Disability Experience: A Contribution from the Margins Towards a Sustainable Future

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Abstract

Humanity is faced with serious socio-environmental problems, the causes and manifestations of which appear more complex than we have ever faced before. At the same time our value system seems unable to cope with these problems. Not only that but the magnitude of many of these problems is such that they are often experienced as overwhelming, which in turn contributes to apathy. In this article I propose that the disability experience of interdependence offer a practical framework towards a sustainable and flourishing world. This experience on, and from, the margins, may be a contributor towards reducing the disabling distance that we have created between the environment and ourselves, and between ourselves and others. I propose that the disability experience of interdependence offers both a vision towards which to aspire and the practical means to towards it. Its transformational path points to the human condition as one of vulnerability and dependency while identifying those resources in human nature that may enable us to live a fulfilling life within inevitable limitations.

Introduction

This article has been adapted from the annual Jennifer Fitzgerald Memorial Lecture hosted by Queensland Advocacy Inc. (QAI), a leading Australian disability advocacy organisation.

Jennifer Fitzgerald (1959-2000) was a lawyer who worked with QAI. In particular she worked on bio-ethical issues and their impact on people who have disabilities. Jennifer had a strong sense of connection between bioethical issues, the social position of people with dis-

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abilities and a broader social and ecological crisis. She saw that in engaging with these matters, society as a whole may be raised to become more humane.

In this article I propose that the disability experience of interdependence is applicable as a framework towards a sustainable world and give some suggestions as to how this may work. To develop this case, I will first touch on the social position of people with disability and the state of the world in which we must all live together. After all, knowledge of the social position of disabled people is not common for most people. Nor are the causes and magnitude of our environmental problems, although perhaps increasingly so, with now almost daily, further evidence of our world's impairments. Next I will touch on dominant social values that underlie these situations. The same fears, values and attitudes that disable people have disabled our natural and social worlds. These include fears of life as it is: entropic, limited, interdependent, often uncomfortable and unpredictable. This, while our dominant values seem to negate this human condition, played out as they are in our individualism and materialism, and in pursuits of control and escapism. Attitudes that are coherent with these fears and values naturally express support for individual comforts and security and devalue dependence, loss of control and limitations, as embodied by many people who have impairments. To make sense of these unwelcome phenomena, and the people that embody them, personal tragedy stories of victims or heroes are commonly applied to people who have disabilities, in doing so distancing disability from our consciousness as just part of human life – a full human life. The disability experience of interdependence involves genuine care, not distance. Reflection on this experience may bring to consciousness the facts of our connection and inter-relatedness with our world as-it-is and offer a practical guide of day-to-day acts of genuine care that anyone may adopt towards a flourishing and sustainable community.

The social position of people with disabilities

At a theoretical level disability is now commonly accepted as arising from an impairment, from one's personal attitudes, and from social attitudes towards the impairment, including how physical and social environments and support (services) are shaped as a results of these attitudes, beliefs and values. Their interactions shape participation, discrimination, acceptance or abuse of people who are often seen as different from the idealised norm of citizens as materially well-off, physically and mentally hale, as physically attractive and contributing consumers. This dominant model of what it is to be human disables impaired people. And the attitudes it spawned have impaired and disabled our social and physical environments.

In my role as a wheelchair-using air traveller, a prominent international airport recently labelled me as "the Other" in its undoubtedly well-meant effort to assist travellers with disabilities. After an off-hand kind of assistance by a young airport employee, who was simultaneously plugged into several means of mobile communication, including a walkie-talkie, sms, music and his mobile phone, I was parked with the other "patients" as they were called. They were a group of mostly mobility-impaired travellers, gathered in a semi-enclosed area. All of us were required to wear a large yellow sticker, to be prominently displayed on the outside of our clothing. The purpose was easy identification by transfer assistants. The sticker read, in bold black letters "I AM BEING ASSISTED", and identified me as receiving a "special service", and gave my full name, flight number and destination. While waiting I witnessed some rather disrespectful treatment of an older female traveller in a wheelchair, whose footplates the airport assistant kicked down angrily after this international traveller did not understand his repeated exhortation: 'leg!, leg!, leg! Travellers with impairments were thus not heard, and merely labelled and processed. They were externalised from mainstream *real* life and humanity and became more vulnerable as a result.

I agree that these are examples that pale next to many subtle and overt abuses and discrimination often visited upon people who are labelled disabled. But what we should note is that many abuses start from small beginnings. Martin Luther King Jr said "men hate each other because they fear each other. They fear each other because they don't know each other. They don't know each other because they cannot communicate with each other. They cannot communicate with each other because they're separated from each other." (Clinton 1996: 130-131) I cannot think that the originators of this airport service for passengers with disabilities were ill-intentioned. Probably the opposite. But as has been said many times, good intentions are not good enough.

According to Joan Tronto's framework of interpersonal human care, proper attention has to be paid to such needs, responsibility must be taken for meeting them, the approach must be competent, and there should be responsiveness to those receiving the service (Tronto 1995: 141-150). In other words true care requires consciousness of what it is that needs to be done, who for and why – involving a consciousness of personal and social values. Consciousness of values and due care are keys to flourishing personal lives as they are to a sustainable world.

