

REPRODUCTIVE DISCRIMINATION

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I REPRODUCTIVE RIGHTS?

In 2004, the National Health and Medical Research Council ('NHMRC') promulgated *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research*.¹ Compliance by Australian IVF teams with the guidelines is secured by the terms of the funding agreements with the Commonwealth.

The guidelines require that pre-implantation genetic diagnosis of embryos ('PGD') must not be used for:

- prevention of conditions that do not seriously harm the person to be born;
- selection of the sex of an embryo except to reduce the risk of transmission of a serious genetic condition; or
- selection in favour of a genetic defect or disability in the person to be born.

This restriction may challenge those who uphold the notions of 'reproductive rights' and 'reproductive freedom', especially those who are of the view that it is their right to choose the sex or other genetic features of their child.

The guidelines also expressed reservations that the practice of selecting against some forms of abnormality may threaten the status and equality of opportunity of people who have that form of abnormality, and that the procedures involve the disposal of some healthy embryos.

The overall rationale adopted for restricting choice in the use of reproductive technology was that '[c]linical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychosocial welfare of all participants, including gamete donors'.²

The jurisprudential dialogue about reproductive rights occurs against the background of the legal tradition that the interests of the child are paramount. This principle found expression in the UN *Convention on the Rights of the*

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1 Australian Health Ethics Committee, National Health and Medical Research Council, Parliament of Australia, *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research* (2004) ('NHMRC Guidelines').

2 Ibid 13.

Child,³ which recognises, amongst other matters, the rights of the child to an identity, nationality, family relations, and, to personal relations and direct contact with both parents. In this respect too, family law has been based on the notion that the interests of the child are paramount. Family law restricts parental choices and resolves conflicts in favour of the welfare of children.

The philosophical point to make is that the child, as a member of the human family and thus a bearer of inalienable rights (in the terms of the international human rights instruments), cannot be the object of another's rights. Reproductive rights, therefore, do not and cannot, in principle, include a right to a child. Given that reproduction is about producing children, then what exactly is the scope of so-called 'reproductive rights'?

There is international recognition of the right to form a family, but it is limited, in the *International Covenant on Civil and Political Rights*,⁴ to the right of men and women of marriageable age to marry and form a family. There have been court judgements about access to reproductive technology, but these have tended to focus on the matter of access to a medical service, rather than the broader issue of whether what is involved is a right to a child.

In the *NHMRC Guidelines*, acknowledgement is made of an on-going debate on these topics and, to that end, there is an appendix that lists issues that need to be debated. One such area is the matter of using genetic technologies in conjunction with reproductive technology.

The document offers reasons for opposing or limiting the use of genetic technologies associated with assisted reproductive technology ('ART'):

Use of genetic technology implies that admission to life is no longer unconditional.

Use of genetic technology may foster reproductive discrimination.

Use of genetic technology establishes the principle that parents may choose the qualities their children have.

The handling, testing and manipulation of embryos in genetic technology procedures may expose them to significant risk of harm. (The weight of this consideration may depend on the seriousness of the outcome that the technology is being used to avert).

The likelihood that the social effects of general acceptance of ART (with genetic technology) as an alternative to natural reproduction will include a diminished tolerance for difference.

Ethical guidelines on the use of assisted reproductive technology in clinical practice and research

Though avoidance of serious disease may be a reasonable use of genetic technology, shaping babies to parents' ideas of perfection (were this to prove possible) is not.

3 *United Nations Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990).

4 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171, art 23 (entered into force 23 March 1976).

Otherwise normal (so-called 'carrier') embryos that would be expected to have a normal life will be discarded.⁵

II WHAT IS REPRODUCTIVE DISCRIMINATION?

Two decades ago, Jonathon Glover asked the question: what sort of people should there be?⁶ He referred to the 'genetic supermarket' and envisaged that the development of gene therapies would result in parents being able to choose the genetics of their children.

Since then, the Human Genome Project ('HGP') has reached the end of the first stage, having mapped the human genome. The second stage – identifying the functions of each of the individual genes – has not yet been achieved.

The expectation that gene therapies would rapidly develop has not been the reality. It is still the case that no gene therapies have become established therapy. What has developed as a spin-off of the techniques developed for use in the HGP is a rapidly increasing capacity to identify genetic difference or abnormality and to correlate this with disease states or propensity for disease.

Much has been written about the possibility of the use of this information in discriminatory ways in relation to employment, financial institutions, personal insurance, superannuation and pension entitlements. But there is an area of discrimination that has already become well-established, that is the area which the NHMRC calls 'reproductive discrimination'.

