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'.[1] 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,[2] 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'.[3] 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.[4] 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.[5]

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.[6] 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

are usually wanted pregnancies), but rather against having a child with a disability.

It is this sort of value-judgement that many people with disabilities object to. For them, life with a disability is not an unremitting tragedy, nor a life with no quality; and to have others judge that it is, must (it seems to me) be personally offensive and disempowering at a very deep level. However, that does not make such a value-judgement *discriminatory* towards people with disabilities. Discrimination involves denial of equal rights, or equal moral status; or social practices which result in outcomes which unfairly deprive people of benefits which others receive, or place on them burdens which others do not suffer. The value-judgement which is involved in deciding to terminate a pregnancy for foetal reasons does not cause or imply any of this: in fact, it cannot, in principle, do so. This is because selective abortion involves a moral judgment about the permissibility of killing a foetus, not a person with disability. Since there is a morally significant difference between a foetus and a person, moral judgements about foetuses cannot imply any moral judgements about persons. Accepting that it is ethically permissible to end the life of a foetus which has an abnormality does not commit one to accepting that it is ethically permissible to end the life of a *person* with a disability. Indeed, agreeing with selective abortion is totally compatible with believing that people with disability have the same moral value, and all the same moral entitlements, as non-disabled people.

This argument focuses on the individual decision to terminate a pregnancy, and, to that extent, I think it is a sound argument. However, I have never been entirely comfortable that the conclusion is the correct one. There are other relevant issues, other ways of looking at the question. In this article, I want to examine one of these other issues – namely, the way in which pre-natal screening actually operates in society, as a social practice, rather than as an individual decision. I will do this by looking at some responses to a decision in Australia to restrict funding for pre-natal screening.

Pre-natal Screening by Early Ultrasound

In Australia, an increasing number of pregnant women are having an ultrasound at about ten weeks of gestation – a so-called 'early ultrasound'. Whilst early ultrasound may be undertaken to investigate specific symptoms such as bleeding during pregnancy, the great increase has been in the numbers having ultrasound without any specific indication – that is, having an ultrasound as a screening procedure, looking for possible foetal anomalies. Early ultrasound is able to detect a number of conditions by measuring foetal nuchal translucency; that is, by measuring the size of the fluid-filled space between the back of the foetal neck and the overlying skin. An increased thickness of this area is well-established to be associated with chromosomal abnormalities, especially Down's Syndrome,[7] and with structural abnormalities in chromosomally normal foetuses, including cardiac defects, diaphragmatic hernia and various rare genetic syndromes.[8]

There is controversy over how reliable nuchal translucency is as a screening test, especially in terms of a high false positive rate; and clearly the skills and experience of the ultrasonographer are an important variable in this. Its use in pre-natal screening is not generally accepted in some countries (including New Zealand and the US)[9]. However, in combination with maternal serum screening (which involves testing the blood of a pregnant woman for a number of biochemical markers associated with Down's Syndrome in the foetus), use of nuchal translucency appears to be more efficient.[10] In Australia, the Victorian Clinical Genetics Service is about to introduce first trimester combined nuchal translucency and maternal serum screening, with the expectation that it will detect approximately 90 per cent of Down's Syndrome and other chromosomal abnormalities (as compared with 82 per cent for second trimester maternal serum screening alone).[11]

Second trimester screening, as the above figures show, is almost as good as first trimester screening at detecting conditions such as Down's Syndrome. The important difference between them is not so much the detection rate as the stage of pregnancy at which detection is possible. First trimester screening allows for a much earlier decision about pregnancy termination. Early termination of pregnancy is generally regarded as much more acceptable to women than later termination, and is cheaper, safer, less emotionally traumatic, and probably results in fewer adverse psychological consequences.

It is against this background that the Australian government has decided to restrict public funding for early ultrasound in pregnancy. The amount of Medicare rebate for early ultrasound will be reduced by $30 to $40, and, more importantly, the rebate will only be available for a specified list of indications, most of which have to do primarily with the health of the pregnant woman. Ultrasound for risk of foetal abnormality may be funded, but apparently only for special factors which increase risk, and not for background-risk screening.[12] (There will be no restriction on ultrasound within the private system, for those who are willing and able to pay.) The overt motivation of the government is financial: the cost of ultrasound has risen 20 per cent per year in recent years, and, according to Health Insurance Commission figures, more money is spent each year on pre-natal ultrasound than on labour and delivery (including complicated births and all immediate post-natal care).[13] It appears that the government wants to put a stop to the growing social ritual of 'happy snaps': ultrasound undertaken simply to provide a pre-natal photograph of the growing baby.

It is the reaction to this restriction from the medical profession that I am interested in. This has largely been negative. The chairman of the Australian Association of Obstetrical and Gynaecological Ultrasonologists, for example, said that 'women will be missing out on *vital* tests – ultrasound tests detect 80 per cent of foetuses with Down's Syndrome, along with anencephaly and spina bifida'.[14] Another spokesman for that Association, Dr Lachlan de Crespigny, criticised the cut on the grounds that it would 'deprive a lot of our community of access to prenatal diagnostic services'.[15] Lying behind these objections, and many similar ones, is a particular view about pre-natal screening which is not at all value-neutral.

