

new developments

Bioethics, the New Zealand Disability Strategy, and the Office for Disability Issues

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The Office for Disability Issues was established in June 2002, within the Ministry of Social Development. The key responsibilities of the Office are:

- to provide strategic policy advice, by leading policy development regarding disability issues across the whole of government, and by contributing a disability perspective to the policy development of other government agencies
- to lead the New Zealand Disability Strategy, through promotion and monitoring of its implementation across the state sector, and
- to support the Minister for Disability Issues, through provision of information and advice.

Bioethics is a topic that the Office recognises as an issue of growing concern for the disability community, with which its policy work will need to engage.

A major area of concern is expressed in the *Universal Declaration on the Human Genome and Human Rights* (UNESCO, 1997). Article 2 of this Declaration states that

- (a) everyone has the right to respect for their dignity and for their rights regardless of their genetic characteristics; and
- (b) that dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

Article 6 states that

no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental

freedoms and human dignity.

Despite these international principles, one commentator (Hurst, 2000) observes:

[I]t has become increasingly clear that advances in genetics are producing serious threats, both pragmatic and attitudinal, to the very existence, uniqueness and diversity of disabled people ... [T]hese threats are hidden by a virtuous mask of the objectives of cure, enhancement and alleviation of suffering.

The myths, fears and stereotypes around disability and our quality of life dominate decision-making and disabled people are predominantly left out of the debate. In seeing disability merely as a biological commodity, our inherent humanity is lost. ... By ignoring the current understanding of disability as the interaction between a discriminatory and disadvantaging society and a person with impairments, the expenditure on cures far outweighs expenditure on services to support inclusion for disabled individuals. Above all, the threat of eugenic practices further isolates us and ignores the tremendous contribution that disabled people bring to society.

Close to home, the recent report *Essentially Yours: the Protection of Human Genetic Information in Australia* (Australian Law Reform Commission, 2003) canvasses a range of concerns around genetic issues. This report refers (paragraph 3.65) to 'genetic essentialism';

... a reductionist view of human beings as essentially consisting of their genes, with human worth describable in the language of genetics. [This] is closely associated

with 'genetic determinism' – the belief that human health and behaviour are basically predetermined by, and co-extensive with, a person's genetic makeup.

The report goes on to note some dangers of genetic essentialism, such as 'over-concentration of research into the field of genetics leading to neglect of the effects on human health of other factors, such as the social, physical, spiritual and economic environments in which people live' (paragraph 3.71).

The report identifies the challenge for

society to maintain its ... ethical compass, supporting those aspects of genetic science that reduce pain and suffering and increase quality of life, while firmly resisting the perverse use of genetic information in a way that diminishes personal freedom and responsibility, and creates opportunity for unfair discrimination (paragraph 3.77).

This inquiry explored the topic of discrimination on the grounds of genetic status in some detail (chapter 9), including the areas of insurance (chapter 26) and employment (chapter 30), recommending that identified issues be addressed within Australia's existing anti-discrimination legislation framework.

It would be timely for such issues to be examined in the New Zealand context. Questions that need to be explored include whether, or to what extent, our Human Rights Act (1993) covers discrimination on the grounds of genetic status.

The *New Zealand Disability Strategy. Making a World of Difference. Whakanui Oranga*, was published under the authority of the New Zealand Public Health and Disability Act 2000 (section 8(2)). This Strategy presents a vision of a fully inclusive society in which people with impairments can say they live in: 'A society that highly values our lives and continually enhances our full participation'.

The Strategy recognises that

Disability is not something individuals have. What individuals have are [physical, sensory, neurological, psychiatric, intellectual or other] impairments. Disability is the process which happens when one group of people

create barriers by designing a world only for their way of living, taking no account of the impairments other people have.

Through this process, people experience discrimination. Hence, the process of breaking down barriers that cause disability is closely linked to the human rights of people with impairments.

To advance towards a fully inclusive society, the Strategy includes fifteen Objectives, each of which is underpinned by detailed actions.

Objectives of the New Zealand Disability Strategy

1. Encourage and educate for a non-disabling society.
2. Ensure rights for disabled people.
3. Provide the best education for disabled people.
4. Provide opportunities in employment and economic development for disabled people.
5. Foster leadership by disabled people.
6. Foster an aware and responsive public service.
7. Create long-term support systems centred on the individual.
8. Support quality living in the community for disabled people.
9. Support lifestyle choices, recreation and culture for disabled people.
10. Collect and use relevant information about disabled people and disability issues.
11. Promote participation of disabled Maori.
12. Promote participation of disabled Pacific peoples.
13. Enable disabled children and youth to lead full and active lives.
14. Promote participation of disabled women in order to improve their quality of life.
15. Value families, whanau and people providing ongoing support.

The full text of the New Zealand Disability Strategy is available on the website of the Office for Disability Issues, at <http://www.odi.govt.nz>

Several of these objectives have relevance to bioethical issues:

- Objective 1 is to encourage the emergence of a non-disabling society that respects and highly values the lives of disabled people and supports inclusive communities. Action 1.4 under this objective is to include the perspectives of disabled people in ethical and bioethical debates.
- Objective 2 is to uphold and promote the rights of disabled people.
- Objective 5 is to acknowledge the experience of disability as a form of specialised knowledge and strengthen the leadership of disabled people.
- Objective 9, relating to lifestyle choices, includes Action 9.1: support disabled people in making their own choices about their relationships, sexuality and reproductive potential.
- Objective 14, relating to participation of disabled women, includes Action 14.4: ensure that criteria and considerations for the health and reproduction related

treatment of disabled women are the same as for non-disabled women.

There is clearly a need for critical ethical debate on these important issues. As the agency responsible for leading the New Zealand Disability Strategy, the Office for Disability Issues is keen to encourage this debate. Objectives 1 and 5 of the Strategy require that debate on disability and ethics be led by disabled people.

References

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