Reproductive discrimination happens when a person or a couple experience pressure not to reproduce a child who has their familial genetic traits, or where a particular type of person is not reproduced because it is judged that his or her genetic traits ought not be reproduced.

Reproductive discrimination may happen through pressure or influence for the purpose of preventing conception or birth of a child with a particular genetic trait:

- Pre-nuptially – by screening individuals who have decided to have a child;
- Pre-fertilisation – by screening or altering gametes, or somatic cell nuclear transfer;
- Pre-transfer – by embryo biopsy and selection;
- Pre-birth – by pre-natal diagnosis and selective abortion;
- Peri-natal – by infanticide.

The reasons for selection may be to:

- Select against disability;
- Select for disability (eg, deaf parents wanting a deaf child);
- Select for or against non-disease traits – gender, sexual orientation, enhanced capacities.

5 Australian Health Ethics Committee, above n 1, 60–1.

6 Jonathon Glover, *What Sort of People Should There Be?* (1984).

Some would argue that reproductive discrimination is not discrimination at all, but simply a matter of respecting the individual choice of the woman and her partner. However, to say that an act of discrimination is an act of individual choice, does not make that choice any less discriminatory. Discrimination is almost always a matter of individual choice. What matters is when that discrimination forms something of a pattern, so that a group or category of individuals suffers as a result of those choices.

III DISCRIMINATING AGAINST THOSE WHO HAVE GENETIC DIFFERENCES

The reasons currently being offered by Western medical authorities for reproductive discrimination concern abnormalities or genetic difference. This matter has been the subject of much discussion internationally – for it re-opens the debates about eugenics – and the debate has become particularly intense in the discussion of the implications of the world-wide HGP.

The United Nations Educational, Scientific and Cultural Organisation ('UNESCO') has prepared a draft *Declaration on the Human Genome and Human Rights* ('*Declaration*'). The draft was prepared at the request of the Director-General of the UN for a committee of governments to discuss the issue in 1997 and to present the outcome for adoption by Member States in 1998. It is worth noting that the draft, which was launched by the French President, Francois Mitterand, in November 1996, explicitly rejected eugenic practices, but the final draft that emerged after the consultation with national governments had lost all reference to eugenics. At the time, there was a concerted, and eventually a successful, effort by those who were both involved with the HGP and party to UNESCO's International Bioethics Committee discussion to exclude the reference to eugenics. Preventing the coming to be of people who were genetically different, in the sense that they might be less able in some way, was held to be acceptable and the practice was not to be given such a pejorative label. Of course, the reality is that the motivation is eugenic, even if the means used is medical suasion of the parents or would be parents rather than downright force. Even though the former may be of such authority supported by social pressure, the effect and the sense of loss of choice may be much the same.

In November 1996, the Council of Europe issued the *Convention for the Protection of Human Rights and Dignity of the Human being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*.

The stated purpose of the UN *Declaration* is to ensure a development of human genetics that fully respects human dignity and human rights, and benefits the whole of humanity; to set out principles which, if universally respected, will make it possible to prevent abuse; and to affirm the need for democratic debate, the dissemination of knowledge and the promotion of the teaching of bioethics.

The actual wording of the preamble to the 1996 draft UN *Declaration* stated: '[t]he applications of genetic research must, however, be regulated in order to guard against any eugenic practice that runs counter to human dignity and human

rights'. The subsequent removal of these words was disturbing. There are those who see these matters as individual decisions and matters of privacy, and those who argue that many private discriminatory decisions ultimately constitute widespread discrimination. This is precisely the point of anti-discrimination legislation: one person's individual personal preference, when part of a broader trend involving many people, creates the injustice of discrimination against a whole class or category of other people. In this case it is discrimination against the somehow genetically inferior, or in favour of the somehow genetically superior, whether that discrimination is on the basis of disability, disease, race, intellectual capacity, appearance, or gender.

There are many quandaries in this debate. Confronted with Sally, a person with a genetic abnormality, I may say of Sally that it is a good thing that she exists. But many would seem to accept that proposition while, at the same time, accept a second, seemingly contradictory, proposition that it is not a good thing that there be people in future generations with Sally's abnormality. This latter proposition would seem to underlie the widespread practice of genetic counseling and genetic screening, and of pre-natal diagnosis and selective abortion.

The proposition is challenged. An international organisation representing disabled people, Disabled Peoples' International, recently published a statement entitled 'The Right to Live and be Different' in which they asserted that a society without disabled people would be a lesser society and they demanded an end to the bio-medical elimination of diversity and an end to gene selection.⁷ This raises broader issues than abortion, because the genetic constitution of future generations could be controlled without abortion by simply screening would-be parents and persuading or coercing carriers of genetic abnormality to not have children. Genetic selection can also occur at the level of screening embryos in IVF programs.

