readily available information
• advocacy and working towards self-advocacy
• counselling, including peer counselling
• accessible and inclusive healthcare provision
3.0 Eligibility for assisted death within the Bill

3.1 According to the Bill a designated practitioner can approve “the formal request” to be assisted to die, if satisfied that the person meets one of two criteria. The second of the criteria is that the person is “permanently incapacitated to such an extent as to not be able to live independently and who finds life intolerable” and that “they are making the request voluntarily and the requesting person is not acting under any undue influence in making the request”.

3.2 We have a long way to go before independent living as outlined at 2.1 and 2.2, becomes the reality in our society, where disabled people can not only “tolerate” their lives, but enjoy them and contribute to their communities. Our political, social and service structures (including, but by no means limited to, education, health, transport, planning and housing) do not yet fully support the entitlements of disabled people to independent living, in terms of ensuring they have choice, control, freedom and dignity in their own lives (please see as a detailed example, the ILiS response to the Scottish Government’s consultation on the Self Directed Support Strategy. May 2010). We believe that the route to ensuring this is to see independent living in the way outlined above. It is to tackle the barriers and to support disabled people to live their lives in the way they choose, as others take for granted.

3.3 Indeed, the Scottish Government see independent living in this way too. Their commitment to it is strong and wide ranging. The Independent Living Core Reference Group, consisting of officials from the Scottish Government, COSLA and the Independent Living Movement has signed a joint agreement that commits them to ensuring independent living is the reality for all of Scotland’s disabled people (Appendix 1). It states that:

“Independent living is about choice, control, freedom and dignity. This is what we (Scottish Government, COSLA and the Independent Living Movement) want for disabled people in Scotland – at home, at work and in the community. We believe that independent living for all disabled people in Scotland is the rights thing to do. It is right for each person – to have equality – no prejudice or discrimination. It is right for all people; more equality means we are stronger together. It is right for our economy – diversity means more success. We want to make changes for disabled people that will last. We want the best. To get the best, we must listen equally to everyone.”

3.4 Despite this agreed approach, the End of Life Assistance Bill does not define living independently in this way. In fact, the Bill defines living independently as “dependency criteria”. This is entirely inconsistent with the Scottish Government’s wider approach, which sees independent living as support to empower disabled people to have choice, control, freedom and dignity. The Bill suggests that the opposite of “living independently” is
“dependency”. This is disempowering for disabled people but also contradicts and undoes the years of work undertaken on this agenda by the Independent Living Movement, the Scottish Government and numerous partners.

3.5 More worrying than this, is the implication that if an individual needs support to live their life in the way they choose, as others take for granted, they are considered “dependent”. If the individual then begins to “find life intolerable”, for any reason (not inconceivable if services and structures continue to view disabled people as “dependents” and so do not deliver on independent living) then they are eligible to be assisted to die. The inclusion of criteria based on the misconception of independence is of concern.

3.6 In addition, and consistent with such misconception, there is no mention throughout the Bill of the barriers facing disabled people that may contribute to them finding “life intolerable”. For example, section 9, subsection 2(b) of the Bill considers only palliative care as an alternative. This does two things. Firstly, it only offers an alternative to those who are terminally ill, suggesting that there are no alternatives to those who need support to live but who are not terminally ill, and secondly, it fails to account for the structures within society that prevent independent living from being a reality and so making life “tolerable”.

3.7 Furthermore, despite such a strong, high level and public commitment to independent living as described above at section 2.1 and 2.2 and outlined in Appendix 1, there is still huge inconsistency in societal understanding of independent living and more importantly, in approaches based on that understanding. This worries the ILiS project further in terms of the roles that the bill prescribes for ‘witnesses’, ‘designated practitioners’ and ‘psychiatric assessors’ in determining whether someone is acting without duress or indeed has all the information about the alternative support available to them.

Case study 1

3.8 “When my social worker told me that they had to cut budgets I had no idea that would mean things were going to get so bad. I need help to go to the toilet. There is not enough money to take me to toilet more than twice a day. When my carer comes in to me in the morning, I go to the toilet and before she goes, she puts on an incontinence pad for me so that I can do the toilet in my chair. I have been told to wet or soil myself. When they come back at night to make my dinner, they change my pad.