The position of people with disability is generally one of devaluation, one I can only sketch here. They are often viewed as a burden, and disability as a fate worse than death. This devaluation is made visible in the facts of their high levels of poverty, abuse, segregation and discrimination. For example people with disabilities are under-educated, under- and unemployed and the professional service system often fails them, even as larger amounts of money have been poured into it than ever before. In Australia young girls with disability are very likely still being sterilised illegally (Brady, Britton & Grover 2001: 57), and people with intellectual disability and mental illness are grossly disproportionally represented in prison populations. There are no reasons to believe that this situation is any different in most countries.

Yet our declining sense of community,

combined with a pervasive paid service culture, means also that there are fewer people to voluntarily stand by people who have disabilities. Government funding strings have transformed many services into business models, inevitably facilitating a reduction in organisational ability to appreciate genuine needs and, in turn, favouring their reduction to mere cost-benefit analyses. Australian disability advocacy organisations have also been constrained by this culture and generally by a fear that governments have of dissenting voices. Other dedicated organisational safeguards for people with disabilities have been weakened, either by political design or in aide of managerialism (in practice of course the two often go hand-in-hand). Furthermore the bureaucracies of some helping agencies have created Monty Pythonesque barriers to communication with their clients, and to the realisation of their entitlements. Jungles of electronic options, access numbers and disconnections have become formidable barriers to genuine service and care.

The socially weak and devalued position of people with disabilities is manifest in various ways. Sadly their perspectives are commonly not acknowledged in debates on such legislation that would enable euthanasia, withdrawal and withholding of treatment, embryonic stem-cell research, abortion and so on. If a disability perspective does enter these debates it is more often one which plays on disability as a personal tragedy, and where cure or elimination are instruments of compassion wielded within the theatre of the medical model. The exclusion of disability perspectives on such medical-legal developments is palpable and worrying. Medical and legal perspectives and their technologies all too often seem to be thought of as sufficient in themselves to do the job even though such models themselves do at times represent severe barriers to health and justice in the lives of people with disabilities.

In 2003, 20 per cent of Australians (or 3,958,300 million people) reported a disability, with 6.3 per cent having a profound or severe core-activity limitation. For example, conditions include hearing loss, which requires the use of a hearing aid, having difficulty dressing due to

arthritis, and advanced dementia that requires constant help and supervision (Australian Bureau of Statistics N. D.). Conditions such as paralysis, acquired brain injury and Parkinson's disease also involve significant levels of disability. These rates of incidence of disability are similar to those in other developed nations but the World Health Organisation estimates a disability prevalence of only 10 per cent worldwide (Jolley 2003). Whichever rate one accepts these numbers reveal a sizeable interest in numbers alone.

But this fact also contributes to them being seen as a growing burden on society. In most OECD countries for instance the causes of increasing health expenditure are an ageing population and increased use of medical technologies and drugs (AIHW 2005). In Australia, in 2003, 2.6 million carers provided some assistance to those needing help because of disability or age. Aging demographics, an associated rise in disability prevalence and a shortage of carers are issues that touch us all, in publicly funded services and in our personal lives. However, until they actually do in our own lives, I fear that it is often seen as outside one's own responsibility, like our environmental crisis.

The perception of disability as a burden increases the vulnerability of people with disability greatly. But perhaps no more so when some philosophers and ethicists would rank their value below those who are said to possess personhood, or for example below that of a trained gorilla. Infamously, influential philosopher Peter Singer and 'green' supporter of a sustainable world has long promoted such views and has stated that "Killing a defective infant is not morally equivalent to killing a person. Sometimes it is not wrong at all." (Singer 1993) That such utilitarian views could be taught in ethics courses in many universities should perhaps not surprise us. Negative public assumptions about people with disabilities are alive and well despite a rising (Australian) public expenditure on support services[1].

It is clear then that tolerance of people with disabilities is as thin as the banknotes that now buttress their lives through funded services, aids and equipment. A faltering economy would quickly pull that rug out from under them and fully expose them to the untempered effects of consumerism and utilitarianism.

A disabled world

The world in which people with disabilities live, as we all do, is straining under the burden of its exploitation. It is a disabled world. Our social problems, in Australia as in other Western countries, have been identified as arising from our individualist, materialist value system include rising rates of suicide, decline in civic obligation and a rise in social disorder, depression, substance abuse, stress, anxiety, violence and crime[2]. It is therefore perhaps not surprising that the World Health Organization predicts that depression will be the second leading cause of the global 'burden of disease' by the year 2020, where presently it ranks fourth (WHO 2003, 2004).

Authors of the 1972 classic work *The Limits to Growth: A Report for the Club of Rome's Project on the Predicament of Mankind* have said in their recent and third report since that time, that the world has now overshot its resources beyond replenishment rates and that catastrophe is imminent within this generation (Meadow, Randers & Meadow 1972, 2004). A Pentagon report leaked in 2003, on global social and ecological threats to the USA, predicted the likelihood of global social, environmental disruption, including wars over water and flooding of some countries, including my homeland, the Netherlands (Schwartz & Randall 2003). These ideologically widely sourced reports, and others, appear to indicate a broad and growing consensus on the seriousness of the state of our world.