Article 4 of the 1996 draft *Declaration* stated:

The protection of the individual with respect to the implications of research in biology and genetics is designed to safeguard the integrity of the human species, as a value in its own right, as well as the respect for the dignity, freedom and the rights of each of its members.

The concept of *safeguarding the integrity of the human species* raised concerns with many of those at the Paris meeting because, apart from being ambiguous, it implies a eugenic aim. This clause was later removed, but the sentiment that drove its removal was not given expression in the final document.

Safeguarding the integrity of the human species is considered a 'value in its own right' in the draft statement. The final part of the sentence seems to me to put the value of the integrity of the human species against respect for the dignity, freedom and the rights of each of its members. This sort of reductionist notion of the integrity of the human species as separable from members of the human family, and as something to be valued distinctly from the dignity of human

7 Disabled Peoples' International, *The Right to Live and be Different* (12–13 February 2000) Independent Living Institute <<http://www.independentliving.org/docs1/dpi022000.html>> at 25 July 2006; Cf Christopher Newell 'The Right to Live and be Different: An exploration of the DPI Europe Declaration on Bioethics and Human Rights' (2000) 13(3) *Interaction* 6.

individuals, appears to conflict with human rights objectives founded upon the inherent dignity of every member of the human family.

Perhaps the Council of Europe's *Convention on Human Rights and Biomedicine* is less ambiguous. Article 13 states:

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

But there is an avoidance of a major issue in both documents. The trend toward elimination of genetic diseases through

- controlled reproduction using artificial reproduction techniques in conjunction with embryo biopsy for selection purposes or the use of donor gametes,
- the practice of ante-natal diagnosis in conjunction with selective abortion,
- the identification of carrier status in conjunction with policies influencing decisions to marry and form a family,
- sterilisation (voluntary or involuntary) of carriers, and
- infanticide of those with undesired genetic features either by fatal intervention or by neglect of reasonable care including the failure to provide adequate nutrition and hydration,⁸

will ultimately affect the human gene pool with fewer people with genetic abnormalities reproducing and hence some human genes heading for extinction. Further, this change to the human gene pool need not be restricted to serious genetic diseases. More and more it is genetic susceptibility to disease, rather than disease itself, that is being identified. There is also a growing scope for selection for or against genetically determined characteristics other than disease states. Height, intelligence, appearance and behavioural traits are just some of the aspects which have a genetic component and which may be the subject of parental or social preference once the genetic determinants become identifiable.

These issues raise profound questions about:

- what sort of people there should be;⁹
- what constitutes disease? what is normality?
- whether the genetic disease variations in human individuals constitute part of the integrity of the human genome that should be protected;
- whether the latter question makes sense when asked in this reductionist way, as though the genes were separate from the people who are the bearers or instantiation of those genes;
- whether the individual member of the human family, including his or her particular genetic structure, should be considered an artefact or an icon;¹⁰

8 It should be noted that infanticide and abortion for reasons of male selection are common practice in China and India, abortion for sex selection is not unknown in Australia, and the withdrawal of ordinary care such as feeding is a common practice in Australia and other Western countries for infants born with serious abnormalities.

9 Glover, above n 6.

- whether respect for the inherent worth and dignity and inalienable rights of an individual member of the human family warrants protection before birth as well as after birth;¹¹
- the right of men and women to marry and form a family.¹²

Article 14 of the *Declaration* gives some recognition to this problem:

States must guarantee the effectiveness of the duty of solidarity towards individuals, families and population groups that are particularly vulnerable to disease or disability linked to anomalies of a genetic character.

A relevant distinction is between treating a person who has a genetic disease, and seeking to eliminate the disease by ensuring that persons, and others like him or her, do not reproduce; or that their affected offspring are eliminated by embryo selection, abortion or infanticide. It is worth noting that such an approach has now become commonplace in ante-natal care and in reproductive technology.

That this may happen with the consent of the parents or would-be parents does not alter the fact that the concentration on early diagnosis is for the purpose of elimination of the diseased, rather than the treatment of the disease. I am prompted to ask: what will be the impact of elimination strategies as the potential pool of those who have an identifiable genetic disadvantage becomes much greater and the capacity to achieve genetic profiling develops?

10 Rev Robert Brungs SJ, 'The Human Body: Artefact or Icon?' in Joseph N Santamaria and Nicholas Tonti-Filippini, *Proceedings of the 1983 Annual Conference of St Vincent's Bioethics Centre* (1983).

11 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3, Preamble (entered into force 2 September 1990).

12 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171, art 23 (entered into force 23 March 1976).