

## Disability Leadership Institute on Bioethics Keynote Speech 25<sup>th</sup> April 2014

(read slide) The last time I visited Washington was in April 2008 when I joined hundreds of disabled activists from ADAPT for their annual direct action - and their fundraising fun run (explain slide).

Never before had I been with so many disabled people protesting for change. I'd been on many demo's in the UK but never had I experienced anything like this - being with over 500 people, many wheelchair users, some without speech, others on ventilators, all marching in single file with the Capitol Building as our backdrop, all prepared to go to jail to ensure disabled people have the right to live in our own homes, with the support and resources we need and the opportunities to really live our lives.

Six years later and I'm back in Washington. This time, there is no John McEnroe-esque headband and no placard in protest but there is even greater urgency; I'm here to join you all in fighting for disabled people's right to exist.

As an actor, I do have a tendency to be a drama queen at times but I don't think I am being melodramatic when I say that I fear disabled people are an endangered species. Yes, I believe that disabled people are at risk of extinction.

Before we're even born we're being screened out, unselected and labelled as not designer enough to exist. Certain impairments have already been sieved out of gene pool. Once born, our lives may be shortened by inadequate health care, by Do Not Resuscitate orders being placed on us against our will, by basic treatment and nutrition being non-consensually withdrawn or by professionals and relatives making misguided decisions about the quality of our lives. And then, if we're lucky enough to have survived all this, we have the very real fear of being prematurely shuffled off this mortal coil thanks to a heady mix of mercy killings, acts of compassion, acts of violence, hatred and neglect, euthanasia and assisted suicide. Disabled people **are** an endangered species. (slide - describe)

Already, I have disabled friends, wonderful, creative and loving people who would not be born today. We are a dying breed. Perhaps one day there'll be tv documentaries with anthropologists and over eager presenters introducing viewers to 'a world when those who had different minds and bodies were allowed to roam the earth'? Museum tour guides will usher school groups through exhibits of 'the lesser known disabled person' at the Smithsonian?

So how can we stop the extinction of disabled people? Being here today is a start, becoming informed about what's actually happening, seeing the bigger picture and developing our strategies together, within our community, before we head out into the big ol' hostile world, ready to

continue the fight. Let's get angry, let's get passionate, here, together, today.

What is exciting as I look around this room and see the wisdom and experience before me, is that we're coming at these life and death issues in so many different ways and from different perspectives. We have to use what we've got and what we're good at to get the message across. Diane with her immense knowledge, integrity and strategy. Marilyn's sharpness, legal knowledge and policy skills. And me? Well, I'm a comedian, a broadcaster, an actor and activist whose 'hobby' is working with Not Dead Yet UK to fight against the further legalisation of assisted suicide. Needless to say, my politics and passions almost always find a way into my work.

For example, I'm currently writing 'Assisted Suicide - The Musical' (explain slide) This show is my response to the mainstream media onslaught of semi naked disabled people who are having their teeth brushed, their hair washed whilst usually hanging pitifully in a hoist as classical music plays in the background and a sombre voiced narrator tells the audience how awful their life is. What's the new term for this? Expiration porn? Objectifying us for the titillation of the observer? Making the viewer feel better about their life? Perpetuating the already engrained view that people like that, people like me, people like us, would be better off dead, I wrote Assisted Suicide The Musical in the belief that a witty showtune will do as much to counter that view as any op-ed. (Play: if time play clip here, first explaining this is a rough and ready clip of one of the songs so apologies for the quality).

I'm a broadcaster, for 7 years I co-hosted the BBC's Ouch! disability podcast enabling us to have a monthly pop at the people and institutions that oppress us. In 2012 and 2013, I was able to couple this experience with my belief that most discussions on the topic of assisted suicide are totally unbalanced and biased towards those supportive of legislation, to create a 2 part BBC World Service Radio Documentary based on the countries where assisted suicide and euthanasia are legal. I wanted to call it 'Euthanasia Road Trip' but predictably the BBC lawyers made me euphemistically call it, 'When Assisted Death is Legal'. (explain Slide)

I visited the 5 countries where assisted suicide and / or euthanasia are legal. First stop USA, to find out about the almost mythic 'Oregon' law which with it's, "16 years, no abuse and no calls to extend it beyond terminally ill people" rhetoric, has become the legal blueprint around the world. Then to little known Luxembourg where on the record, the legislators admitted to drafting a 'safe' bill that applied initially only to terminally ill people in order to get it passed but that their ultimate intention is to widen it's scope to children and people with dementia. In Belgium, they've cut out the middle man and gone straight for a euthanasia law ie. the doctor actively kills you. In recent months, they've extended the law to include children, they've euthanased a non-ill transgendered person and deaf twins. In Switzerland, I visited more

death clinics than is healthy, giving decorating tips, eating cake and taking pictures outside the ubiquitous Dignitas where 'death tourists' from all over the world are welcome to avail of their deadly services. Finally, to The Netherlands where they have radio ads encouraging euthanasia and the next 'big thing' is something called 'completed life' for older people who are not ill but just tired of life. And practically no one mentioned the legacy of the recent past. Incredible.

