

**"Rights, Rhetoric and Disability Strategies:
Reflections of a euphemistically challenged other"**

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Abstract: In this conference we evaluate the New Zealand Disability Strategy, evaluating it from the perspective of those who live with disability. In so doing, we come to evaluate how far we have come in terms of rights and explore the implications of the global push for disability rights found in the negotiations about the UN Convention. In evaluating the role of disability strategies we face a fundamental challenge: the realisation that for all the rhetoric of rights, and the installation of wheelchair ramps, people with disabilities still are other, outside of the nice, normal and natural moral community. In this paper, this is attested to my exploration of everyday experiences of living with disability and personified in the bioethical debates where, despite disability critiques, the biotech juggernaut rolls remorselessly onwards. In addressing these problems we are challenged to explore disability not just in terms of individualism, but to reclaim the communitarian dimension to human rights. We will also discover that no matter what the language, we will continue to know the dark, devastating experience of being other until the structural dimensions which create and replicate disability are addressed. Welcome to the reflections of a euphemistically challenged other!

E nga mana, e nga reo, e nga iwi: Tena Koutou katoa
(To all backgrounds, to all languages, to all people: a very warm greeting)

In commencing this address I want to record how deeply thrilled I was when I was asked if I would be prepared to give this address. However, soon after I had accepted your most gracious invitation, I had second thoughts and the feeling of honour rapidly gave rise to a dread: how could I possibly assist you with evaluating the New Zealand Disability Strategy. Because we need to consider my disabilities, and they are obvious: that's right, I am Australian, and I am an academic. Well, as the saying goes, we all have our disabilities! In commencing I want to offer a dedication for this address:

To the memory of those activists who have gone before us in their struggle to promote human rights for people with disabilities;

To the ongoing and unsung stories of people whose daily experience is the denial of their human dignity; and

To future generations, in the fervent hope that this conference will help to foster a society which embraces all.

Such a dedication reminds us that we are engaged in serious business, not just about the past and present but also engaged in shaping the sort of society that we want for the future. So what sort of future do we want? Here is one suggestion:

It is the year 2010. Judy, a woman in her mid-40s of Pakeha and Maori descent is a person with a speech disability compounded by physical impairment. She has long been a member of the disability rights movement and can remember back to those early disability conferences, especially the Disabled People's Assembly national conference in Palmerston North, way back in 2004, and to speeches by activists who have long since vanished into obscurity, which encouraged her to be all that she could be.

Judy extended her political activism associated with the disability rights movement into party politics. She found it was difficult to overcome the barriers of limited thinking regarding communication technology, physical access and attitudinal stereotypes in the early days. However, as communication technology improved, as the physical access, she also found that many of her colleagues started to value her life experiences as a person with disability. She knew what it was like to be on welfare, to be marginalised, and had a great deal of support from the general population, who saw her as someone who had battled to achieve against the odds and who had great personal empathy with them in their problems. She had learnt how to recognise and to express grief associated with disability and discrimination, she had been affirmed in relationships with others including having a partner and two children, and had most importantly learnt to value herself as someone with inherently important attributes for New Zealand society.

As Judy advanced in politics, her colleagues, in including her, had been challenged in not only in their ways of doing things and thinking about normality but even in the way in which they met. They found that much of what they thought was communication was actually empty posturing. They learnt to respect how every time Judy communicated it was succinct and worth listening to. They learnt an economy of words, the importance of doing as opposed to talking. Judy has achieved the unachievable, and done the unimaginable – she has today in 2010 been elected to the highest office in New Zealand. Welcome to the world of 2010 where New Zealanders with disabilities participate as equals in political and social life.

By now you might be saying “What has all this got to do with the New Zealand Disability Strategy?” Well, quite a bit. Since I would suggest that in evaluating it from the perspective of those who live with disability¹ we need to evaluate how far we have come in terms of rights, as well as asking where we want to be, and daring to dream of the unthinkable. For the scenario I have just presented is unrealistic, unthinkable and

¹ In exploring this I am aware that some members of the disability community view the Disability Strategy as a form of treaty, which is not just about government actions. However overwhelmingly the reports on progress regarding the Strategy speak of a “partnership between disabled people and government” (*Progress in implementing the New Zealand Disability Strategy 2003- 2004*, p 7).

even, for some, obscene. Yet, if we really want to achieve the goals and ideals found in the New Zealand Disability Strategy then I would suggest that it is that fundamentally that we need to be prepared to do.

