

12 August 2014

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Kia ora Mike

Thank you for bringing to the attention of the Human Rights Commission (the Commission) the issue of Down Syndrome screening and our role in monitoring the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

1. Independent Monitoring Mechanism (IMM) Report

As included in my email from Friday, the IMM on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD) has released its monitoring report for the period July 2012 to December 2013. The full report includes the following piece on Article 10 Right to Life.

Article 10 - Right to life

The Disability Convention requires governments to reaffirm that every human being has the inherent right to life. Governments shall take all necessary measures to ensure disabled people effectively enjoy this right on an equal basis with others.

The right not to be deprived of life is included in the New Zealand Bill of Rights Act.

Issues such as euthanasia, pre-natal testing, termination of pregnancy, access to medical care and assisted suicide are often discussed in the context of the right to life.

These matters can inspire strong passions which may polarise people within the community. This can make it difficult for a disability perspective to be recognised or heard. However, bioethical and legal issues like these can be of particular significance for disabled people. In many cases, the potential impact of changes can be far greater for members of the disabled community than for other population groups.

The voices of disabled people, their families and Disabled Person's Organisations (DPOs) need to be at the forefront of national debates in relation to these matters.

Recommendation 8

That high priority be given to the perspectives of DPOs, disabled people, and their families in relation to policy development on the right to life and bioethical issues which have a high impact on disabled people and/or public perceptions about disability.

The summary version of the report includes the above recommendation and the following from the list of next year's priorities. <http://www.hrc.co.nz/wp-content/uploads/2011/10/Making-disability-rights-real-A4.pdf>

Full report <http://www.hrc.co.nz/wp-content/uploads/2014/07/Making-disability-rights-real-full-report.pdf>

- guidance provided by the Disability Convention in relation to bio-ethical issues such as pre-natal testing
2. People First, the Government's Disability Action Plan (DAP), and the New Way of Working

The IMM is made up of HRC, the Office of the Ombudsman, and the Convention Coalition of Disabled Person's Organisations (DPOs). DPOs include People First, who expressed a strong interest in this work, and I understand they and other DPO's such as Disabled Persons Assembly (DPA), and organisations not in the Convention Coalition such as the Down Syndrome Association, are part of Saving Down's.

DPOs have an active role in monitoring the disability convention, and are now engaged with the government in implementing the convention through their involvement in the development of the DAP. Chief Executives of government departments have signed up to a new way of working with DPOs. This means engaging with them on key issues.

The current DAP has been signed off, and I understand there will be a process for updating this each year. I believe People First are in a strong position to take this issue forward with government, in consultation with other interested groups.

The New Zealand government have chosen to nominate Robert Martin, a person with an intellectual/learning disability and a leader within People First, to election for a position on the UNCRPD a first in the world. If Robert is successful in the 2016 election, he will take up a position on the committee and increase his, and the New Zealand disability community's, influence on the monitoring and interpretation of the convention.

3. Human Rights Commission work on bio-ethics

The Commission has bio-ethics and disability rights as a priority for the next two years. The extent and speed of bringing this work to fruition depends on attracting partners and funding.

As part of this I am working with Strive, a group of young leaders within the Down Syndrome Association, introducing as sensitively as possible the issues around screening, encouraging those who want to be involved to learn more and to be able to speak from their own lived experience perspective, and respecting those young leaders who choose not to be part of such a conversation.

I have been engaging with the Donald Beasley Institute (DBI) (which focuses on intellectual disability research with a strong rights approach) on how to use their expertise on bio-ethical issues, and with DBI and Otago University on developing a centre for research excellence on disability issues, and developing and sustaining a disability research program, along with other interested organisations and tertiary institutions.

I have met with the Otago Bioethics centre in response to their article on Down Syndrome screening. They are willing to engage with the Commission more regularly, including bio-ethics conferences. They were interested in being part of a dialogue on screening, including DBI, people with Down syndrome and their families, as the Commission would like to host such a dialogue in Dunedin as part of our bio-ethics work.

I have met with international lead thinkers, including Michael Stein (Harvard Disability law Project leader) and Janet Lord, who are both interested in doing further work on this issue. With New Zealand nominating Robert Martin, who Michael knows and respects from their experience in the development of the UNCRPD, there is an increasing interest in how New Zealand develops its responses to bio-ethical issues and screening, and an increased willingness to support New Zealand and be part of finding a world leading response consistent with the CRPD.

Beyond screening, in a paper to the Commission's Board I framed up the bio-ethics and disability rights issues that have come to the Commission into four groups.

I. Fertility, family, and bodily integrity

The CRPD states that disabled people have the same rights as everyone else of same age and gender to exercise their legal capacity in healthcare, maintaining fertility and bodily integrity. This includes the right to consent or refuse health treatment, contraception, sterilisation, abortion, sex education, choice of intimate partner, to raise a child. For many disabled people to realise these rights of support is required, and the CRPD also STATES disabled people have the right to this support. (The general right to exercise legal capacity through supported decision making will be directly worked through the CRPD monitoring project). The means to give support or realise these rights is not understood. The perspectives of family and clinicians are given priority over disabled person's. Non-consensual sterilisation is an example, New Zealand unlike Australia, has no legal safeguards to enable disabled girls retain their fertility.

II. Prenatal disability screening

Sometimes this is framed as a conflict of rights and values. While abortion as an issue, and polarises people, the disability community spanning both sides have disentangled the pro choice/pro life debate from the issue of prenatal disability screening, and also recognises the voices and opinions of those who reflect and represent the impairment/condition being screened for. Most decisions at government or personal level are not informed by such perspectives. The disability community thinking is reflected in the CRPD committee decisions and some international legal opinion, while other legal opinion differs. Downstream effects of the screening program include bullying, trauma, and pressure on children, pregnant women, and women who have or haven't aborted.

III. Life ending decisions

Death with dignity, euthanasia, either self determined, or determined by family or clinicians. A private members bill is likely to be reintroduced to parliament after the election. The conflict between the right to life and the right to self determination goes back to the origins of human rights thinking in the tauwi western whakapapa. Views are passionate and polarised, and strongly influenced by a particular personal experience. Also newborn disabled children may be deprived of the necessities of life for treatable injuries and conditions, when an adult with a similar condition would always be treated and rehabilitated. Though for some disabled people they say death with dignity is a legitimate goal to pursue, they still say of greater priority is legislating for and ensuring life with dignity consistent with the CRPD.

IV. voice and identity

The economics of health rationing and Genetic research are advancing and leaving behind the ethics and rights based responses to the questions raised. Prevention of impairment is assumed to be desirable. Disabled people's voices are seldom part of the decision making mix. Underpinning a disability rights perspective is identity, many of us might choose to be someone different, and many of us would choose who we are but prefer to live in an inclusive world.

I look forward to continuing to work with you on the important issues you have raised.

Yours sincerely



Paul Gibson, Disability Rights Commissioner
Kaihautū Tika Hauātanga