**Right rights, authentic autonomy: disability as a human rights issue**

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In June 2011 the World Health Organisation and the World Bank Group jointly produced the first ever World Report on Disability. One of the Report’s stated aims is to follow Article 1 of the UN Convention on the Rights of Persons with Disabilities (CRPD), namely “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, and to promote respect for their inherent dignity”. As the CRPD points out, in a perfect world the rights enumerated in the Universal Declaration of Human Rights of 1948 should be enough to protect everyone. However “in practice” it admits that certain groups fare worse than others [1]. Taking up the CRPD cause the Report describes some of the inequalities people with disabilities experience when it comes to matters such as access to healthcare, employment, education, participation and inclusion in society. The Report recognises that people with disabilities are subject to violations of dignity through violence, abuse, prejudice and disrespect. It acknowledges that they are also denied autonomy by, for instance, involuntary sterilization, being confined to institutions against their will, being regarded as legally incompetent because of their disability [2]. So the Report confidently proclaims that “disability is increasingly understood as a human rights issue” [3].

Certainly it is a sad state of affairs that makes it necessary for the CRPD to highlight the “inherent dignity and worth and the equal inalienable rights of all members of the human family” when it has to add that “everyone” “includes persons with disabilities” [4]. However significantly both the UDHR and the CRPD identify inherent dignity as well as freedom and rights as separate goods to be promoted and respected. Moreover these declarations support difference not a levelling out: they underline the fact that people are different whether in colour, sex, creed or capacity. Nevertheless this difference is not a reason to deny equality or dignity. In particular, and remembering that the UDHR emerged from the Nazi atrocities of the Second World War, difference cannot be a reason for eliminating someone.

The Church has always taken a positive attitude to the proclamation of inviolable human rights [5]. Indeed Pope John Paul II acknowledges that various human rights declarations demonstrate “a growing moral sensitivity, more alert to acknowledging the value and dignity of every individual as a human being” [6]. Moreover, in contrast to some modern perceptions the Church makes clear that rights are indissolubly linked to duties [7]. The Church further clarifies that these rights are not the result of the will of states or legislatures but are “universal, inviolable, inalienable” [8] and “inherent in the human person and in human dignity” [9]. However Pope John Paul is too well aware that violations and also the risk of distortions of rights and declarations on human rights call the Church and “all people of good will” to ensure that “the acceptance of their ‘letter’ mean everywhere also the actualization of their ‘spirit’” [10].

There is a difficulty in seeing disability as principally a ‘human rights issue’ not least because one distortion that seems especially prevalent in today’s field of healthcare is the tendency to conflate rights and human dignity with autonomy.The problem is exacerbated by the tendency to interpret autonomy simply as the freedom to choose where an autonomous decision becomes merely a matter of capacity with no necessary link to either reason or moral thinking. When it comes to disability this conflation raises two problems in particular: firstly it feeds into demands to make autonomy an absolute principle in healthcare. This demand is particularly disturbing when it comes to the persistent calls for legislation to enshrine a right to assisted dying, legislation that seeks to make death a healthcare choice and healthcare professionals merely administers of that choice. Secondly, it fosters a hierarchy of disability which favours the autonomous person over the non-autonomous human being and the intellectually disabled person inevitably ends up at the lower end of the hierarchy. Quite rightly some people with disabilities point to inequalities and discrimination and call for the right to independent assisted living, proper support and enabled choice. However often those who can speak up for themselves think that they speak for all the disabled and so people who will always be radically dependant, who make choices, if at all, on a most basic level, appear to be further marginalised.