We need to be prepared to assist people to be all that they can be and identify, as the Strategy seeks to do, a variety of strategies and ways in which we can actually achieve that. Governments right around the world are currently engaged in exploring how they can “manage” the problem of disability, sometimes however with only the veneer of human rights used. Moves yet again at an international level for a UN Convention on the Rights of People with Disabilities are welcome, and ones which have been strongly supported by the New Zealand Government. The strong support for such a UN Convention is an enormously important tangible expression of the real values of the New Zealand Government and it’s commitment to fostering an approach to disability which is about action rather than mere words.

Yet, as I read through the New Zealand Disability Strategy I couldn’t help reflecting that for all of the rhetoric of rights, and the installation of wheelchair ramps, the development of advisory committees, and even legislation to the contrary, right around the world today people with disabilities face a daily devastating reality: we are the *other*, outside of the nice, normal and natural moral community.

Some 23 years after the International Year of Disabled Persons in 1981 the management of institutions and services will proudly inform us about how they don’t refer to us as “handicapped” any more. We are now objectively “the disabled”, the disease labels so important in a world dominated by medical and charitable discourse, or perhaps in a way which inspires simultaneous hysterical laughter and projectile vomiting on my part: “differently abled” or “physically challenged”. In a variety of corporations we are following the American trend to move from “equal opportunity” to “diversity management”.²

Yet, as I recover from the joys of being treated so specially on the trip over, thankful for the opportunity to be medically certified as safe to travel, grateful for the promise of anti-discrimination legislation which supposedly delivers us a few rights, even though the exemptions and definitions of reasonable just seem to escape my everyday reality, I cannot but ruefully wonder whether or not in the shift in language from “handicapped” to “disability” and “diversity” and even affirming “individual difference”, whether the change in language has actually really brought about a change in society? Even in terms of “making a difference” is disability really affirmed in terms of difference or indeed is disability as difference a devastating experience of otherness? For I still know what I am – not just “other” but now a euphemistically challenged other.

At it’s best, the New Zealand Disability Strategy provides tangible processes and structures which can be seen as important ways of moving disability from other to us, part of the moral community. The creation of a portfolio of a Minister for Disability Issues in December 1999, and the requirements of the *New Zealand Public Health and*

² Dreachslin, Janice L. *Diversity Leadership*. Chicago: Health Administration Press; 1996.

Disability Act, passed in January 2001, are very important structural wins for the disability movement – and for New Zealand society. Likewise the creation in 2002 of the Office for Disability Issues (one which actually employs people with disabilities I might add!) is also a very tangible and important expression of the values of Government. I say this with enormous envy as these sorts of positive moves are currently not present in Australian society where the Office of Disability – or indeed the Public Service in general is not place I would look to find senior manager with disability, and where our Disability Strategy should be called “The Australian Strategy for Keeping Crips Disabled”, with an emphasis on disability services, as Government recognises that ultimately disability is a big business.³

Likewise in looking at the achievements under the New Zealand Disability Strategy we can certainly identify that there are a variety of tangible steps made by the Government to enact the rights of people with disability – helping in tangible ways to bring the unthinkable to the future scenario I suggested just a little bit closer. Further, the participation of people with disabilities at a variety of strategic levels, in training and in real policy and employment under the guises of the Disability Strategy is a real plus.

The National Advisory Committee on Health and Disability helpfully groups the 15 objectives of the New Zealand Disability Strategy as:

1. Rights of citizenship for disabled people
2. Government capacity and the development of support for disabled people
3. Delivery of support for disabled people
4. Issues faced by population groups within the wider group of disabled people.⁴

Yet, as I considered the reports written by the New Zealand Government about the Disability Strategy several things struck me.