'When Assisted Death is Legal' is perhaps more balanced than I'd like it to be but despite that, I am proud that the programme contains voices and arguments that are rarely acknowledged in the assisted suicide debate - let me know what you think as after the conference, a summary of my trip, of who I met, the transcript and links will be emailed out.

In the UK, I am now mostly known for my role as forensic scientist, Clarissa Mullery in the BBC primetime drama, Silent Witness - a very English CSI. (describe slide) When I offered the role I said I'd only accept if they'd guarantee not to kill me off in an assisted suicide storyline. Sometimes strangers stop me on the street to ask if I'm that woman off the tv. So last month, when I was having a very luvvie lunch with a very luvvie friend of mine and a stranger approached, I assumed he was going to ask me about Silent Witness. 'Are you Liz Carr?', he asked. People don't normally know the name of the show, nevermind my real name. 'You were on Newsnight once? In 2008, talking about assisted suicide?'. I was totally taken aback. He introduced himself as a retired ethics professor who had watched that programme and had used the clip of it in his classes until his recent retirement. 'You've changed a lot of people's minds', he said, 'students have written essays about what you said'. He reminded me that during the interview, I had said I was probably the most hated person in the UK for my opposition views. 'You weren't the most hated person at all. Many people were glad for what you said'. He left and my friend looked at me stunned - "you've got ethics?".

"You've changed a lot of people's minds", he said. Collectively, in this room and amongst those who campaign on these life and death issues, I wonder how many people's minds we've changed? How many successes we've had? Many. Many more than we probably realise. We have challenged people's perspectives by talking to them, we have impacted policy decisions by being round the table, we have fended off laws by campaigning. There are people in this room who have stopped bills and initiatives being voted through. Election night 2012, forget Obama all we cared about was Question 2 - The Massachusetts "Death with Dignity" Initiative. And now Connecticut. If I could applaud, I would.

In England, a consistent 80%+ of the population will say that they want assisted suicide to be legal and their appetite for it is growing at a terrifying rate. Just last week we heard of an 89 year old English woman who died at Dignitas because she felt alienated by the modern world. Listening to phone ins and following the news coverage, the

support for her actions is overwhelming. In the past decade, there have been numerous attempts to introduce physician assisted suicide through legislation similar to the Oregon Law with another one currently trying to make it's way through the House of Lords. But as yet, state sanctioned killing by a doctor is still illegal in the UK. Just.

Instead of a law, however, we do have guidelines and a prosecutorial discretion which mean that if a non-medical person assists a consenting adult to end their life for wholly 'compassionate' reasons, then they are unlikely to be prosecuted. Essentially, assisting an older, ill or disabled person to book that one way ticket to Dignitas, grab a pillow or secure some barbiturates are viewed as compassionate acts and therefore avoid prosecution.

When the ethics professor approached me, the interview he remembered, concerned the assisted suicide of a 23 year old disabled man, Daniel James who had become paralysed from the neck down following a rugby accident. He hated being what he called, "a second class citizen" and within 12 months of the accident, he had apparently begged his parents to take him to Dignitas. His parents eventually and reluctantly agreed so, less than 18 months after his accident, Daniel James was assisted to die. The press and public saw the act as tragic but totally understandable and his parents were lauded as brave heroes. In the interview, I go head to head with the former poster girl for assisted suicide in the UK, Debbie Purdey. My arch nemesis in these debates, she is worried her husband will be arrested if he helps her go to Switzerland. (play the interview)

I was clearly nervous - it was a live interview. I spoke very fast and I did fluff my words. It's in no way a text book interview and I will be glad to attend the advocacy and media workshops for some top tips. But what I did do is put up an alternative viewpoint - assisted suicide? 'not in my name'. I looked frailer than my nemesis and yet I choose life. I broke the spell that says 'surely every compassionate, rational, liberal human being would support another being assisted to die?' I dared to question their interpretation of Daniel James' problem and the ultimate solution. And, I got the last word. I didn't want to do the interview but I'm glad I did it because 6 years later, a complete stranger came up to me and told me that my brief contribution changed minds.

When the assisted suicide celebrities are wheeled out saying they want to end their life, they merely perpetuate the pervading mainstream view that our lives must be awful, painful and without value. Their very public decisions to end their life affect every one of us and mean that those of us in opposition have to fight extra hard to counter years of these entrenched and institutionalised discriminatory views. That is why we have to be part of these discussions and debates and that is why we have to speak out.