Both the exaltation of autonomy and a hierarchy of disability are implicitly played out in the debate on assisted dying. Of note is that the language has moved away from assisted suicide perhaps to avoid the stigma of suicide or perhaps to suggest that the choice for assisted dying is a rational one when suicide is often characterised as irrational. Moreover the focus on assisted *dying* allows for what the first assisted dying bill, presented by Lord Joffe in 2004-2005 envisaged: euthanasia [11]. However the presence of absolute autonomy and a hierarchy of disability in that debate do not simply raise concerns about slippery slopes. It also raises the spectre of unlevel pathways that inevitably become dangerous for people with disabilities. On the one hand some people argue that legislation that allows for assisted dying where the last act, the drinking of the barbiturates or pressing of the drive syringe, must be done by the person himself does in fact discriminate against those with the greatest physical impairments. Such a claim was made by Tony Nicklinson who had locked-in-syndrome, and who would have been unable to do the final act. Thus on the grounds of discrimination the door is opened for active euthanasia. On the other hand the demand for assisted dying, particularly when it is made by a disabled person, reinforces the notion that the lives of some people, notably his or her fellow ‘sufferers’ who are not as vociferous, are not worth living.

What is clear here is that there is no difference between the abled and the disabled but this is not on the grounds that at some point we may all develop impairments. Rather, all human beings are vulnerable and the sense of worth of all human beings is affected by not only how individuals but also how society sees, treats and welcomes them. If society accepts that some lives are not worth living then this has impact on people whether or not they consider themselves to be disabled or abled. To use a metaphor that is not necessarily convivial to some people with disabilities but one that conveys the message, we all stand or fall together. So, although the slippery slope argument is often a good reason to pay particular attention to what is being proposed, it is not enough to argue that calls for assisted dying should fail on the grounds that such calls cannot protect the disabled nor is it satisfactory to claim that assisted dying should benefit all the autonomous whether they can do the last act themselves or not. Arguments in the debate on assisted dying may encompass talk of the needs of the abled and disabled and the arguments presented by supporters of the ‘right to die’ may claim to rule out putting pressure on the vulnerable disabled. Nevertheless ultimately the argument against assisted dying is the same for all human beings: we are all vulnerable to anguish, grave fear, soul pain. Pushing people over the brink is assistance but it is not genuine or even helpful aid.

**Conflating rights, dignity and autonomy: the assisted dying debate**

In 2006 Deborah Annetts, the Chief Executive of the organisation formerly known as the Voluntary Euthanasia Society explicitly conflated rights and autonomy when she celebrated the Society’s name change to Dignity in Dying. As she explains “the word ‘dignity’ emphasises, for me, that the dying person’s wishes must be paramount” [12]. Putting aside the fact that most people seeking assisted dying or euthanasia are not necessarily dying the organisation Dignity in Dying argues, quite properly, that “everyone has the right to a dignified death” [13]. In the light of scandals concerning poor care and neglectful or indifferent or even abusive healthcare treatment dignity both during and at the end of life has become a pressing concern. However the proposal to change the name of the Voluntary Euthanasia Society to Dignity in Dying led the Association of Palliative Medicine to complain that the Society had in effect hijacked the concept of dignity. As the Association pointed out people do want ‘dignity in dying’ but in the sense of good care not euthanasia or assisted suicide [14]. In contrast Dignity in Dying reductively describes dignified death simply in terms of choice, control and a person’s right to decide about their own life and the timing and means of their death [15].

Notably whilst the language of a ‘right to die’ dominates media discussion and case reports on assisted dying Dignity in Dying and the supporters of the Assisted Dying Bill prefer the language of choice. The language of choice seems more appealing in a pluralistic and tolerant society where tolerance rather narrowly refers to the acceptance of the opinions of others regardless of whether that opinion corresponds to any objective standard. It also avoids some of the contentious and problematic aspects of rights seen in an individualistic light. More significantly and presumably as a matter of a change in strategy on the part of Dignity in Dying the language of choice rather than rights has been adopted since appeals to rights have so far failed: in law there is a right to life but not a corresponding right to death. In the courts campaigners for assisted death have repeatedly but unsuccessfully invoked Article 3 of the European Convention on Human Rights that denying the right to be freed from unbearable suffering amounts to inhuman and degrading treatment and Article 8 that it is a violation of privacy and family life. Dignity in Dying does not therefore appear to be promoting ‘hard’ individualistic rights but rather it says it is supporting the softer demands of choice and in a tolerant society ‘everyone’ should respect another’s choice. Furthermore in the draft Assisted Dying Bill put together by an informal parliamentary group Choice at the End of Life and by Dignity in Dying in 2012 as a potential template for legislation on a right to die it expressly says that assisted death is not suicide. Rather it is “another way of dying” [16].