In the first place, there is no literature by people with disability evaluating the New Zealand Strategy. For all the welcome inclusion of a message from DPA every year, there is no extensive report card by an organisation like the Disabled People’s Assembly evaluating how well the Strategy is going, identifying the problems, and praising and critiquing where it is due. Secondly, there is no literature by academics with disability – or indeed any academic - which actually explores in depth the New Zealand Disability Strategy.

Likewise, I want to suggest that in general we need to ask whether to not the Strategy delivers the cultural change which is necessary to move “disabled people” from *other* to *us*. Let me say that again, recognising the analysis of our bothers and sisters in British society – those who are disabled by society – disabled people.

³ See for example: Albrecht, G. L. *The Disability Business-Rehabilitation in America*. Newbury Park: SAGE Publications, 1992.

⁴ *Progress in implementing the New Zealand Disability Strategy 1 July 2002- 30 June 2003*, p.12

Here there is one profoundly important step, which we need to applaud, and that is the New Zealand Sign Language Bill and the profoundly important recognition of New Zealand Sign Language and Deaf culture. As someone who has long lobbied politicians with regard to disability issues I wept as I read the cross-partisan support and the recognition of the social and cultural nature of disability within *Hansard*. Even more movingly, a politician who belongs to the hard of hearing world speaking in such a moving way in recognising his Deaf brothers and sisters. I quote from Gerrard Eckhoff:

It is as if by some chance of fate that I have just lost battery power to one ear ... The right and the need to express real emotion, opinion, thoughts, disapproval, love and indeed, hate, by language is, to me, the most essential part of my being. The language of the Deaf is every bit as real as the words spoken and received by those of us who are blessed with hearing ... Let us hope that this Bill is the start of a new awareness of the needs of our Deaf community.⁵

Yet, this particular disabled MP actually mirrors the dominant disablist rhetoric in talking about unintended consequences, the cost for businesses, etc. Whenever we seek to disrupt the meta-narratives of disability, the accounts of those of us with disability as having “special needs”, without looking at the structural reasons why this is so, we always come up with a variety of objects to implementing the rights of people with disabilities. These include, just in case you haven’t got them all handy:

It will cost too much.

They don’t deserve it.

Does he really need it?

It’s not fair! Fairness means giving everyone the same go, not special treatment.

Be realistic – things change slowly.

But everyone wants to have good health – why shouldn’t the thrust for disability be a technical cure?⁶

Yet, whilst we are always prepared to look at how much disability support costs, and ask how we can afford it, why is it that as a society we never ask how it costs society to disable us?⁷ To require us to be on welfare in the first place? Indeed, even more

⁵ *Hansard*, 22 June 2004

⁶ I here acknowledge modification of ideas found in Goggin, G. & Newell, C. *Disability in Australia - Exposing a social apartheid*, UNSW Press, Sydney, 2004.

⁷ See for example economic arguments made in Bowe, F. *Handicapping America: Barriers to Disabled People*. New York: Harper & Row; 1978; Bowe, F. *Rehabilitating America*. New York: Harper & Row; 1980.

provocatively, we talk about how much it costs to provide for people with disabilities and yet we never seem to ask for a justification of the perks of offices associated with being a CEO or dare I even suggest a member of parliament.⁸ Disability is still conceptualised in terms of net cost to society, rather than those of us who have something to contribute to society being needlessly disabled via structures and dominant ideas about our deviant minds and bodies.

Another profoundly disturbing aspect of how despite the rhetoric to the contrary, the status of people with disabilities as *other* remains not only unchallenged but is increasingly perpetuated and magnified as to be found in the world of biotechnology. Of course, the moment I mention that word many people with disability- and many citizens in general- mentally step back, saying “Oh that’s technical, how could we possibly understand or participate?” Yet, the disability sector needs to be to the forefront of not just discussing but indeed challenging governments to explore the lived values found in legislation to do with biotechnology.