Even if we don't want to. Even if we don't think we have anything to say. We must take these opportunities and use them because you cannot underestimate the individuals, the groups, the hundreds, the thousands and the millions of people who may agree with you, who have never heard the different perspective that you present and those who need to hear our truth. It is our duty to speak out.

And the good news is, we don't have to win people over completely, we just have to create 'reasonable doubt' ie. give people enough fresh information, different perspectives and create sufficient doubt in people's minds that legalising assisted suicide is not the right solution. It is our role to create reasonable doubt.

I have also learnt that if we want to be as persuasive as possible in our debates then there's two things we shouldn't talk about - God and the Holocaust. Yes the biggies. I don't know if it's the same over here but proponents of AS in the UK dismiss any opposition as being from the 'right to lifers'. In Not Dead Yet UK, we have some brilliant religious allies in our campaigns but usually, as soon as 'faith' is brought in as a basis for what we're saying, proponents of AS will dismiss us, our arguments and our credibility.

As for the Holocaust, you've probably heard about ol' Godwin? Godwin's law asserts that if a discussion goes on long enough, sooner or later someone will talk about Hitler or Nazism and that once this happens, the argument has been lost. Talk about in the same breath as assisted suicide and euthanasia and your opposition will roll their eyes and say you're being ridiculous. On Wednesday, I went to the Holocaust Memorial Museum. I saw Nazi propaganda from the 1930's that portrayed disabled people as "useless eaters" and as people who had "lives unworthy of living". There was propaganda stressing the high cost of supporting disabled people and it sounded terrifyingly familiar. It is not easy to avoid comparisons with the Holocaust but we must if we are to be listened to and taken seriously.

What I do always talk about in debates, is how the current economic climate makes the introduction of AS particularly abhorrant. Disabled people are being hit harder than many by the current ideological revolution masquerading as austerity. This gives us the clear message that our lives are worthless. There is documented proof of the suicides of disabled and ill people which are directly attributable to the vicious cuts to welfare and the prevailing policies of 'work at all costs' that we are currently experiencing in the UK. Cuts to funding for the essential support that many of us need to survive, nevermind thrive, are also pushing people to feel like burdens, useless, hopeless and suicidal.

In the UK, in employment law, there is a term known as constructive dismissal. It refers to when an employee feels they have no choice but to resign from their job because the conditions they're working in are so bad eg. they're being bullied, harassed or undervalued? How many

disabled, ill or older people will feel they have no choice but to resign from life because the conditions they're living in are so bad? With essential health and social Care are becoming increasingly unavailable, is it any wonder people want to die? Daniel James 'chose' to die because he couldn't bear to live like a second class citizen. That's not ending your life out of choice, that's ending your life because you have no choice.

A disabled friend of mine, Ann Whitehurst, recently posted something on Facebook - no, not another cat video - but instead, a call to arms, to campaign against these atrocities:

"Many disabled people have & are facing a complete absence of rights & the government is encouraging this - to what ends we can only guess but dead people don't rebel, they cause no fuss & no bad publicity, they don't vote & don't demand equal rights. This campaign is about you & me ensuring disabled people won't be in horrendous neglect due to cuts... Neglect kills, sometimes more slowly & tortuously but inexorably. Disabled people are being deprived of the right to exist by denying us the means to live".

Disabled people want assistance to live, not assistance to die. (explain slide).

Disabled people know what we want and what we need. Born out of the experience of being excluded from decisions about our lives - as individuals and as a community - for too long, our rallying cry is 'Nothing about us, without us'. Living with our impairments in a disabling society has taught us so much which we **must** contribute to these life and death discussions. For example:

**(slide) Dignity is not related to wiping your arse**

It's true, I can't wipe my arse but I still think I live with dignity. When people imagine how awful it must be to be old, ill or disabled, they worry about the lack of control, fear of pain, being a burden, loss of role and identity, no quality of life, dependence, incontinence, sheepskin, velcro, hoists and commodes ie. the everyday experiences of many disabled people. Many would rather die than be like us. They say it enough - sometimes to our faces, 'if I were like you, I don't think I could cope...'. 'shoot me if I ever get like that...'. We are people's greatest fears, the living embodiment of their worst nightmares. A living reminder of the fragility of life and of mortality itself. People imagine how awful it must be to be us but you don't know your limits until you hit them and 90 seems old - until you're 89. Imagining isn't reality and **we** know that not being able to wipe your arse is not a sufficient justification to deny us life.

**(slide) Being disabled is not a death sentence**

Those of us who have lived as disabled people for all or most of our lives, know that quality of life is not measured by how much you can

physically do for yourself or by normalised definitions of attainment and happiness. There is so much more to life than that and yet the way illness, age and disability are portrayed would have you think otherwise. Being disabled is not the end of the world, it's just the beginning of a different one but it can take time to learn this, time that people like Daniel James sadly weren't allowed. The pervading views of negativity towards disabled people have ensured that fewer are being born. Looking at the other end of our lives, I wonder if assisted suicide laws were more readily available, how many disabled and ill people would have availed themselves of it in times of depression and adjustment? Indeed, how many of us would not be here today?

