End of Life Assistance (Scotland) Bill

Inclusion Scotland

1 Background

1.1 Inclusion Scotland is a network of disabled peoples' organisations and individual disabled people. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives and to encourage a wider understanding of those issues throughout Scotland. We are well placed to comment from the perspective of expected “beneficiaries” of the End of Life Assistance (Scotland) Bill’s provisions.

2 Questions: “Do you agree that a person should be able to request end of life assistance from a registered medical practitioner?”

2.1 No: Inclusion Scotland questions whether the State should ever give support to the idea that a person in despair be given State assistance to end their lives. Though suicide rates in Scotland have been in decline over the last decade, we still have the highest suicide rate of any of the four nations of the United Kingdom\(^1\). The Scottish rate of suicides amongst young men is twice as high as in England & Wales. Ironically the Scottish Government has just begun an expensive, high profile media campaign to dissuade people in a depressed state from committing suicide. Yet this Bill endorses the view that there are some circumstances in which suicide or “assisted death” is a valid option.

2.2 This Bill’s provisions divide society into two groups. One group would be eligible for state assistance in committing suicide; the other would not. We question the grounds on which this division has been made.

2.3 The first group eligible for assistance are those with a terminal illness and likely to die within the next six months. This group are treated as disabled people in terms of entitlement to Disability Living Allowance. The second eligible group are people who “are permanently physically incapacitated to such an extent as to not be able to live independently and who find life intolerable...”. This can include all disabled people who have acquired physical or sensory impairments as well as people with congenital, progressive or irreversible conditions.

2.4 Thus all of those who would qualify for assistance would be disabled people. The vast majority of those excluded from assistance would be non-disabled people. That suggests that the lives and existence of one group are being treated as of less value than the other. Yet, with the exception of a few vocal individuals, assisted dying legislation is not supported by disabled people.
2.5 This is demonstrated by the formation of “Not Dead Yet UK”\(^2\) an organisation of disabled and terminally ill people opposed to assisted suicide in response to an earlier assisted suicide Bill at Westminster.

2.6 Other disabled people’s organisations opposed to assisted dying include RADAR (Royal Association for Disability Rights); National Centre for Independent Living; UK Disabled People’s Council and Disability Awareness in Action.

“If as much work, effort, time and money went into improving the lives of disabled people as has been spent over the years on the idea that disabled people would be better off dead, then perhaps we would not be so disabled and would find work.” – Kenny Milne, Contact 100 member

2.7 We note that to qualify for assistance a person would also have to find life “intolerable”. Yet a non-disabled person who finds life intolerable would not receive assistance. This suggests that the “dependency” that a disabled person experiences is somehow more worthy of death. The State, in assisting their suicide, would be condoning the stereotype that disabled people’s lives are so valueless, tragic, burdensome and insufferable that they must want to die.

2.8 If this Bill succeeds it will create invidious pressure on the disabled and terminally ill to do right by their families and the state. It will be the cheapest, quickest and simplest option. The so-called safeguards in the Bill would not prevent insidious and sometimes even unconscious pressure being brought to bear on disabled people by carers, health and care professionals, as all it seeks to bar is pressure brought to bear for monetary gain.

2.9 All research studies conducted on assisted dying show "not wanting to be a burden" as the principal reason for seeking death. This point is made in the Financial Memorandum to the Bill pointing out that costs of ending disabled and terminally ill people’s lives will be significantly less than providing care & support.

2.9 Inclusion Scotland believes that the Assisted Dying Bill will begin a journey that ends in an accepted culture of "mercy killing" of disabled people. Legalising premature death of disabled people undermines their right to support to live with dignity and the State’s responsibility to ensure their access to support and care services. If this Bill succeeds, despair at disabling conditions will be endorsed as a reasonable expectation for which early state-sanctioned death is an effective remedy.

3 Question: Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

3.1 No. We object to the wide 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…” There is no attempt to define not being “able to live independently”; anyone who requires even minimal care
and assistance (e.g. meals on wheels or help in reading their mail) could conceivably fit this criteria. This is referred to within the Bill as “the dependency criteria”. Physically impaired people are categorised as “dependent” if they receive any support whatsoever.

| “The morality of helping disabled people to kill themselves rather than providing care and support has to be questioned. By analogy, parents who decided that they no longer wanted their children, should be allowed to kill them, because this is cheaper than looking after and supporting them” - Marion Hersh, Contact 100 member |

3.2 Disabled people object to this categorisation of “dependency” as it is demeaning and contradicts the social model of disability which states that it is society’s failure to make necessary adjustments to impairment which “disables” an individual and restricts their ability to participate fully in community life.