Hence, as I contemplated the welcome initiatives associated with the New Zealand Disability Strategy I could not help reflecting that there is a significant contradiction between the recognition of Deaf culture and legitimacy and its legitimacy via the recognition of New Zealand sign language and the recent introduction of the Human Assisted Reproductive Technology Bill. Here’s how the *New Zealand Herald* highlighted the legislation:

Guidelines clear way for gene-screen babies

New Zealand parents will soon be able to have babies free of serious genetic disorders and babies whose tissue can be used to help ill siblings.

But they will not be able to choose the sex of their unborn child.

Ethical guidelines issued yesterday for public consultation allow use of a controversial test which checks an embryo for serious genetic conditions before it is implanted into a woman's uterus.

"Pre-implantation genetic diagnosis" (PGD) is used with in vitro fertilisation and will help couples who carry disorders such as Huntington's disease and haemophilia to have healthy babies.

It will also enable couples with a sick child to have a baby with healthy tissues that can be used to save the sibling's life.

PGD will also improve the chance of a successful pregnancy in older women - who are at higher risk of miscarriage - by checking the condition of an embryo before it is implanted.

⁸ I here wish to acknowledge my indebtedness to feminist thinkers, especially: Waring, M. *If Women Counted: A New Feminist Economics*. London: MacMillan; 1988.

The highly controversial technology was approved by Health Minister Annette King last year on the condition draft guidelines were created to tackle ethical issues such as sex selection.

The guidelines, formulated by the National Ethics Committee on Assisted Human Reproduction, now make it clear that "designer babies" will not be allowed.

Parents will not be able to choose the sex or physical attributes of their baby, to the relief of many groups...⁹

Media is a particularly important indicator regarding the place of people on the margins and this news item and indeed the legislation raises issues not tackled at all in the article and in social policy, including by many of my colleagues in bioethics.

For example, in these debates there is usually a suggestion that sex is a social reason but somehow or other disability is a medical reasons, made value neutral via the use of the medical terminology. Screening on the grounds of sex or race are rightly socially abhorrent but not on the grounds of disability?

Further, as ever, no voice of people with disabilities featured. Indeed when looking at the legislation we can see that in societies around the world eugenics is alive and well – it's just we use the language of choice and therapy. The account goes that, of course, there are good genes and bad genes and the bad genes just happen to be those who have disability. Highly significant given that there is a significant genetic component to deafness.¹⁰

In these debates disability becomes a moral trump card that removes any claim to life itself. In reviewing the Third Annual Report on progress with regard to the implementation of the Strategy when it discusses bioethics I frankly failed to be impressed by the suggestion that the inclusion of an article to do with bioethical issues for people with disabilities in a special issue of the *New Zealand Journal of Bioethics* and the fostering of discussion amongst disabled people constitutes some form of advance.

Frankly, as someone long involved in these areas¹¹ I am tired of discussing these issues until I am blue – indeed black – in the face. We have discussion after discussion highlighting significant issues for people with disabilities and yet as ever the biotech juggernaut rolls on, sustained by the rhetoric of choice without actually exploring the

⁹ Binning, E. "Guidelines clear way for gene-screen babies", *New Zealand Herald*, 5 October, 2004, accessed 18 October, 2004.

<http://www.nzherald.co.nz/storydisplay.cfm?storyID=3597521&thesection=news&thesubsection=general>

¹⁰ Newell, C. "Critical Reflections on Disability, Difference and Genetic Testing" in O'Sullivan, G., Sharman, E. & Short, S (Eds) *Goodbye Normal Gene*, Pluto Press, Sydney, 1999, pp 58-71.

¹¹ See for example: Newell, C. "Disability: A Voice in Australian Bioethics?", *New Zealand Journal of Bioethics*, Vol 4, No 2, June, 2003, pp 15-20.

problems associated with choice and individualism, and how disability is constructed as the antithesis- the enemy- of choice. Indeed usually it is our lives and bodies which provide the justification for what is now a very lucrative business around the world. It is in these bioethical arenas that we discover the real values of society, which I would suggest include:

“Better off dead than Disabled.”

“Thank God I don’t have a disability.”

“Disability is about “the Other” rather than “US.”