Implicit Value Messages

These objections are premised on the view that pre-natal screening is not simply an optional matter, which people are free to take up if they want to and can afford to (along the lines of music lessons and skiing). Rather, having access to pre-natal screening is a basic good – part of what is required

for a good life – hence, everyone has a moral entitlement to such access, and the government has an obligation to provide it, so that the poor are not discriminated against and the privilege of the wealthy is not entrenched. On this view, the claim to access to pre-natal screening is morally very similar to the claim for access to education: both are something which everyone ought to have the opportunity to take up. And why is pre-natal screening so important? It is presumably because having a child with a disability is so bad that everyone ought to have the opportunity to avoid it.

Note that there is no necessary implication that women *ought* to take up pre-natal screening, or *ought* to terminate their pregnancies if pre-natal diagnosis shows an abnormality – avoiding the birth of a child with a disability is not so important that it is compulsory (here the analogy with education breaks down). However, there is an implication that having a child with a disability is such a significantly bad thing that no one should miss out on the opportunity to avoid it, if that is what they want. I do not wish to argue that this view is incorrect, or morally misguided – that is not the issue in which I am interested here. What I do want to highlight here is the value message inherent in the view that pre-natal screening should be funded by the government. Providing public funding for the opportunity to choose termination of an affected pregnancy, and regarding it as a matter of social justice that everyone has access to the choice, in effect endorses that choice. It endorses it as morally acceptable, as 'for the best', as sensible and reasonable, even as socially responsible. It is not simply a choice that some people may wish to make. The lack of this choice will cause suffering, will diminish the quality of people's lives – that is why it is important that everyone has this choice.

Recognising this value message in the public funding of pre-natal screening adds an important new dimension to the question of whether pre-natal diagnosis discriminates against people with disabilities. We are not just talking about the private decision of a woman or a couple to seek pre-natal diagnosis, and to terminate the pregnancy if an abnormality is found. We are also talking about a social practice funded and hence endorsed by government. Whatever negative or offensive value-judgements about disability are involved in the private decision, are multiplied greatly by the public endorsement of such decisions. The opportunity to make a choice about terminating an affected pregnancy moves from a mere freedom, a negative liberty (on a par with a liberty to choose to smoke cigarettes) to an actual good, a positive entitlement (on a par with a freedom to choose to be educated).

Of course, this is still very far from showing that the practice of pre-natal diagnosis involves an aspect of discrimination against people with disabilities: it may still be that the value-judgement about the quality-of-life effects of disability is a legitimate judgement to make. It is, after all, still clearly distinguishable from a judgement that people with disabilities have a lower moral status, or fewer moral rights, than everyone else. However, recognising the implications of public funding does challenge us to think more carefully about the possibility of systemic discrimination, which may go unnoticed because the system is so familiar to us. It also challenges us to take greater notice of the potential impacts of public policy on pre-natal diagnosis, and to consider how it is possible to make choices available to those who want them, without sending the message to people with disabilities that their existence is an unwanted side-effect of a failure to provide universal access to pre-natal services. I still think that this can be done, but the task is not an easy one.

Notes

1 The term 'abnormality' is in itself a value-laden one, and its use is in some ways problematic, since it has negative implications about disability that some people with disabilities will reject. However, alternative terms that are more acceptable are not easy to find – talking of foetal 'defect' is certainly no better. For the sake of convenience, I will continue to use 'abnormality' or 'anomaly' in this article as a useful catch-all to refer to the various genetic and congenital conditions that are detectable pre-natally, while also remaining conscious of its short-comings.

2 Wendy Busfield, 'Mums cash blow'. *Herald Sun*, Melbourne,10 Jan, 2000, p. 1.

3 Christopher Newell, (1999). 'Critical reflections on disability, difference and the new genetics'. In Gabrielle O'Sullivan, Evelyn Sharman and Stephanie Short (Eds) *Goodbye Normal Gene*. Annandale NSW. Pluto Press, p. 59.

4 Newell, p. 59.

5 Allison Davis, (1989). *From Where I Sit*. London. Triangle, p. 19.

6 Lynn Gillam, (1999). 'Pre-natal diagnosis and discrimination against the disabled'. *Journal of Medical Ethics*, 25(2), pp. 163-71.

7 Therese I. Stewart and Fergal D. Malone, (1999). 'First trimester screening for aneuploidy: nuchal translucency sonography', *Seminars in Perinatology*, 23(5), pp. 369-81.

8 Patricia Devine and Fergal D. Malone, (1999). 'First trimester screening for structural foetal abnormalities: nuchal trans-lucency sonography', *Seminars in Perinatology*, 23(5), pp. 382-92.

9 See Stewart and Malone, p. 379.

10 See Stewart and Malone, p. 369.

11 Julian Savulescu, 'Reduced funding for ultrasound in pregnancy: a better way forward'. Forthcoming in *Australian Medicine*, Feb. 2000.

12 Victoria Button, 'Scan cuts will cost pregnant women', *The Age*, 10 Jan, 2000.

13 Commonwealth of Australia, (1999). *Rocking the Cradle: Senate Inquiry into Childbirth Procedures*, p. 45.

14 See Busfield, *Herald Sun*, 10 Jan, 2000. The emphasis is mine.

15 See Button, *The Age*, 10 Jan, 2000.

Peer-reviewed Section

It is my pleasure to announce that, as from the next issue, there will be a peer-reviewed section within the *Otago Bioethics Report*.

This exciting new development will mean that those writing articles for possible inclusion in subsequent issues can ask to have them assessed by members of the proposed international editorial board. The editorial board is in the process of being formed and will be announced in the next issue of the *Report*.

Those interested in submitting an article for consideration in this new section are asked to contact the Editor:
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