Nevertheless, whether the issue of assisted dying is framed as a ‘right to die’ or a ‘right to choose’ it remains a distortion of the spirit of rights legislation. Despite pushes to give primacy to autonomy it has never been the case that autonomy seen as the right to choose holds absolute sway in healthcare ethics. Certainly a person with the relevant capacity has the right to refuse treatment that is futile or where the burdens of treatment outweigh its benefits and legally that applies where the refusal is unreasonable and even morally questionable. However neither under common law nor under human rights legislation can a person demand that healthcare professionals assist in an act that in any other circumstances would be suicide. There is no patient right to oblige healthcare professionals to provide treatment that from the perspective of conscientious professional judgment is not in the patient’s own best interests, that is no longer of any benefit or is likely to cause disproportionate suffering and this is not simply a matter of compromising the autonomy of healthcare professionals.

**Slippery slopes and unlevelled paths**

Dignity in Dying offers the apparently reassuring claim that throughout its campaign “vulnerable groups of people have not been negatively impacted on by physician assisted dying or voluntary euthanasia” [17]. This is principally because the organisation asks for assisted dying only in the case of “terminally ill people” who are likely to die within a year of their diagnosis. Specifically the organisation says it does not apply to the disabled (unless they are terminally ill) [18]. Here there is no discussion of what it is to be disabled or of any particular model of disability. In its section on frequently asked questions Dignity in Dying explains that people with illnesses such as cancer are not disabled [19]. The proposed Bill defines a terminally ill person as someone who has been diagnosed as having “an inevitably progressive condition which cannot be reversed by treatment” [20]. While in everyday language a person who requires assistance is presumably not able but is in a sense dis-abled, in the language of the Bill people with progressive and untreatable conditions are distinguished from people who are disabled. Technically, by ‘letter’ rather than ‘spirit’ the Bill is correct in that under the Equality Act 2010 disability only applies to an impairment that has a long term adverse effect [21] and the Bill claims it only applies to those with less than twelve months to live. However the Bill rather ambiguously suggests that those who have initially been given a “longer life expectancy” (but presumably who are not considered disabled under the terms of the Bill) could “subsequently ask their doctor to reassess their progress, and if this were twelve months or fewer the patient could start the process of requesting an assisted death [22].

To support its claim that vulnerable groups like the disabled are not negatively impacted Dignity in Dying cites loss of autonomy, being less able to enjoy activities and loss of dignity as the principal reasons for choosing assisted death [23]. By saying that suffering and feeling a burden do not figure highly the organisation implicitly suggests that these issues rather than loss of autonomy or dignity characterise the experience of disabled people. However this separating out of the terminally ill from the disabled seems to ignore that generally it is not the healthy who seek assisted dying, if of course it is accepted that certain mental health issues such as depression are a matter of ill health. Even if Dignity in Dying claims that the terminally ill are not disabled the personal stories on their website where often the ‘end of life’ phase lasts for several years come out of the debilitating experiences of illnesses such as multiple sclerosis, motor neurone disease, cancer, Huntington’s disease, AIDS, early onset Alzheimer’s and dementia. Repeatedly people speak of the fear of suffering, degradation and indignity, the dread of living a “diminished life”, a “life no longer acceptable”; they “do not want to be left incapacitated”, of “ending up like that” [24]. The personal opinion that ‘my’ life is not worth living cannot but be a reflection of the belief that any life with diminished autonomy or the risk of indignities is a ‘life not worth living’.