Eminent Australian epidemiologist Tony McMichael (McMichael 2001) lists our challenges as humans having:

> *doubled [their] average life expectancy, quadrupled the size of our population, increased the global food yield six-fold, water consumption sixfold, the production of carbon-dioxide twelve-fold and the overall level of economic activity twenty-fold. In so doing, we had by the turn of the century*

exceeded the planet's carrying capacity by approximately 30%. That is, we are now operating in ecological deficit. These rates of change are unprecedented in history. This is why there is a need to seek an understanding in ecological terms, of the underlying determinants of human population health. This is Big Picture stuff (McMichael 2001: 318).

The big picture is that the values that we have developed over the last 500 years, since the period called the Enlightenment, obviously no longer serve us well. Francis Bacon urged the control of nature to relieve man's estate but the subsequent progress project has instead delivered Dystopia to many. We have sought refuge from an unpredictable, insecure world through material and technical innovation and in the process have come to identify ourselves as merely material, disconnected individual parts rattling around in a universe without inherent meaning or purpose. We prize invulnerability from the world's processes through technological control, we prize our independence, physical and intellectual beauty and prowess. We use the world's resources to feed these ever-growing needs. In the process we have created loneliness, depression and distance from others and from our environment. These ingredients are all part of the same recipe to which disasters such as hurricane Katrina in New Orleans, and our global warming-caused or enhanced droughts, heatwaves, floods and social disruption appear to be cooked. This is also the exact same recipe that causes us to marginalise people who are highly vulnerable and dependent and has us deny vulnerability and dependence as essential to life. It is this values environment in which we make our day to day decisions as consumers and producers, and in which we legislate for medical and personal decisions about life and death. There is much talk about sustainability but all too often its meaning is found in the values of the consumer culture, rather than in the social or environmental components of the much-quoted triple bottom line. Our current values system has made us more clever but it does not seem to have helped us to make wiser decisions. Our problems are more complex and we do not have the values system to keep it in check.

Yes, this *is* big picture stuff. For all of us and for people with disabilities especially so. The best-ramped buildings in the world, the best-accessible parking bay, the juiciest individual rights to choice, are not going to help much in a world of ecological and social chaos. They did not help during the European heatwave of the summer of 2003 when some 15,000 died in Paris, France alone, many elderly and who knows how many people with disabilities among them. They did not help in New Orleans, in the country that pioneered legal protections for people with disabilities. There were reports of abandoned nursing home patients who died, if not from drowning, then from lack of care. Triage was reported as doctors saw so-called euthanasia as the only option open to them patients for whom they no longer had the means to care. One doctor was quoted as saying: "people would find it impossible to understand the situation. I had to make life-or-death decisions in a split second. It came down to giving people the basic human right to die with dignity." (Daily Mail 2005) And even during lesser events, causing power shortages or disruption of transport can mean serious problems for people on respirators, use electric wheelchairs and appliances and who need to obtain life-saving medication. A lesson from disability experience then is that it is generally foolish to predominantly rely on technology or rules to combat our wider problems of a seriously impaired world. For people with disabilities events surrounding Katrina may be a glimpse into a insecure future – that is, not much of a future – even if sustainability advocates carry the day.

For if the dominant value framework cannot fix the problems that it caused there also seems reason for alarm about some solutions proposed by those who strive for a sustainable world. Influential Christian authors, one of whom an ex-World Banker, and sustainability advocates Daly and Cobb (Cobb, Daley 1997) want to reduce population growth in a number of ways. In the interest of population control they advocate active shortening of life. In words that remind one of the 1970's sci-fi film Soylent

Green (Green N. D.) and of Thomas Moore's[3] treatise on a place for euthanasia in Utopia, Daly and Cobb say in their work entitled *For the common good*:

> *Older people should have the right to die on their own terms. A major dread of the elderly is that they will be kept alive at great expense to society and with much trouble to their children long after their lives have ceased to have any meaning for themselves and for others. This is, on any large scale, a problem brought about by the triumphs of modern medicine. The proper response cannot be found in ancient religious texts that came out of a very different social and demographic situation. Society is beginning to take a few tentative steps toward releasing doctors from the need to take extreme measures in preserving the life of one who wants to die we hope that with due caution it will go considerably further. Quite apart from any general demographic considerations, a proper respect for human freedom and the needs of the elderly should grant them the right to die and aid them in implementing their decision. In a world where population presses upon ecological limits, there are additional reasons to take these humane steps (p.250).*

In this work Daly and Cobb show also how some abstract notions, the symbols of economics, have been adopted as if they were real, that which they call "the fallacy of misplaced concreteness". Thus the value of land, how we measure economic success, the nature of The Market and even human nature are commonly misjudged in our economics-driven world. In this instance they appear to have committed this fallacy themselves in interpreting the nature of human suffering and its causes. Should we remove the sufferers or act on the causes of their suffering?

Convergence between such philosophies and the world's need to control human population size, allocate finite resources while using its hi-tech ability to genetically manipulate life and develop social policy that may end lives, presents grave dangers to highly dependent and vulnerable people – the new 'useless eaters'.