3.3 It would mean that over 80% of those currently receiving Attendance Allowance (116,000 people) and Disability Living Allowance (another 144,000) on the grounds of physical or sensory impairments would meet the criteria for end of life assistance. In total over 250,000 Scots would be eligible for assistance as they have either care or mobility needs to be met in order to support them in living “independently”. Please also note that an estimated 30% of those entitled to these benefits do not apply for them.

3.4 We note that the Scottish Government and COSLA endorsed a “Shared Vision of Independent Living” last December which states that “It is right for the individual….to participate within society as full and equal citizens”. The Government is therefore committed to supporting disabled people to play their full role as contributors to the economic and social wealth of society. Yet this Bill questions whether their lives are worth living at all if they have care needs.

3.5 Many disabled people’s lives are severely restricted – trapped in residential and nursing homes, isolated and segregated from their families and friends; trapped in inaccessible housing; denied an equal education and training opportunities; confined by inaccessible transport, prejudice and lack of access in the workplace; provided with support services which meet basic needs only and denied engagement in social and community life.

3.6 In such circumstances many of those 250,000 disabled people do occasionally become depressed and desperate. They should not be encouraged to consider suicide at such points in their lives. Instead Inclusion Scotland urges the Scottish Parliament to commit to safeguard and invest in care & support services that enable people live their lives to their full potential. Disabled people want the right to live, as non-disabled people do, and not the right to die.
4 Assisted Dying in Holland

4.1 According to the American experience, cited in this Bill’s Financial Memorandum, the numbers likely to take the option of assisted death will remain low. However the Memorandum fails to mention our near neighbour, Holland, where euthanasia law was liberalised several decades ago. Surely its experience of how the law and practice of assisted dying has developed is relevant?

4.2 In 1991, the results of the first official government study of the practice of Dutch euthanasia were released. The Remmelink report documents the prevalence of voluntary and involuntary euthanasia in Holland. The report indicates that despite court-approved euthanasia, guidelines developed to protect patients, abuse has become an accepted norm. In 1990:

- 2,300 people died as the result of doctors killing them upon request.
- 400 people died as a result of doctors providing them with the means to kill themselves (physician-assisted suicide).
- 1,040 people died from involuntary euthanasia, i.e. doctors killed these patients without their knowledge or consent. Of these patients 72% had given no indication that they would want their lives terminated.
- 8,100 patients died due to doctors giving them overdoses of pain medication, not for the primary purpose of controlling pain, but to hasten death. In 61% of these cases the overdose was given without the patient's consent.

4.3 According to Remmelink, Dutch physicians intentionally ended the lives of 11,840 people – accounting for over 9% of the annual Dutch death rate. The report found that the majority of all euthanasia deaths in Holland at that time were involuntary. Dutch euthanasia law has led to a climate where doctors routinely euthanise patients with or without their consent.

4.4 Figures from the Dutch official monitoring body show the number of registered cases of euthanasia in Holland rose to 2,500 in 2009. In 2007 Dutch experts said that around 80% of assisted deaths are registered with the monitoring body. This means that approximately 3,000 sick and disabled Dutch people were assisted to die last year.

4.5 If assisted dying were to be introduced in Scotland and grew over time to Dutch levels this would equate to 1000 assisted deaths a year (the Dutch population is three times our own). However if involuntary euthanasia also became more prevalent, then 9% of all Scots deaths might eventually become attributable to “mercy killing” – equivalent to 5,000 deaths per annum.

4.6 Although the Dutch law on euthanasia is liberal by British standards, it is still much more restrictive than that envisaged in the current Bill’s proposals. In 1981 the Dutch courts restricted the availability of assisted
dying to “patients experiencing unbearable pain”, a much smaller group than all terminally ill people and those disabled people dependent on some form of care.