**Disability and terminal illness are not the same thing** (slide)

In the interview that I showed, Debbie Purdey said repeatedly that disability and terminal illness are not the same thing. That's one thing we can agree on but then as a woman with MS, why was she fronting a campaign to legalise assisted suicide for terminally ill people and defending the right of a paralysed man to end his life? To blur the lines, to confuse the 'audience', to widen the remit of an assisted suicide law before it's even been enacted? Legislation through confusion? All the while, the public don't see any difference between terminal illness and disability, they just watch and think, 'if I was like that, that's what I'd want...'. It's essential therefore that we highlight that disabled people are not inevitably terminally ill but that terminally ill people will often be disabled and as such, we can provide a great deal of insight to debates about quality of life.

**(slide) Pain doesn't have to be a pain**

Although pain is often cited as the primary reason for enacting assisted suicide laws, Oregon's 2013 Death with Dignity Act Report indicates that "as in previous years, the three most frequently mentioned end-of-life concerns were: loss of autonomy (93 per cent), decreasing ability to participate in activities that made life enjoyable (88.7 per cent) and loss of dignity (73.2 per cent). These are all disability, not pain issues. Many ill and disabled people live with pain, have experience in managing it and would say 'kill the pain, not the person'.

**(slide) Independence is a myth**

Living with an impairment teaches many of us the truth that independence is not about doing everything for yourself but instead it's about having the help you need under your control.

**(slide) Life can be bloody good (and bloody awful)**

Life is good and bad. It has its ups and downs and I think living as a disabled person helps you discover this reality. Life isn't always pretty and death, whether with assisted suicide or not, rarely is. Bringing up a disabled child will have its moments and the last weeks and months of your life will be filled with many things, good and bad. But a lovely velvet pillow death? With 100 tablets, vomiting and an unknown time for the drugs to work?

**(slide) Doctor's aren't Gods or Goddesses**

Disabled people are likely to have had greater encounters with the medical profession than the majority and so we know all too well their fallibility. Many of us have lived way beyond the prognosis our doctor's once gave us so how do we trust their assessments of what someone's future will be or how long they may live? How many have lived past their predicted sell by date? Doctor's make mistakes. They already have great power over our lives and the resources we can access. We know first hand their role as gatekeepers so do we want to give them even more power and make them gatekeepers of our lives? General practitioner's in the UK don't even want this role. In a recent survey, the Royal College of GP's voted against Assisted Suicide by 77%, concerned that physician-assisted suicide would be detrimental to the doctor-patient relationship, that the most vulnerable groups in society could be put at risk and that it would be impossible to be sure that every request for 'assisted dying' was entirely voluntary.

**(slide) We're not the problem! Barriers are!**

Discussions about life and death issues are usually individualistic and impairment focussed and overly emotional. That's certainly what the media want - 'if it bleeds it leads'. However, those of us who live with impairments know that a large percentage of the time, it is the barriers that disable us, not our impairments. We need to focus our limited time and resources on removing the barriers and the results will benefit many of us, disabled and non, rather than an individualistic, medical solution for just a few.

**(slide) Choice is bullshit**

When making the documentary on assisted suicide, I asked disabled people what they thought about having choice about how you die? Ellie Jenny, a disabled woman from Oregon who had few resources yet very great needs, said, "how can you have choice when you don't have the most basic choices in your life?" Her fear being that choice will become a duty. People already have choice over how they die. What they want though is to legitimise their choice as the right, socially approved, choice. As activist and Michael Bailey said, "The issue is not whether you have choice, the issue is whether you have government involvement in that choice"

Before I leave you, I have a quick quiz. (slide) Which one of these is the odd one out - and why? The Banner-tailed kangaroo rat, the African elephant, the Gray-handed night monkey or the person with Down syndrome? Ding! That's right, the odd one out is the person with Down syndrome because whilst all of them are at threat from extinction, the person with Down syndrome has no protection in law. The animals however are all covered by the 1973 Endangered Species Act

There is now a 90%+ termination rate for Down syndrome and spina bifida. If you're a rat, monkey or elephant with a 90%+ termination

rate, you are on the 'endangered' species list and receive full legal protection and attention.

How many more impairments do we have to lose, how many lives have to be extinguished, how many of our community have to disappear before disabled people are afforded legal protection at the beginning, middle and ends of our lives?

We have legislation that discriminates against us, that denies us life and that enshrines in law that disabled people's lives are without value. What we need, is legislation that protects us from extinction. Perhaps it's time for the Disabled Person's Endangered Species Act 2014

Thank you and questions?