I am so embarrassed, I don’t let my friends visit me anymore. I am so isolated and sometimes I can’t see a way out”.

Jean, 58

3.9 We would suggest this case illustrates that the inclusion of those defined as being “permanently incapacitated to such an extent as to not be able to live independently and who find life intolerable” in this
legislation, must be considered in terms of the support available. In addition, it must 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.

3.10 Due to our concerns about the understanding and interpretation of independent living, we would argue that the legislation has been too broadly drawn with the inclusion of the provision to assist an individual to die on these grounds.

3.11 In addition to our concerns around language and understanding, we believe that to include people who are ‘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 is illustrated in the following case studies:

Case study 2

3.12 I am a disabled woman who cannot live without support, I have a personal assistant with me 24 hours a day. According to the Bill, I cannot “live independently”. I have recently gone through some troubling times in my life, including that I have split with my partner. Sometimes, like many people in this circumstance, I have found life intolerable as a result.

I am alarmed that, unlike my peers who have also found life intolerable at the loss of a significant relationship in their life, I could be assisted to die, if I sought that support. The pre-requisite of which is that I need support to live.

Disabled woman, 28, Stirling

3.13 The public and media perceptions of the case of Daniel James, a young man who had severe depression and who was also tetraplegic as result of a sporting injury, further illustrates this. He 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”

4 Conclusions

4.1 We object to the use of the criteria of people who “are permanently physically incapacitated to such an extent as to not be able to live independently and who find life intolerable”

4.2 We believe, that the Bill is inconsistent with the overall approach to independent living taken by the Scottish Government and to which is committed, morally and publically (Appendix 1).
4.3 To include specifically people who are ‘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.

4.4 The inconsistency in language and understanding of “independent living” means that for those whose life has become “intolerable” (possibly as the result of barriers in society preventing them from fully enjoying life), the checks and balances provided in the bill do not offer any comfort that they have any safeguarded alternatives, other than to be assisted to die.

5 Link to ILiS DVD on YouTube

http://www.youtube.com/user/EqualityHumanRights#p/a/u/0/QBHuVfKXmyk

Pam Duncan
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Independent Living in Scotland project
c/o Equality and Human Rights Commission
Appendix 1

Independent Living – A Shared Vision

This statement is jointly signed by the Scottish Government, COSLA (Convention of Scottish Local Authorities) and the Independent Living in Scotland (ILiS) Steering Group. It sets out our agreed vision, based on the core principles of choice, control, freedom and dignity, that disabled people across Scotland will have equality of opportunity at home and work, in education and in the social and civic life of the community.

The Scottish Government, local government and the Independent Living in Scotland Steering Group are committed to working together, as equal members of the Independent Living Core Reference Group. Our commitment to independent living for all disabled people in Scotland is founded on our belief that it is the right thing to do, and it is in Scotland’s interest:

- It is right for the individual – to be free from prejudice and discrimination; and to participate within society as full and equal citizens;
- It is right for society as a whole – a more equal society will have greater strength and social cohesion; and
- It is right for our economy – the more diverse an economy, the more innovative and high growth it is; and the more successful it will be at attracting talent.

We have much to learn from one another, and our working partnership is based on a model of co-production and inclusion. We recognise that there is scope to deliver lasting change for disabled people living and working in Scotland. This can only be achieved by thinking and acting aspirationally and by ensuring that all voices carry equal weight and are well respected. This approach will help deliver our shared vision across our respective areas of responsibility.

Our vision and objectives fits strongly with the National Performance Framework and with the Single Outcome Agreements, agreed by Community Planning Partnerships across Scotland. We will work to make these outcomes inclusive of independent living principles and practices, so that disabled people can be an integral part of Scotland’s future development as a country of equality of opportunity and quality of life for all of its citizens.

We believe that by working with disabled people, the Scottish Government, local authorities and their community planning partners across Scotland will be better equipped to identify the best approach to achieving agreed outcomes, making the most effective investment of resources and taking account of the priorities and needs of all of local communities.
Our overall objective is to deliver real choice and control for disabled people in all areas of life and all parts of Scotland. We recognise that this will require continued effort by all partners. It will take time to achieve this vision, but this joint statement is an important milestone in developing the shared strategic approach that will make it a reality.

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