The Consequences of Euthanasia Legislation for Disabled People

'Individual actions, which may ostensibly be seen as for humane purposes, can have inimical consequences for a whole category of people.' This is one of the concluding comments in the affidavit from Not Dead Yet Aotearoa (NDYA) in the Lecretia Seales court case (Wicks and Hunt, 2015), and it is the starting point here. The community of disabled people and their interests is the focus of this article, which elaborates on some of the probable consequences of changing the law to legitimise euthanasia or assisted suicide.

Definitional debates will not be addressed here; given that there is wide disagreement, definitional issues are a substantive discussion to be had elsewhere. Rather, this article outlines some of the dangers of euthanasia and assisted suicide legislation for the community of disabled people; in particular, consequences that are likely to arise from any legalisation in New Zealand. Whether intended or unintended, consequences are real in their effects. To paraphrase the words of Bion of Borysthenes, a Greek philosopher of around 300BC, while boys may throw stones at frogs in fun, the frogs do not die in fun, but in earnest. Similarly, disabled people may be at considerable, albeit unintended, risk from the acts of others.

Background

The interrelated concepts of assisted suicide and euthanasia have a large 'footprint', and the space is vigorously contested, with definitions, rights and principles briskly traded. There is also a considerable media campaign being waged, in which slick and disingenuous stereotypes of the motives of those who oppose assisted suicide are disseminated to an audience overly willing to suspend critical analysis. Slick though they may be, the stereotypes are only partial. A large group is absent from adequate discussion; indeed all but invisible in writings on the issue. That group is disabled people.

But this does not imply a lack of interest on the part of the absent ones. For many years disabled people have considered, discussed and debated euthanasia and assisted suicide measures as proposed via laws and policies. As with non-disabled people, there is a range of views on the matter. However, the most recent 'push' for assisted suicide in New Zealand has crystallised concerns among disabled people about the inimical implications

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and the absence of their voices. They have come to believe that that absence has signified an implicit assumption that the euthanasia and assisted suicide debate was of little importance to disabled people, and that their views would be those of uncontested support. This has proved to be inaccurate and their unease has intensified.

Although there is regular polling in New Zealand on the topic, there is little information about what disabled people think. But a poll conducted for British disability charity Scope in 2014 found that most disabled people feared that changing the law on assisted suicide would lead to disabled people being pressured to end their lives prematurely (Scope, 2014). While such disabilityspecific polling has not been conducted in New Zealand, NDYA is confident that the results are similar to the views expressed to it by other disabled New Zealanders.

A disability voice in New Zealand

In response to the concerns expressed, Not Dead Yet Aotearoa was set up to provide a voice for disabled people opposed to euthanasia and assisted suicide early in 2015. NDYA's basis is a disability (human) rights approach, as articulated in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2014). This is most notably in relation to article 10 affirming that disabled people have a right to life (not death), and to article 4.3 requiring governments to actively engage with disabled people in relation to law and policy. NDYA is part of a worldwide network of opposition by disabled people to euthanasia and assisted suicide. Thus, there are autonomous Not Dead Yet organisations in the United States, the United Kingdom and Canada, and like-minded bodies in Australia and Ireland.1

The legal case taken by Lecretia Seales provided an occasion whereby NDYA could speak out for the collective interests of disabled people in relation to euthanasia and assisted suicide, as it joined a diverse alliance of perspectives in opposition to the case. Our affidavit expressed the organisation's concern that legalisation would present a series of inimical consequences for disabled people. Following from this contribution, it can be expected that NDYA will undertake an active advocacy for disabled peoples' interests in legislative and political avenues. However, it is clear that there remains a considerable lack of public knowledge of what the consequences of legalising euthanasia or assisted suicide are for disabled people; this article aims to contribute information to address this gap.

Stereotypes and consequences

Disabled people already occupy а marginalised and disadvantaged place in society. Who and how disabled people are is not characteristically expressed in affirming and expansive terms. Instead, negative descriptions and terms such as 'dependent', 'loss of dignity', 'struggle', 'deficits', 'unable', 'burden' and 'suffering' (to name but a few) permeate writing and speech. Such terms undermine the innate worth of disabled people. Assumptions such as these about the lives and existence of disabled people are reflected in laws, policies and systems that are based on false ideas and most often designed and run by non-disabled people. The cumulative impact of this is seen in multiple social disadvantage. Disabled people face limited educational and employment opportunities and economic independence. Access to health, transport, housing, home ownership and adequate support services are compromised (Statistics New Zealand, 2014), and poverty is a common experience.