Utilitarianism and survivalism with an overlay of rights-to-choice-and-dignity-speak is an awful combination. They justify fears of a new eugenics. In this work Daly and Cobb portray population reduction through death-by-choice as a noble act for sake of the common good. They do what Einstein warned against. They use present-day utilitarian values in trying to fix problems that arose from those values in the first place. They allude to, but do not *name* abortion, euthanasia or medically-assisted killing. For good reason. The world has seen such (self) deception before and one such example involved the wearing of yellow stars and many deaths, including those of people with disabilities. It is therefore important that *Green* advocates are explicit about what they mean when they talk about the means towards a sustainable world. A world that excludes some people cannot be sustainable.

Suffering is an inalienable part of life and its experience primarily depends on the ways in which we view it and on the quality of our social interactions and support. It is a question of where a civil, a sustainable society would put the emphasis: is it on care, or on cure and elimination of the sufferers. How we collectively answer that question determines the quality of our community, and the human qualities that would predominate within it.

Human nature and care

Prominent environmental scientists acknowledge that "the problem of sustainability is not the environment, it is human nature" (Ehrlich 2000). But what is it in human nature that creates our problems and what resources may we find in it to assist us with them? In 1992, 1500 scientists signed a warning about ecological decline and called for a new ethic. They said that this new ethic "must motivate a great movement, convince reluctant leaders and reluctant governments and reluctant people themselves to effect the needed changes...". And in calling for a new ethic they effectively identified it. They said that we must find "a new attitude towards discharging our responsibility for caring for ourselves and for the earth (Union

of Concerned Scientists 1998: 306). In making this statement these scientists identified an ethic of care, one involving an appreciation of the link between the health of our environment and of our human relations. As E.O.Wilson (Wilson 2002: 151) biologist and environmental scientist confirms: "the new strategy to save the world's fauna and flora begins, as in all human affairs, with ethics." But if we think that an ethic of care is what we need then how to arrive at a widespread adoption of such an ethic, one opposed to current dominant social values?

Change is hard to conceive when we have been so far removed from the realities of life for so long. For example, according to Paul Ehrlich (Ehrlich 2000), who famously first warned of the effects of the human population explosion in 1968, the majority of the human population now lives in cities where the "average city dweller has no idea what's involved in supplying her food and has a mental picture of environmental hazards that often ranks them in reverse order of their seriousness. He says: "Because nature's services are simply unrecognised by most humans today, remarkably few people are aware of the potential seriousness of the massive global changes now under way (307)". It is our past choices that have brought us to this point and we must make better ones. But the overwhelming nature of our problems and our culture of value-free private choices, including on matters of public impact are barriers to making new choices. It is easy to observe it is yet another beautiful day and environmental disasters will not happen to us, in the same way that disability, or *you-genics* will only happen to you, not to me. It's too difficult – let's go to the shops. Perhaps the overwhelming nature of our problems and many ready avenues of escapism underlie post-hurricane Katrina efforts to rebuild New Orleans in its exact, highly vulnerable location. We quickly forget. Our minds are exercised when crises strike but our sense of urgency seems to leave us when the storm lies down and we can perhaps paper over the doubts in our minds with tsunamis of public money and with many distractions.

A practical guide from the margins

Genuine change often comes from the margins, true in human affairs as in ecology. It can come unexpectedly like the fall of the Berlin wall – or perhaps like the bright pink and black ball that I saw thrown over the high walls of a road-side child care centre. It rolled onto the road, and one driver stopped the long lines of rush-hour traffic by collecting this ball, by her act showing all the banked-up drivers in their auto-mobiles who they all once were.

I propose that the disability perspective of interdependence is a practical guide from the margins to making new choices that may lead to a just and sustainable world – one that reduces the distance between each other and our environment.

The interdependence framework that I propose is grounded in the experience of resilience and wellbeing in the midst of the difficult circumstances of impairment. Of course not all people who have disabilities and their parents and carers, would agree. There is much ongoing heart-ache, frustration, tiredness and messiness in the experience of disability. No doubt about that and I do not ignore that reality. But many studies also point to the role of good social relationships and support in transforming that experience. Those who have done so report a life-satisfaction that is equal to, or better than the average citizen.[4] Conversely, those with disabilities who lack good social relationships and support report a low life satisfaction. And, of course none of this should surprise us because relationships and social support are core to anyone's health and wellbeing. Studies show that lonely people are more prone to physical and mental health problems and live shorter lives than socially well-supported people.

The disability experience of interdependence is congruent with dictionary entries on the meaning of the word sustainability. Sustainability involves "keeping a person or community, the mind, or spirit from failing or giving away." It is about "bearing up" and "keeping in being." Furthermore there are similarities

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with what is known as the "strong" version of sustainability, which involves a critical social view of the dominant value system. The disability experience of interdependence likewise emphasises the unhelpful role of our dominant values in achieving whole, flourishing lives. This value framework also answers Tony McMichael's concern that "there is a need to seek an understanding in ecological terms, of the underlying determinants of human population health." For we will only be able to use any such understanding well when we come to *accept* what the social and psychological determinants of wellbeing are. We already *know* what they are and they are not those contained in our dominant social value structure [5].

