



# OTAGO BIOETHICS REPORT

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## Editorial

### Protecting the Unborn

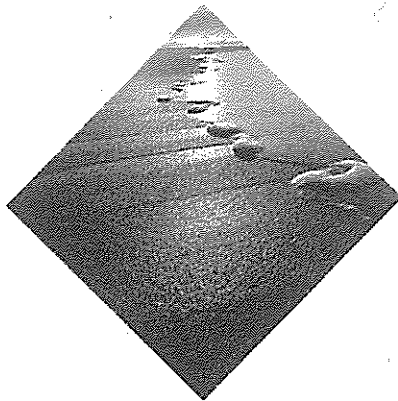
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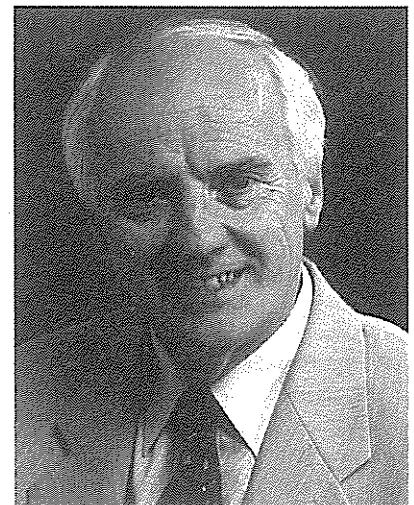
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The ethical challenges of human reproduction continue to grow in number and complexity as new techniques emerge and new cases present themselves. Take, for example, the emerging use of stem cells in therapeutic interventions and the possibility of the prenatal testing of foetuses for compatibility with recipients in order to harvest the cells from the umbilical cord at birth. How do we weigh the interests of the developing foetus with the interests of the desperately sick recipient? Do we treat the foetus simply as a source of human tissue, or do we regard it as having interests which should be protected?

Medically assisted reproduction demonstrates our continuing power to control reproductive processes. We have realised for a long time that in this field what is possible is not always what is ethically desirable. Thus, countries which have legislated controls over such medical activity have generally proscribed certain procedures such as cloning or the transfer of human embryos into other species.

But how can we be confident that respect for these standards is maintained in New Zealand where there is no specific regulation in the area of human embryology and assisted procreation? We have a special ethics committee (The National Ethics Committee on Assisted Human Reproduction, NECAHR), which has been given certain responsibilities in this regard. But, as its chairperson Rosemary De Luca and Sandra Coney point out in this edition, such a facility is not

adequate for the task in hand. Most other developed countries have enacted legislation to prevent the *ad hoc* development of public policy on such matters. Some of these regulations are very restrictive (Germany and Austria), others are cautious (such as France, Denmark and Sweden), and some are liberal (the UK). Yet they all place the welfare of the child high on their agenda. One might argue that, in some cases, the legislation is not child-centred enough, such as in the UK Act. There the interests of the commissioning parents seem to prevail over the interests of the child in preserving the secrecy of infertility and the identity of gamete donors. Nevertheless, in all these regulations safeguarding the child's welfare is proclaimed to be important.



Professor Donald Evans

The child's interests figure variously in a number of papers in this volume. Wayne Gillett and Katy Crozier are concerned to develop adequate access criteria to assisted reproduction services which are in short supply. How far should the interests of the child be used to prioritise patients for treatment? Lynn Gillam and James Chisnall are both worried about the

interests of the disabled. They wonder how far prenatal genetic testing should go in determining what is in the interests of developing foetuses and what are the consequences of such determinations for disabled members of our community. Andrew Moore reflects *inter alia* on the role which the interests of the child play in applications for posthumous reproduction.

It is clear from the papers as a whole that the kind of regulation which we currently have in New Zealand is inadequate and that the sooner good legislation is adopted the better it will be for patients, practitioners and the children of our country.

## Article

### Value Messages in Pre-natal Screening

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Some disability advocates claim that pre-natal screening and testing for foetal abnormalities devalue, oppress and discriminate against people with disabilities. This, they claim, is due to the unreasonably negative view of disability that is supposed by such services, and also to the way in which the existence of the services promotes termination of affected pregnancies as the obvious course of action. In contrast to the views of such disability advocates, those who perform or support pre-natal screening maintain that it makes no value judgements about people with disabilities, and its purpose is simply to give women and couples the opportunity to make informed choices about what is best for them. Whether they choose to terminate a pregnancy when a foetal abnormality is detected, or whether they choose to continue, is entirely up to them. Whatever choice they make will be supported.

In this article, I reflect on these two different views of pre-natal diagnosis and screening for foetal 'abnormality'.<sup>1</sup> Is this really a value-neutral practice? And if it isn't, does this matter? Is there anything wrong with a medical practice being value-laden? I will focus the discussion on responses to a recent Australian government decision to restrict public funding of early ultrasound,<sup>2</sup> as these responses reveal something about the values implicit in pre-natal screening.

#### Views of Disability Advocates on Pre-natal Diagnosis and Screening

Christopher Newell, an Australian disability advocate and lecturer in medical ethics at the University of Tasmania, summarises rather mildly (in comparison to some) the view of some disability advocates about pre-natal diagnosis and screening, when he says that 'the new genetics may actually serve to further the oppression already experienced by those who identify, and are identified, in society as having disability or difference'.<sup>3</sup> This is because screening, and the decisions to terminate pregnancies which often follow it, are premised on the view that disability is so bad that a baby is better off never being born at all, than being born with a disability.<sup>4</sup> To some people with a disability, this is an insupportably negative view of disability, which, in particular, involves a failure to realise that disability is socially constructed. Social construction in this sense means that what makes physical difference of various kinds disabling is the way in which society excludes and ignores the needs of people who differ. On the social construction view, disability in itself is not a bad thing – it is only made bad by a society which fails to cater for difference. As the disability advocate Allison Davis, who describes herself as having severe spina bifida, comments:

If I lived in a society where being in a wheelchair was no more remarkable

than wearing glasses, and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society that handicaps me, far more seriously and completely than the fact that I have spina bifida.<sup>5</sup>

Pre-natal screening, then, is seen by these disability advocates as embodying and endorsing an impoverished, indeed incorrect, view of disability. It is this that makes it discriminatory or oppressive.

I myself have previously argued that the practice of selective abortion (termination of pregnancy because of foetal abnormality) is not discriminatory to people with disabilities, even though it embodies negative value-judgements about life with a disability.<sup>6</sup> This argument was based on an analysis of both the components of the decision to terminate a pregnancy because of apparent foetal abnormality, and the meaning of the concept of discrimination. When a woman or a couple decide to end a pregnancy because the baby, if born, would have a disability of some sort, this decision inevitably involves a value-judgement about life with a disability. The decision only makes sense if life with the disability is felt to be so bad that it would be better for that child if he or she did not exist (or perhaps also it would be better for the whole family that the child not exist, since many couples take into account the effects on existing children). It is not a decision against having a child (pregnancies terminated for foetal reasons