“Cloning and People with Disability"

Submission to the House of Representatives Standing Committee on Legal and Constitutional Affairs Inquiry into the Scientific, Ethical and Regulatory Aspects of Human Cloning

by

The National Caucus of Disability Consumer Organisations

Written by

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Introduction

The National Caucus of Disability Consumer Organisations (NCDCO) is a network of disability peak bodies which was formed in July 1995 and funded through the Office of Disability in October 1995. The main roles of Caucus are :

- Policy development and advice.

- Facilitating appointment of consumer representatives to government, business and community working groups.

- Coordination of campaigns on issues of shared interest.

Currently, the Caucus has ten (10) participating organisations and receives many requests for involvement of other organisations. The Caucus has associated membership enabling Sate-based organisations not directly represented through one of the National peak bodies to develop a close working relationship with Caucus.

Participating Organisations

Australian Psychiatric Disability Coalition (APDC)
Carers Association of Australia (CAA)
Deafness Forum of Australia (DFA)
Head Injury Council of Australia (HICOA)
National Association of People with AIDS (NAPWA)
National Council on Intellectual Disability (NCID)
National Ethnic Disability Alliance (NEDA)
Blind Citizens Australia (BCA)
Physical Disability Council of Australia (PDCA)
Women With Disabilities Australia (WWDA)

Introductory Comments re this Submission

This submission is necessarily brief and seeks to identify issues for people with disability. There is no doubt that cloning raises vitally important issues for people with disability and their paid and unpaid carers, and we urge the committee to consider this issue in full. Most arguments in support of cloning are because of claims to alleviate disability or disease and yet there is no evidence in the professional literature of perspectives of health care consumers or more specifically people with disabilities, despite their conditions supposedly being the focus of such technology.

In general we wish to be supportive of the recommendations and thrust of the Report of the Australian Health Ethics Committee (AHEC) on “Scientific, Ethical and Regulatory Considerations relevant to Cloning of Human Beings". In particular, we recognise with appreciation the opportunities for health care consumers and people with disabilities to input into this report via representatives from these groups appointed by the Australian Health Minister to membership of AHEC. In this way Australia leads other parliaments with regard to the inclusion of consumers in deliberations regarding public policy and bioethical issues.

Regulation and the Common Good

There is much to be said for the prohibition on the cloning of human beings and embryos found in the above-mentioned guidelines as well as the prohibition of experimentation with the intent to produce two or more genetically identical individuals, including development of human embryonal stem cell lines with the aim of producing a clone of individuals.

Regardless of our views of the status of the embryo, fetus, zygotes and human tissue, there is no doubt that there are significant public concerns at a variety of developments involving genetics and cloning. Issues for people with disability include the exclusion of our perspectives from many ethical debates and the way in which our bodies are often the sites for intended therapy, and yet rarely are our voices sought or heeded in the development of technology. See Appendix 1, which is a resolution of a recent international conference for and of people with disability about bioethical issues.

This country still does not have uniform regulation regarding reproductive technology let alone cloning. While the Australian Health Ethics Committee has recommended uniform legislation with regard to reproductive technology in its 1997 report,[1] this has not occurred.

Therapeutic Cloning?

Of course, a variety of scientific Australian perspectives argue for human cloning. They claim a clear difference between therapeutic and reproductive cloning. Many commentators seem to agree, for a variety of reasons, on a ban on reproductive cloning. Yet, if we are not careful then claims by scientists for experimentation based upon the notion of therapy could inflict serious harm and have negative consequences for those society regards as having disability. So often people with disability have differing opinions from health care professionals as to appropriate interventions. It is important for this committee to review the literature regarding the views of people with disabilities regarding emerging genetic technologies and the bioethical debates.[2]

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[1] National Health and Medical Research Council. *Ethical Guidelines on Assisted Reproductive Technology*. Australian Government Publishing Service, Canberra, 1996.

[2] For recent examples of Australian perspectives and critiques, see Newell, C. "Biomedicine, Genetics and Disability: Reflections on Nursing and a Philosophy of Holism", *Nursing Ethics*, Vol 7, No 3, 2000, pp 227-236. In Press. Also, 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, pp 58-71.

Of course, the future potential for cloning without the use of embryos or foetus raises important issues. There is no doubt that the future projected possibility of cloning human parts is seductive as a possibility, but will still involve morally significant tissue. These possibilities have not been widely discussed by the broader community despite the major ethical questions raised by cloning of body parts/organs. There is much to be said for a moratorium on the cloning of human body parts and tissues and the use of human embryonic stem cells, to be reviewed in a few years after public discussion. After all, science and technology should be driven by our society.

Creating Disability?