So in the hierarchy of those who have “an inevitably progressive condition which cannot be reversed by treatment” there are the vociferous who strenuously argue that life for them is worthless, that their current or future impaired existence is a less than human existence. Then there are the vulnerable disabled who are to be protected from the potential slippery slope. Dignity in Dying correctly sees that people with disabilities are vulnerable and are to be protected. However the claim that the autonomous terminally ill person falls out of the category of the disabled is problematic. It may be that those who are autonomous do not want to think that they too are vulnerable, crippled by paralysing fear of loss of control rather than fear of paralysis or fearful of becoming the subject of the discriminatory attitudes of others. There appears to be a disabling framework of attitudes that does not see how autonomy instead of being a source of freedom and self-governance can be a source of tyranny. It is this framework of discriminatory attitudes, attitudes often held by those who themselves seek assisted dying, that rights declarations attempt to challenge. Such attitudes are not addressed by killing off the subject of potential discrimination.

**Right rights, authentic autonomy and human dignity**

As the quarrel between the Voluntary Euthanasia Society (Dignity in Dying) and the Association of Palliative Medicine show, one of the main issues in the assisted dying debate is the notion of dignity. As international documents on human rights demonstrate the promotion of human rights goes hand in hand with the promotion of inherent dignity. Certainly the notion of dignity has been criticised for being vague and imprecise, and some claim that since it means no more than respect for autonomy it is in fact useless [25]. To be sure rights language is also problematic not the least because the claim to a right seems to trump all other claims and at times apparent ‘rights’ seem to conflict. As the utilitarian philosopher Jeremy Bentham famously said in reference to natural rights as opposed to rights created in law, the notion of natural rights is “nonsense upon stilts” [26]. However the conflation of dignity with autonomy is by no means accepted or even commonly held and as for difficulties with rights, as has often been pointed out, in countries where floods are common houses built on stilts save lives.

That rights or autonomy are not the overriding principle and that dignity and autonomy are not to be confused can already be found in various strategies that have been taken up following the high number of suicide cases in Bridgend, Wales. Launched in 2012 the National Suicide Prevention Strategy, a strategy to “save lives”, categorically states that “every suicide is both an individual tragedy and a terrible loss to society” [27]. Certainly suicide prevention strategies clearly see that promoting the dignity of a person deepens that person’s sense of hope and self worth, factors that are important in addressing suicidal intent. However in recognising the inherent dignity of all human beings the Strategy also acknowledges that there are disadvantages and barriers for disabled people in society and it sees the need for “an inclusive society that avoids the marginalisation of individuals and which supports people at times of personal crisis”. Above all it calls for “protective factors” to promote “strength and resilience” and to ensure that the vulnerable are supported and connected in a network of interdependent relationships [28]. The Strategy may say that “whether the law on encouraging or assisting suicide should be changed is a separate issue outside the scope of the strategy” [29]. Nevertheless it seems to be the case that for people who are healthy there is suicide prevention, for disabled people and the ‘terminally ill’ there is a push to getting them help in committing suicide. Adding the words ‘physician assisted’ to suicide does not make it less than suicide. Calling the act ‘assisted dying’ may be an attempt to take the act out of the realm and perhaps stigma of suicide. Nevertheless it also opens up the possibility that if the act is botched another could finish it off or indeed do the complete act: euthanasia.

As strategies for the prevention of suicide implicitly demonstrate the right to choose the manner and timing of death is not an authentic right not least because it is contrary to the interests of every human being who is vulnerable whether or not that person is disabled. Moreover calls for assisted suicide and dying are often fuelled by fear of poor care, inadequate pain relief, being treated as less of a person, being in undignified situations. To be sure soul pain is, for some, a barrier that cannot be overcome. Nevertheless the promotion of an apparent right to assisted dying as ‘dignity in dying’ seems to move the focus away from the imperative to remedy these inequalities and injustices and to attempt to ease soul pain. It equates being in an undignified situation with having lost human dignity when it is more the case that dignity is violated when a human being is considered to be ‘better off dead’ or his or her life is seen as worthless.