4.7 The most frequently cited reasons given by Dutch health professionals for ending the lives of patients *without* their knowledge or consent were: “low quality of life,” “no prospect for improvement,” and “the family couldn't take it anymore.”

4.8 Inclusion Scotland believes that where euthanasia is an accepted medical solution to patients' pain and suffering, there is little incentive to develop programs which provide modern, available, and effective pain control for patients.

“I have cerebral palsy. When I was twenty-one I could have said to my mother that I wished to take my own life but now I am a campaigner for disabled and older people’s rights. I have been extremely successful in my life despite being in care for forty years” – Jimmy MacIntosh, Disability Activist

5 Terminal Illness, Palliative Care & Assisted Living

5.1 Scotland has an aging population and the incidence of impairment rises as age increases. Disabled and older people are at risk of being subtly pressured into contemplating ‘assisted dying’ by both their families and health professionals.

5.2 Health professionals sometimes judge whether care will be provided, rationed or withheld on the basis of a patient’s “quality of life”. This has previously resulted in “Do Not Resuscitate” notices sometimes being placed on disabled patients’ beds when neither they nor their families have made any such request. Even Baroness Jane Campbell, ex-Chair of the Disability Rights Commission has experienced difficulty in obtaining life-saving treatment because of health professionals' attitudes.

5.3 It is acknowledged that health professionals reflect prejudices towards disabled people held in wider society. Parliament should instead foster attitudes in society that recognise the value of all people, regardless of impairment. The focus must shift from assisted dying to the more humane concept of Assisted Living, valuing all lives irrespective of impairment and the provision of high quality palliative care.

5.4 Birth and death are life events affecting everyone. There is a huge disparity in the way we treat people at the beginning and end of life. In 2008 there were 55,699 deaths and 60,041 births in Scotland. There are approximately 850 maternity beds in specialised NHS units and health visitor/midwives are attached to every general practice. In contrast, nearly all terminal care beds are wholly or in part supported by the Hospice Movement.
Many people currently die in busy general wards where staff are overstretched, with no specialised training in terminal care and with no opportunity for spiritual and psychological support. In the community, district nurses do their best but there is under-staffing and poor out-of-hours provision. It is therefore understandable why some terminally ill people might choose to die with some dignity and relatively free from pain. However Inclusion Scotland believes very few would make that choice if good quality palliative care was genuinely available.

It is now widely accepted that a person’s state of mind can directly affect their physical health. A person who can look forward to quality terminal care and support will remain healthy longer and will use fewer resources. Many relatives and companions of terminally ill patients suffer great distress at the current ‘end days’ of their loved one. This, again, can directly affect their physical health leading to increased use of NHS resources.

Therefore Inclusion Scotland welcomes the proposed Palliative Care Bill. We believe that NHS Boards should be under a statutory obligation to provide high-quality palliative care, increasing the number of palliative care beds and district nurses with palliative care training.

6 Conclusion

Inclusion Scotland believes that this Bill’s proposals are dangerous and offensive. A person’s life should not be seen to be at an end if they have a physical impairment. We therefore wholeheartedly oppose the reasoning behind, and proposals contained within, this Bill.

The End of Life Assistance Bill will not only encourage disabled people’s suicide and, over time, their involuntary euthanasia but also gives tacit support to discrimination against disabled people within wider society by treating them as second class citizens whose lives are not worth living.

The Scottish Government’s “Independent Living Core Reference Group” (CRG) has accepted the core values of independent living as Freedom, Dignity, Choice and Control and are working together to make independent living a reality. It is ironic that these same values are being used to promote ‘assisted dying’, just as this work to create real opportunities for ‘assisted living’ is beginning.

A society which cannot first guarantee opportunities for good quality assisted living is a society where disabled people will be pressurised into feeling a burden on others, which in turn will inevitably force many to make the choice of assisted death. Let us therefore invest resources and effort into making Assisted Living for Scots disabled people a reality rather than Assisted Dying.

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References:

2. See website: http://www.notdeadyetuk.org/
4. Source DWP: http://83.244.183.180/100pc/dla_ent/tabtool_dla_ent.html#infotab
7. Ibid., p. 15.
8. Ibid., p.50, table 6.6.
9. Ibid., p. 58, table 7.2
10. Ibid., p. 72.