The many failures prior to the so-called "successful" cloning of Dolly must occasion significant caution. Clearly Dolly also may have been regarded as having impairment – created by the very technology which is supposed to have been therapeutic in bring her to life. Yet because the media was so focused on the technological determinist message, it forgot critically to ask what right we as a society have to use a technology which occasions the limitations and harms experienced by Dolly- what society would call a disability. We clearly have a long way to go before we can get clear benefit and minimal harm from this technology. If we are not careful then technology claimed by vested interests to be of benefit runs the risk of creating needless disability. It will also reinforce stereotypes which see disability as a condition to be avoided at all costs rather than being treated and supported.

Low Tech Technology and Care

It is also clear that cloning technology will never deliver us from disease or disability. We request that the Committee address the existing great unmet need amongst people already living with disability and disease. This need for accommodation support, respite and personal care, and support with living and education options can be addressed with low tech non-controversial technology with no adverse side-effects. It is a great unwritten news story. Cloning is supposed to deliver us from disease, but our society already has important low tech ways of increasing the quality of life and meeting the needs of people with disability now. Even a small proportion of the budgets devoted to genetic and cloning research could produce important outcomes for people already condemned by our society to live low quality lives because disability care is not the "sexy" issue that cloning and genetics is.

Discrimination and Oppression

We also have a concern that any benefits which flow from developments in genetic technology may not flow equally to people with disabilities. In a society which regards those with disability as "not quite the full quid" and "better off dead than disabled" it is all too easy to dismiss those with disability as not the ideal recipients for therapeutic intervention. This oppressive attitude easily flows through to individual acts of discrimination difficult to pick up in individual clinical settings. It is also worth noting that as many people with disability are some of the financially disadvantaged in society, in a user pays world, there are very real issues associated with gaining access to technological innovation in the same way as other members of society. We urge the committee to investigate these inter-related issues.

Further Discussing this Large Issue

The Caucus would welcome the opportunity to discuss these matters further with the Committee, especially issues to do with the complexities of notions of health and acceptable research regarding cloning from a disability perspective.

APPENDIX A: RESOLUTION OF DPI EUROPE CONFERENCE

DISABLED PEOPLES' INTERNATIONAL EUROPE
11 BELGRAVE ROAD, LONDON SW1V 1RB, UK
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dpieurope@compuserve.com

The Right to Live and be Different

On 12/13 February 2000, 130 disabled people and parents, delegates from DPI organisations in twenty-seven countries in Europe, African, Australia and North America, met in Solihull, UK to discuss bioethics and human rights. This was the first occasion of its kind and it is with pride that we make the following declaration.

First and foremost we demand:

Nothing about us without us

Up until now most of us have been excluded from debates on bioethical issues. These debates have had prejudiced and negative views of our quality of life. They have denied our right to equality and have therefore denied our human rights.

We demand that we are included in all debates and policy-making regarding bioethical issues.

We must be the people who decide on our quality of life, based on our experiences.

We also call on our organisations to give support, encouragement and reassurance to those of us who are representing our views on bioethical regulatory bodies.

Particular support must be given to empower the voice of mental health survivors, people with learning difficulties, people who cannot advocate for themselves and disabled children, in the debate.

Richness in Diversity

We are full human beings. We believe that a society without disabled people would be a lesser society. Our unique individual and collective experiences are an important contribution to a rich, human society.

We demand an end to the bio-medical elimination of diversity, to gene selection based on market forces and to the setting of norms and standards by non-disabled people.

Biotechnological change must not be an excuse for control or manipulation of the human condition or bio-diversity.

We recognise that the only way to ensure universal support for and positive recognition of our particular qualities is through stating our right to diversity clearly, with good arguments, in open and democratic discussion. We must form alliances with scientists, the medical professions, ethicists, policy-makers, human rights advocates, the media and the general public.

All Human Beings are born free and equal in Dignity and Rights

Human rights are the responsibility of the state as well as the individual. Disabled people, our organisations, families and allies must work to ensure that international, regional and national legal instruments include the implementation of rights throughout all scientific advances and medical practices concerning the human genome, reproduction, assessments of quality of life, therapeutic measures and alleviation of ‘pain and suffering’.

Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected.

In particular we demand:

- An absolute prohibition on compulsory genetic testing and the pressurising of women to eliminate - at any stage in the reproductive process - unborn children who, it is considered, may become disabled

- The provision of full and accessible (ie. jargon-free, easy to read and in alternate media) information from which people can make informed decisions

- That European governments do not ratify the Convention on Human Rights and Biomedicine as some sections are in contravention of the two documents adopted at the 1999 UNESCO Conference on Sciences

- That disabled people have assistance to live - not assistance to die

- That having a disabled child is not a special legal consideration for abortion

- That no demarcation lines are drawn regarding severity or types of impairment. This creates hierarchies and leads to increased discrimination of disabled people generally**.**

Disabled people must join together in solidarity to ensure our voices in

these life-threatening issues.

STRENGTH IN UNITY!