Australian Michael Cook responds to the way in which our system of biomedical ethical regulation is increasingly being used to determine social policy in an article provocatively entitled: “Designer Babies? Don’t leave it to the bureaucrats to decide”:

I feel gobsmacked. It reminds me of the opening scene in The Hitch Hiker's Guide to the Galaxy when a Vogon spaceship announces that the planet is about to be annihilated. "People of Earth, your attention, please. As you will no doubt be aware, plans for the redevelopment of personhood, family, and sexuality and morality require the building of a hyper spatial express route through your values, and regrettably they have been scheduled for demolition. An independent ethics committee has given its approval. The process will take slightly less than two of your Earth minutes. Thank you.¹²

Cook is timely to raise the vital issue of ethics committees being *de facto* setters of social policy. Yet this is a symptom of another systemic problem. Disablism¹³ – the establishment of disability as other –is perpetuated in social institutions which inform the dominant accounts of what is nice, normal and natural. The current tendency in legislation towards ethics committees regulating and deciding about biotechnology fails to recognise the disablist norms that prevail. Even when a person with disability is included on such committees, as has happened with me for some years, I find myself up against the dominant values I have mentioned.

Likewise I notice the New Zealand debate to do with euthanasia, something I would suggest will recur time and time again. Strong leadership is required from governments in these areas. Precisely because people with disabilities live with the very conditions and situations whereby we become members of categories who may, and indeed should, die covered under euthanasia legislation.¹⁴ Sadly, all too often euthanasia¹⁵ advocates are not interested in taking on board the reality of disability- precisely because our lives are seen as exactly what they want to avoid. We are the opposite of choice and freedom according to non-disabled values. I say this as someone who once desperately sought

¹² Cook, M. “Designer Babies? Don’t leave it to the bureaucrats to decide” *The Age*, April 23, 2002.

¹³ For a discussion, see Oliver, M. *Understanding Disability From Theory to Practice*, Houndmills, MacMillan Press, 1996.

¹⁴ For a discussion of some of the issues, see for example: Newell, C. "Medical Killing and People with Disability: A Critique", *Australian Disability Review*, No.2., 1996, pp 28-37.

¹⁵ This term is used to mean many different things. However I here use it in terms of “medical killing”.

death from a health professional in really appalling circumstances, and am always grateful for a response which supported me as a person rather than just viewing this as an understandable request.

As I come to review the disability strategies around the world, time and time again I wonder where the plans are for appointing people with disabilities to be members of important government boards, heading up government authorities dealing with disability and health questions. Where, dare I suggest, are the plans in New Zealand for a funded Chair in Disability Studies within a New Zealand University, with that chair occupied by a person with disability? What a long way we have to come before we start seeing that in such circumstances, rather than being the epitome of the challenge to the academy, there is a significant need for people with intellectual disabilities not only to participate in all aspects of university and tertiary study but indeed to be employed as academics. When, I wonder, will we see an Associate Professor with intellectual disability appointed to an academic position where an essential requirement is knowledge of what it is to be in receipt of services, to be the despised other, to be so far away from the norm of what it is to be nice, normal and natural?¹⁶ What of a situation where University students will do placements as support workers with leaders with disability as part of their training to be health professionals? When, I wonder, will governments recognise that some of the biggest bigots that we produce are those who actually have a tertiary education and are even employed in universities as they perpetuate accounts of justice and equity that effectively marginalise those of us with disability and perpetuate accounts of “equal disappointment opportunity”?

It also strikes me that any government disability strategy by itself can only do a certain amount. Right around the world people with disabilities need governments to be helping the non-government sector, business and wider society to learn how to embrace those of us with disabilities. This is far more than providing wheelchair ramps. Far more than learning to be nice to those that we previously referred to as handicapped, possibly even shaking their hands and then rushing off to wash our hands afterwards.

Sadly, in some areas New Zealand government policy seems to have taken the leaf out of the book of a variety of other countries around the globe, and especially the abhorrent extremely selective immigration practices of Australia. I used to hope that it was only Australia that had such appallingly restrictive immigration laws. Yet, as someone who once upon a time used to think seriously about the possibility of possibly even taking a position in New Zealand, I can but reflect on how profoundly disappointed I was to learn this year that the government that proudly claims it's success with regard to disability strategy is in it's immigration selection procedures provides screening for those who live with disabilities. I know that as a person with disability I certainly wouldn't pass the restrictive test for admission to Australian society and wonder if I would pass the test for

¹⁶ For a piece imagining a very different academic future, see for example: Goggin, G. & Newell, C. “When Tomorrow Finally Comes: Imagining Disability”, *Australian Journal of Communication*, September 2004. In press.