The wisdom that I call the disability experience of interdependence involves making real choices, removed from the rhetoric of rights to value-free individual choice. It is about acknowledging limits, knowing what to accept and what one may change. It is about skilfully riding the wave rather than seeking to control it. It is about resilience and bearing up through committed relationships, with oneself, with others and with the environment, and it is about creativity in living and about personal transformation. It is about flourishing individuals within flourishing community [6].

Many people with disabilities face a lifelong state of high vulnerability and dependence on others. They have had to let go of the illusion of individual independence. For to hold on to that, and perhaps live for nothing but a cure that always appears no closer than the horizon, can cause great Tantalian suffering. The process of interdependence then, involves a conscious choice, at some point, to accept the *fact* of the impairment itself and a recognition of the *social* factors that largely shape the *experience* of disability. They cannot change those social factors alone so they reach out to people around them, first their carers and then others too. At first this can happen out of a sense of self-preservation but deeper, mutually committed relationships can flow from this reaching out. Like one participant in my own study said: "I get treated better in hospital when the staff know me so I make an effort to get to know them." (Leipoldt 2003)

Issues of dependence and so-called losses of dignity caused by needing to be assisted with the most personal and intimate tasks may evaporate in the light of committed assistance and relationship. A sense of dependence is then reframed into a sense of personal independence, paradoxically through being assisted by others, just like the early Independent Living Movement saw it. Like a participant said in my study with people with quadriplegia, someone with a high level spinal cord injury:

It's a fact of life. I mean, I am dependent on my carers to get me up in the morning so that I can become independent – put my spoon on so that I can feed myself, so that I can get to my water and tea and stuff – but I cannot prepare a meal, but they can do that and we can sit down together and have breakfast together like a normal family would do. Sure, it's not a family situation, but it's still a family to me.(Leipoldt 2003)

Personal transformation can occur as actively reaching out to others and engaging in rewarding relationships requires the development of qualities such as assertiveness, openness, clarity, kindness, generosity, and humour. In the process dependence and independence lose some of their reality while relationship becomes more real. Relationships then can become the main source of wellbeing while the direct impairment-caused limitations remains as they are. The day to day practicalities involved a lot of creative planning and negotiations around limitations and barriers. Behaving like this transformed their world as it did themselves and some began to consciously see the world as different too: as interdependent.

So, within that unromantic and often messy and painful disability experience meaning and transformation may be hidden. To find them is to find a sustainable life. Like a seriously chronically ill psychiatrist wrote (Rus 2004: 31):

I do not know whether an illness has a deeper meaning, because animals and plants also get diseases and die. I do think that illness and death therefore are just part of life ... However ill I have ever been, I have never wanted to swap with anyone, knowing that this ill life is my life. A path

upon which I have to learn to deal with dependency, while I still hold final responsibility. I have noticed that it is quite an art to be dependent on people without losing oversight, without over-asking, without putting your own frustrations in your tone of voice, without seeing yourself as a victim ... [...]. Because even though your body is a prison and you feel unfree because of your dependency, inside you can choose for freedom at any moment. So, illness does have meaning., as long as you give it that.

As we are all prisoners of our bodies we are also prisoners of our planet. It is exactly that importance of the *fact* of our connectedness, of our interdependence, socially and ecologically, that is too often denied in modern life.

Contributions from disability experience

I see the disability experience of interdependence as of three-fold interest to a long-term or perhaps permanently disabled world. Firstly this experience shows what sustainability really means. It is *not* about *buying* health, community, securities and comforts, it is about choosing to live life as well as we may within its limits and insecurities. And deep down we know that, even just by reflecting on the minority of people that can expect a superannuation pay-out that could adequately support them even materially in their old age. Secondly, values of interdependence promise more than just grim-faced resilience. They promise resilience, creativity, a sense of meaning *and* a sense of wellbeing. Thirdly, as some studies show, such wellbeing may include a sense of inner growth, or transformation. This growth is contrasted with the material growth fetishism, as Clive Hamilton (Hamilton 2003) has it, which makes us ill. Imagine instead a world, which would put as its central values that of relationship and consequently accorded *every* individual human being equal value on the basis of their potential for inner growth. We already know this to be a powerful assumption. For example education is known to be a powerful factor in reducing num-

bers of births, so important to an overpopulated planet. Perhaps our individual and collective wisdom would be more adequate in dealing with many difficult bioethical issues, including euthanasia, cures, abortion and so on, as well as our pressing socio-environmental problems, if relationship and inner growth were central. Notably Dutch ethicist Van Renselaer Potter, who coined the term *bioethics* in 1970, describes bioethics as encompassing the "integration of biology and values...designed to guide human survival" but with a broader understanding that incorporates medicine, environmentalism, public health and spirituality. (Moreno 2005)

I propose that this disability experience represents an ethics of care that the 1500 scientists from the Union of Concerned Scientists were calling for: a different value system for real change. This is not just another Utopian idea. The interdependence view does no more than point us to the human condition and to those inner resources that enable us to live with that. Utopia literally means 'nowhere' whereas the practical values of interdependence arise from engaging and struggling with life as it is, the raw here-and-now, including its paradoxes and uncertainties. In essence many people with disability develop resilience in the face of impairment by re-arranging internal order in a disordered body. They adapted to the unchangeable aspects of their impairment by transforming their vales and practices. This seems a worthwhile general template for action towards a sustainable society.