While it is fully acknowledged that disabled individuals can and do achieve many indicators of a good life, it is nevertheless clear that the above snapshot is a fair and accurate collective picture; one where stereotypes and social consequences reinforce one another, and which is still the more common experience for disabled people. In particular, negative stereotypes hopelessly conflate health and disability. Catherine Frazee encapsulates the situation thus:

The belief that disability and illness inevitably lead to a lower quality of life is widespread both among people working in the healthcare system and people in the general population. This belief often leads to a lack of healthcare options because the idea of trying to prolong a life that is assumed to be unpleasant seems futile. However, this belief is not based on the experiences of people with disabilities, whose perspectives are rarely incorporated into healthcare systems or decision making. (Frazee, 2011)

Additionally, stereotypes are most relevant when considering the wording of euthanasia or assisted suicide legislation. The wording of euthanasia or assisted suicide legislation is phrased in such language as feeds directly into negative stereotypes: a 'terminal illness' or 'irreversible condition' 'makes life unbearable'; 'there is unlikely to be relief of unbearable suffering', 'dependence on others' and a 'loss of dignity'. Given that many disabled people live their lives every day depending on others for support and having an irreversible condition or a disability that is considered to be terminal, such legislative descriptions of their everyday reality as worthy of death would not inspire a calm and confident approach to life. All of the above phrases can be taken to any degree of imprecise and conflicting interpretation.

Legislation and consequences

In a series of video interviews about assisted suicide and euthanasia,² British actress Liz Carr points out that laws about assisted suicide have effects far beyond what might be expected, noting that laws brought into being for just some can and will jeopardise others. There is a wider context to (euthanasia and) assisted suicide laws, she says, but that wider context is likely to be overlooked in a focus on giving a legislative 'solution' to concerns for individuals. There are two particularly pertinent illustrations of this: suicide prevention, and abuse and violence.

Our society takes a general approach to suicide that it represents some disorder of thoughts or emotions and that assistance in dealing with this should be given. But legalisation of euthanasia and physicianassisted suicide sends a message that the situation is in effect reversed when the person is disabled. Philippa Willitts encapsulates this succinctly:

This huge contradiction says a lot about the value we place on disabled people's lives. We must stop people committing suicide! Oh wait, they're disabled and want to commit suicide? Sure, hand them the pills. (Willitts, 2015)

Diane Coleman makes a similar point, and also highlights the coercive effect of such legislation:

For individuals who internalise social oppression that declares disability to be undignified, the legalisation of assisted suicide may convey the message that suicide is the best way to reclaim their dignity. It may even convey the message that suicide is the most honourable way to make one last contribution ... a mentality that tells the disenfranchised and despised to get out of the way, without ever seriously considering the decisions and motives of the policy makers who shape the culture we live in. (quoted in Wicks and Hunt, 2015, p.16)

Her message is echoed by the Scottish Parliament, which this year considered an assisted suicide bill and expressed its concern not only for the message it would send to certain members of the community, but also that it undermines and damages society as a whole.

Legislation allowing euthanasia or physician-assisted suicide has a very real risk that the 'right to die' is seen to be a 'duty to die' for a disabled person. Abuse and coercion of disabled or older people to follow this legislatively-enabled pathway and 'choose' assisted suicide is a very real possibility. Public declarations have been made in New Zealand by disabled individuals that they would not be vulnerable to any such coercion (so, by implication, the rest of us should be similarly immune, and coercion can only be seen as a figment of the disordered imagination). This perspective lacks credibility: all of us are, at one point or another in our lives, vulnerable to the persuasions, urgings or sometimes coercive arguments of others, and those in a position of relative powerlessness will be more vulnerable than most.

The legalisation of euthanasia or assisted suicide will only provide a tool for the strong against the weak, an argument also made compellingly by Baroness Campbell in opposing the British Assisted Dying Bill at the beginning of this year (Campbell, 2015). As arguably the group most effected by any possibility of euthanasia or assisted suicide legislation, the voices and concerns of disabled people must be involved, as required in the Convention on the Rights of Persons with Disabilities. Legalisation must not be contemplated in our absence.

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References

- Campbell, J. (2015)) "Like Stephen Hawking, I'm past my sell-by date but this law to help people die is wrong": the moving speech by severely disabled peer against Assisted Dying Bill', *Mail Online*, 18 January, http://www.dailymail.co.uk/news/article-2915030/Like-Stephen-Hawking-m-past-sell-date-law-help-people-die-wrong-movingspeech-severely-disabled-peer-against-Assisted-Dying-Bill.html
- Frazee, C. (2011) Expert Evidence to Canadian Department of Justice in *Carter et al. v Attorney General of Canada*
- Scope (2014) 'New research: majority of disabled people fear change to assisted suicide law', media release, 17 July, http://www.scope.org. uk/media/press-releases/july-2014/assisted-suicide-law
- Statistics New Zealand (2014) Disability survey: 2013, http://www. stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_ HOTP2013.aspx

- United Nations (2014) Convention on the Rights of Persons with Disabilities, http://www.un.org/disabilities/default. asp?navid=15&pid=150
- Wicks, W.A. and R.M. Hunt (2015) Affidavit filed on behalf of the Care Alliance, 8 May, http://www.carealliance.org.nz/ uploads/1/8/9/6/18960817/affidavit_of_wicks_and_hunt_8_ may_2015-2.pdf
- Willitts, P. (2015) 'I am disabled and people tell me on a regular basis that they would rather die than be like me', 31 January, http:// www.xojane.com/issues/assissted-suicide-leans-towards-helping-nondisabled-people

² https://www.youtube.com/watch?v=I2IDeMfeYMU&feature= youtu.be.