New Zealand society as well.¹⁷ Hence, the true lived values of society and governments become apparent when we discover in so many different aspects of public policy not just contradictions but people with disabilities being effectively second-class, non-citizens, un-people. In the Animal Farm world of so much global policy, of course all people are equal; it's just that some are not even people, citizens or are just not as equal as others.

Finally, as I contemplate the disability strategies and public policy about disability around the Western world, I also find a devastating lack of acceptance of the wisdom of indigenous people especially as the ethos of individualism and “autonomy rules OK” rules the public policy day. We need to reclaim the wisdom of indigenous peoples around the world. The challenges aren't as just mere individual economic actors – in the message of Maggie Thatcher and Rogernomics that there is no such thing as society, just individual economic actors. We need to reclaim the communitarian dimension to human rights, and indeed constantly need to claim that human rights are not just abstract entities but are actually discovered in everyday relationship and in all of the every day domains of what it is not only to survive but thrive as a human being.

Hence, today I have certainly shown why it is that, for all the benefits of disability strategies, unless we structurally address some of the deep causes creating people with disabilities as *other*, we will continue to know that dark, devastating experience that no amount of wheelchair ramps and accessible toilets will adequately tackle. We will continue to be the euphemistically challenged other – those that society talks about, rather than listening to, without valued authoritative roles in every aspect of society.

Today I deliberately commenced with a challenging picture, Judy in the year 2010 doing the impossible, achieving the unthinkable. There are many other dreams we need to picture for the future. For example, in imagining Owen:

Owen in 2010

Owen has an intellectual disability. Owen lives in his own home with his flatmate Rhonda. They have been sharing Owen's house for three years since Rhonda answered an ad in the local paper. Rhonda does not have a disability.

Owen works two days a week in a commercial nursery where he does a range of jobs from watering and feeding the plants to assisting customers with their purchases. For two days a week he volunteers at his local Community Centre. On his other days Owen enjoys many different activities including visiting friends and family, going to restaurants, fishing, and greyhound racing.

¹⁷ In saying this I do need to recognise the profound challenges associated with people from a variety of less developed countries travelling to New Zealand for health care. Yet this is a symptom of a problem whereby despite the Universal Declaration of Human Rights too many of the peoples of the world do not have access to adequate health care, something that requires more than the closing of borders by governments, and in tackling the systemic disadvantage that leads to this situation on an international level.

Owen receives help from family and friends to organise his home and activities. He also has paid workers of his choosing to help him with shopping, transport, cooking, medication and personal care. The paid workers supplement the assistance he gets from family and friends.

Owen is looking forward to taking a holiday in Queensland later this year. Owen's life is by no means radical or remarkable except that back in 2004 few people with an intellectual disability achieved the lifestyle that Owen enjoys.¹⁸

Perhaps it is only when we ask about all of the things that are required by governments, by non-government organisations, by business, by broader society and dare I suggest even in tackling the negative values and stereotypes we bring to such an engagement as well, that we will really start to bring about all of the structural and ideological changes that are necessary. Disability strategies are a means to this end, but not an end in themselves.

Ladies and gentlemen, thank you for the privilege of being here with you today, the opportunity to show why it is that I should be immediately deported back to Australia, as I conclude in suggesting the fundamental challenge that we face today and tomorrow: moving people with disabilities from the exotic *other* to *us*, part of the New Zealand community.

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¹⁸ I here acknowledge with gratitude the work of Mr Ken Hardaker in crafting this scenario for another purpose. It is clear such an emphasis is reflected in the valuable report: *To Have an 'Ordinary' Life*, A report to the Minister for Health and the Minister for Disability Issues from the National Advisory Committee on Health and Disability, September 2003.