The potency of using the disability experience of interdependence arises from its common ground of human experience. It removes the boundaries between disability and non-disability, between each other, and between us and our environment. We are all dependent on other people and on our environment all of the time. None of us is completely independent. The food we eat, the clothes we wear, the transport we use and so on has come about as a result of the efforts and co-operation by others, using resources found in the environment, produced under conditions that are part of the environment. Furthermore all of us were

dependent on our mothers before birth, relied on our parents and others when a dependent, vulnerable baby, a toddler and a child. We needed others to care for us when ill and will again have be cared for when frail aged and dying. In fact our perceived times of independence rely on those times when we were helpless and were nurtured and cared for by others. This was often an unconditional commitment and love which did not depend on those receiving the care entering into a contract to return this care one day. (MacIntyre 1999) It is in our human nature to act with care and empathy towards others and it is in fact why we have survived as a species despite that part of our nature that is competitive, self-interested, seeks material security and avoids the human condition. Acknowledged interdependence reveals that there are no real boundaries between the black and white divide between disability and non-disability, just as there is none between skin colours.

Paul Ehrlich, talks of human micro-evolutionary changes over a long time as having shaped our present world. Many intertwined social, political and economic changes have influenced issues at the very centre of our human predicament – "issues of how we behave toward one another and toward our environments and of our values and ethics (Ehrlich 2000: 306)." It is in this sort of detail that he thinks the devil lives. So if we really want to grab the devil by the horns so to speak, we must start with the small steps that Martin Luther King identified as instrumental in how we treat each other. We must also grasp the big picture, that is understanding of our predicament as well as the values we need to live well. As values, actions and consequences dance in a self-feeding circle, transformation is inevitable in that dynamic process. Whether that's upward or downward is our choice. Aristotle said it in words like these: an act becomes habit, which becomes a character, which becomes a destiny.

Perhaps some of that change is already underway. Responding to a need for a meaningful life in a faltering system, phenomena such as downshifting, where people adopt simpler lifestyles and try to live within limits, have been recorded in Australia, the USA and UK. Whereas sometimes this may equate to no more than a comfortable retirement in a spa bath in Byron Bay, it does seem to be a real trend with promise of the kinds of attitudes to life that are contained in the interdependence experience. So the interdependence paradigm taps into universal human experience and perhaps into a spirit of our times. It is experience that we have suppressed and devalued but it is there. All we need to do is facilitate close, regular engagement with those experiences of interdependence in order to turn on the light and not repeatedly have it dimmed by the pull of the current value system with which we grew up.

Many opportunities may open in choosing to take that road. I will suggest just three broad approaches.

First, just as the policies and practices of the self-interested market place have successfully promoted certain values we can choose to change direction and put relationship, vulnerability and dependence at the forefront of our thinking in our lives and in our work settings. Privately and publicly we can put relationship central, with a focus on vulnerability and dependence as inevitable parts of life. Taking this path immediately takes the edge off the overwhelming nature of our global problems because in many small but significants ways, almost anyone can thus make a contribution to deeper relationships with those around them. And in public policy for example, we can enable people to be closely involved, to be supported and to be of service during times of birth, illness, disability, and dying. We could promote policies that help children develop in families where parents can give them the sort of time and attention that genuine care requires. Policies that facilitate a closer knowledge of each others' cultures and the facilitation of communities where people know each other. And we can build on developments such as universal housing access design, in particular where these are combined with environmental sustainable design[8]. Universal housing design (UHD) recognises the dwelling as a home that ought to be flexible and adaptable to changing requirements over a human lifetime, avoiding disability

and old age becoming barriers to living at home in one's community, as too often they do now. Sustainability is also a longitudinal, inter-generational concept and would be enriched by being informed by UHD. Importantly, still uncommonly practiced advocacy such as that of QAI's bioethics project, in defence of the lives of those who are most vulnerable, should form a far greater part of the disability movement's thinking and work. Disability and our human natures being what they are, even in a sustainable society advocacy will be needed to protect the interests of vulnerable people and keep society on track as a civil one. And yes, perhaps airports, hubs of international travel and communication could influence many if they put their most vulnerable passengers first in ways that accord them obvious value and respect. For the structures of any organisation that give service to be coherent with integrity, they must be designed to internally also encourage care and community – a point on which we presently also see little advocacy.

Second, language is essential to the formation of our values. In general therefore, but particularly in human services we can choose to avoid the language of the current system, that of consumers, customers, rules, outcomes, purchasers and providers. Instead we could emphasise relationship, process, vulnerability, community and perhaps even that four-letter word "love" – that which Paolo Coelho calls the Language of the World [7].