An understanding of dignity as reflected in how many times my preferences prevail and autonomy as the right not to be manipulated by others sets the individual alone and against others. Moreover to attain such a dignity and autonomy entails the manipulation of others. In contrast Pope John Paul perhaps best expresses the spirit of rights legislation in his 1987 message on the World Day of Peace. He explains that the “oneness” as well as the “diversity” of the human family and so this “basic solidarity” is the “fundamental condition of life together on this earth” [30]. He adds that this solidarity means “promoting effectively and without exception the equal dignity of all as human beings endowed with certain fundamental and inalienable human rights” [31]. However, part of the enterprise of solidarity is to “promote values that truly benefit individuals and society” so that people can attain what is “good and true” and choose things that “enhance life” [32].

[1] Convention on the Rights of Persons with Disabilities (CRPD) http://www.un.org/**disabilities**/**convention**/**convention**full.shtml

[2] *World Report on Disability* 9 June 2011, p.9. <http://www.whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf>

[3] *World Report on Disability*, p.xxl.

[4] CRPD Preamble a.

[5] Second Vatican Council *Dignitatis Humanae,* 1966, 1.

[6] Pope John Paul II, *Evangelium vitae* 1995, 18.

[7] Pope John XXIII *Pacem in Terris*, 1963, 259-264; Second Vatican Council *Gaudium et Spes*, 1966, 1046-1047.

[8] Pope John XXIII *Pacem in Terris*, 1963, 278-279.

[9] Pope John Paul II *World Day of Peace* 1 January, 1999, 3.

[10] Pope John Paul II *Redemptor Hominis*, 1979, 17.

[11] <http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8610.htm#a53> Ch.7, 243.

[12] D. Annetts, January 2006, <http://www.dignityindying.org.uk/news/general/n4-voluntary-euthanasia-society-changes-name>

[13] [http://www.**dignityindying**.org.uk/about.html](http://www.dignityindying.org.uk/about.html)

[14] <http://news.bbc.co.uk/1/hi/health/4638766.stm>

[15] <http://www.dignityindying.org.uk/assisted-dying/faq.html>; Assisted Dying Bill, Foreword p.6 http://www.appg-endoflifechoice.org.uk/pdf/appg-safeguarding-choice.pdf

[16] Assisted Dying Bill, p.17 <http://www.appg-endoflifechoice.org.uk/bill_consultation>

[17] <http://www.dignityindying.org.uk/research/slippery-slope.html>

[18] <http://www.appg-endoflifechoice.org.uk/pdf/appg-safeguarding-choice.pdf>

[19] <http://www.dignityindying.org.uk/assisted-dying/faq.html>

[20] Assisted Dying Bill 2, <http://www.appg-endoflifechoice.org.uk/pdf/appg-safeguarding-choice.pdf>

[21] Equality Act 2010 s.6 (1) (a).

[22] Assisted Dying Bill p.14

[23] <http://www.dignityindying.org.uk/research/slippery-slope.html>

[24] <http://www.dignityindying.org.uk/personal-stories.html>

[25] Ruth Macklin, ‘Dignity is a useless concept’ in *BMJ* 2003 327:1419.

[26] Jeremy Bentham, 1824, *Anarchical Fallacies* Article II <http://www.oll.libertyfund.org/title/1921/114226>

[27] http://www.dh.gov.uk/health/files/2012/09/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf p.9

[28] [http://www.dh.gov.uk/health/files/2012/09/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf p.9](http://www.dh.gov.uk/health/files/2012/09/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf%20p.9), p.26.

[29] [http://www.dh.gov.uk/health/files/2012/09/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf p.4](http://www.dh.gov.uk/health/files/2012/09/Preventing-Suicide-in-England-A-cross-government-outcomes-strategy-to-save-lives.pdf%20p.4).

[30] Pope John Paul II *World Day of Peace,* 1 January, 1987, 1.

[31] Pope John Paul II *World Day of Peace,* 1 January, 1987, 2.

[32] Pope John Paul II *World Day of Peace,* 1 January, 1987, 6.