Thirdly, those who would progress the interdependence paradigm could look for alliances around the significance of fragility, limits, dependency and vulnerability that make for a whole life, beyond labels of disability, children, aged people, dying people, indigenous people, or chronic illness. Social movements around palliative care, the environment, and genuine Citizen Advocacy (a form of advocacy that matches vulnerable people with disability with advocates found within the community) are some examples that come to mind. A joining of disability movements and environmental movements around a banner of interdependence would be challenging and potentially fruitful.

Jean Vanier founded the L'Arche move-ment: small communities where people choose to live with people with intellectual disabilities. This experience involves opportunities to learn what it is to be fully human as it challenges our certainties about life. He urges that to understand ourselves is to understand others. Such understanding: "comes not only from the intellect but the truth is also ... in the "earth of our own bodies" (Vanier 1998: 2) It is about:

> *... discovering our common humanity, allowing us to be ourselves, intertwined with each other, and to give to others, receiving and giving life from one another. Do we not all share the same earth and sky? Are they not for us as we are for them? We all belong to each other, we are all for each other. (...) ...people can only get involved in the common good of a nation if they discover how we are all called to be people of service, of peace and of justice (Vanier, p.61).*

Thus direct engagement with life in all its paradoxes, from impairment to wholeness, independence to dependence, the head and the heart, can ground our ethics and efforts towards sustainable community in a sustainable natural world. Such engagement may transform our values, ourselves, and our world.

At this point I have a confession to make. My brief story about the pink and black ball is only partly true. The ball did come sailing out on the road from the child care centre. But no-one stopped. The ball was bounced between the wheels of cars until it would have met a messy end. But I choose for a different vision.

I think it worth advocating for a vision of the day that people with disability may slap a gold star on a truly sustainable society.

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Notes

1. See for example, (Barnes N.D.; Morris 1991; Sobsey 1994a; Wolfensberger 1984, 1987, 1990, 1992, 1994, 1998.)
2. See for instance (Goleman 1996; Norton 1994; Popenoe 1994; Seligman 1992; Seligman 1992; Taylor 1992.)
3. Moore, T. *Utopia*. More, T. (1516, N.D.). Utopia. London: Heron Books.

   The sick ... they see to with great affection, and let nothing at all pass concerning either physic or good diet, whereby they may be restored again to their health. Such as the sick of incurable diseases they comfort with sitting by them, with talking with them, and, to be short, with all manner of helps that may be. But if the disease be not only incurable, but also full of continual pain and anguish, then the priests and the magistrates exhort the man seeing he is not able to do any duty of life, and by overliving his own death is noisome and irksome to other and grievous to himself, that he will determine with himself no longer to cherish that pestilent and painful disease; and, seeing his life is to him but a torment, that will not be unwilling to die, but rather, take a good hope to him, and either despatch himself out of that painful life, as out of a prison, or a rack of torment, or else suffer himself willingly to be rid out of it by other. And in so doing they tell him that he shall do so wisely, seeing by his death he shall lose no commodity, but end his pain. And because in that act he shall follow the counsel of the priests, that is to say, of the interpreters of God's will and pleasure, they shew him that he shall do like a godly and a virtuous man. They that thus be persuaded that finish their lives willingly, either with hunger, or else die in their sleep without any feeling of death. But they cause non be such to die against his will, nor they use no less diligence and attendance about him, believing this to be an honourable death else he that killeth himself before that the priests and the council have allowed the cause of his death, him as unworthy either to be buried or with fire to be consumed, they cast unburied into some stinking marsh. (More 1516, Pp. 98-99)

4. The following is from Leipoldt (2003):

   People with disabilities, including those who have quadriplegia, rate their own lives as good or better than of others (Crewe 1996; Eisenberg & Salz 1991; Stensman 1985) and there is no significant difference between quality of life of non-disabled and disabled people (Cameron, Titus, Kosti & Kostin 1973; Eisenberg & Salz 1991; Fine & Asch 1988; Stensman 1985; Titley 1969; Wacker, Harper, Powell & Healey 1983; Weinberg 1984; Yerxa & Baum 1968). People with disabilities have been shown to view their lives as better post injury than before it (Ray & West 1984; Weinberg 1984). Despite many "potential problems and health complications" ageing people with quadriplegia, combining two concepts that are usually assumed to imply negative wellbeing, felt "pretty good" and were "happy with their lives and ... glad to be alive". (Gerhart, Charlifue, Menter, Weitzenkamp & Whiteneck 1997). Life satisfaction of people with disabilities is not linked to gender, age at onset of disability or age and degree of disability (Bach & Tilton 1994; Dijkers 1999; Emanuel, Fairclough, Emanuel 2000; Woodrich & Patterson 1984; Kennedy, Gorsuch & Marsh 1995). Instead life satisfaction and adjustment to disability is most often related to social factors including support from family and friends (Ville et al 2001; McColl & Skinner 1995; Li & Moore, 1998). Personal value change and personal growth of people with disabilities towards sociability and feelings of intrinsic worth have also been reported (Bach & McDaniel 1993; Crewe 1996; Keaney & Glueckauf 1993). Many aged people and people who are dying also face heightened states of dependency and vulnerability. But here too, empirical data indicate that similar processes of values change, personal growth and wellbeing can be found (Boston, Towers & Barnard 2001; Carstensen 1998; Friedan 1993; Imara 1975; Luke 1987; Mroczek & Kolarz 1998; Thomas 2001; Vaillant 2002). Also indicating values change, research suggests that the closer one's experience with care and dying, the less support for EPAS one holds (Chochinov et al. 1995; Chochinov, H.M. 1997; Emanuel, Fairclough & Emanuel 2000; Lee, Nelson, Tilden, Ganzini, Schmidt & Tolle 1996; Olde Scheper & Duursma 1994; Seale & Addington-Hall 1994). Also see (Bach 1993, 1994; Boston

2001; Carstensen 1998; Chochinov 1995, 1997; Cameron 1973; Crewe 1996; Dijkers 1999; Eisenberg 1991; Fine 1988; Friedan 1993; Kennedy 1995; McColl 1995; Mroczek 1998; Lee 1996; Li. L., & Moore 1998; Ray 1984; Ray, & West 1984; Stensman 1985; Thomas 2001; Vaillant 2002; Ville 2001; Wacker 1983; Weinberg 1984; Yerxa 1986)

5. There is a large literature on the social and psychological determinants of wellbeing. Here are only some major references: (Peterson, Seligman 2004; Myers 1992; Goleman 1996; Vaillant 2002; Peck 1993)

6. The lived disability experience of interdependence points to the validity of Tronto's conceptualisation of care. It also points to the essence of community. Geographical and cultural community or a community of interest are only the external shell of community, where nothing in itself guarantees anything about the safety and wellbeing of its vulnerable members. Peck's concept of community appears to go to the depths where a true sense of and genuine experience of community is grounded. He has summed up community as:

1. to communicate with authenticity (open and honest communication);
2. to deal with difficult issues;
3. to bridge differences with integrity;
4. to relate with love and respect.

7. see for instance Helen Keller and Paulo Coelho:

I remember the morning that I first asked the meaning of the word "love". This was before I knew many words. I had found a few early violets in the garden and brought them to my teacher. She tried to kiss me; but at that time I did not like to have anyone kiss me except my mother. Miss Sullivan put her arm gently round me and spelled into my hand, "I love Helen". "What is love?" I asked. She drew me closer to her and said, "it is here", pointing to my heart, whose beats I was conscious of for the first time. Her words puzzled me very much because I did not then understand anything unless I touched it. I smelt the violets in her hand, and asked half in words, half in signs, a question, which meant. "is love the sweetness of flowers?" "No", said my teacher. Again I thought. The warm sun was shining on us. "Is this not love?", I asked pointing in the direction from which the heat came. "Is this not love?" It seemed to me that there could be nothing more beautiful than the sun, whose warmth makes all things grow. But Miss Sullivan shook her head, and I was greatly puzzled and disappointed. I thought it strange that my teacher could not show me love. A day or two afterward I was stringing beads of different sizes in symmetrical groups – two large beads, three small ones, and so on. I had made many mistakes, and Miss Sullivan had pointed them out again and again with gentle patience. Finally I noticed a very obvious error in the sequence and for an instant I concentrated my attention on the lesson and tried to think how I could have arranged the beads. Miss Sullivan touched my forehead and spelled with decided emphasis, 'think'. In a flash I knew that the word was the name of the process that was going on in my head. This was my first conscious perception of an abstract idea. For a long time I was still – I was not thinking of the beads in my lap, but trying to find a meaning for love in the light of this new idea. The sun had been under a cloud all day, and there had been brief showers, but suddenly the sun broke forth in all its southern splendour. Again I asked my teacher, "Is this not love?" "Love is something like the clouds that were in the sky before the sun came out," she replied. Then in simpler words than these , which at that time I could not have understood, she explained, "You cannot touch the clouds, you know, but you feel the rain and know how glad the flowers and the thirsty earth are to have it after a hot day. You cannot touch love either; but you feel the sweetness that it pours into everything. Without love you would not be happy or want to play." The beautiful truth burst upon my mind – I felt that there were invisible lines stretched between my spirit and the spirit of others. (Keller 1974)

"...it's not love to be static like the desert, nor is it love to roam the world like the wind. And it's not love to see everything from a distance... . Love is the force that transforms and improves the Soul of the World. When I first reached through to it I thought the Soul of the World was perfect. But later I could see that it was like other aspects of creation and had its own passions and wars. It is we

who nourish the soul of the World, and the world we live in will be either better or worse, depending on whether we become better or worse. And that's where the power of love comes in. because when we love we always become better than we are." (Coelho 1998)

8. See http://www.dsc.wa.gov.au/default.aspx? et=3&ei=71&subSiteID=48 and http://www.dsc.wa.gov.au/default.aspx?et=2&ei=172&subSiteID=48
on universal access design in housing. See also: http://www.subiacosustainable.com.au/ and http://www.housing.qld.gov.au/initiatives/smarthousing/elements/index.htm
for examples of a combined access/sustainable approach to housing. Genuine accessible transport policies also contribute to a society that acknowledges disability as part of the human condition.

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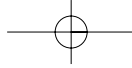
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