

Issues for the National Ethics Committee on Assisted Human Reproduction in its Review of Medically Assisted Surrogacy, with Wider Implications for Ethical Review

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My purpose in this paper is to identify some of the issues for the National Ethics Committee for Assisted Human Reproduction (NECAHR) in its review of proposed surrogacy arrangements in New Zealand. Following this introduction, I outline progress that has been made in the ethical scrutiny of proposed surrogacy practices since centralised ethical review of surrogacy proposals from fertility clinics was formally established by the Ministry of Health in 1993. I also identify some of the current issues for NECAHR. The last section of the paper asks some questions which have wider implications. I have written this paper as an academic member of staff in a university rather than as chairperson of NECAHR, although, of course, my chairperson's role has informed the content of what follows.

In New Zealand, surrogacy in the context of formal ethical review has, until now, been that which requires intervention by medical specialists. It also involves the gametes of at least one of the couple requesting the surrogacy, and a medically defined condition which precludes the woman who is requesting the surrogacy from a pregnancy. There is no doubt that



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surrogacy involving conception by natural means does occur, and neither communities nor Government have seen any need for ethical review in such circumstances. Arguments for the exclusive focus of ethical review on family formation using reproductive technologies include the possibility of risks to the physical and psychological health and wellbeing of the persons involved and any resulting child, and the possibility of commercialisation and commodification in regard to a human life.

Progress in the Ethical Review of Surrogacy in New Zealand, 1993-99

One interpretation is that ethical review of surrogacy arose partly from the caution of fertility specialists presented with requests for interventions which would involve surrogacy at a time when there was growing debate internationally about its ethical acceptability. There were in place for fertility clinics accreditation requirements for an ethics committee to monitor IVF (in vitro fertilisation) procedures. Also, the Standard for Ethics Committees in New Zealand required ethical review of innovative treatment. Although the necessary medical procedures were little, if at all, different from those already occurring in the well-established practice of IVF, the fertility specialists themselves acknowledged the newness of some aspects of what they were proposing, and sought ethical review. Who should be responsible for those aspects of surrogacy which are not medical is a question which has recently been raised again by some fertility specialists, particularly because of the time involved in adequately informing their clients about non-medical matters.

Perhaps there was some sense, at the time of requests for ethical review, that the potential to alter something so in-

tegral to the fabric of our society as the way a human life begins extended beyond the responsibility fertility specialists were prepared to accept as solely theirs. Regional ethics committees who were approached for ethical review of surrogacy were reluctant to take on the responsibility. They also believed that there should be a consistent approach across the country. Eventually, the Minister of Health established the Interim National Ethics Committee on Assisted Reproductive Technology (INECART, later to become NECAHR) to review 'research and new, untried or unorthodox treatments related to assisted reproductive technology', and advise the Minister about developments in the field of reproductive technologies. The democratic nature of our Government implies that somehow such review could be accorded a basis in the will of the people. And in so far as most of its members were drawn from regional ethics committees, INECART could claim a basis in community.

INECART was established under pressure in May 1993, and at first operated on an interim basis. In 1986 the Government had set up an Interdepartmental Monitoring Committee on Assisted Reproductive Technology (IMCART), which monitored developments but had no brief to propose formal policy. In April 1993, a two person Ministerial Committee on Assisted Reproductive Technologies (MCART) was appointed to study and report on assisted reproductive technologies. It was required to report to the Minister of Justice by 30 April 1994, but the date was later extended to 31 July 1994. While MCART was studying for and preparing its report, INECART was created and placed in the position of reviewing a proposal for surrogacy. Although the committee's terms of reference broadly referred to assisted reproductive technology, review of proposed surrogacy was the catalyst for the committee's

establishment and continues to be the major focus of its successor's work. The committee declined to give ethical approval to surrogacy on two occasions, in 1993 and 1994. At the end of 1997, it gave ethical approval for a specific proposal for non-commercial surrogacy involving IVF as treatment. Since then thirteen applications have been reviewed, and ten have been given full or provisional approval.

As events have developed, review by NECAHR has become the principal mechanism for 'regulating' the application of reproductive technologies. The Assisted Human Reproduction Bill, placed before a Select Committee in the term of the last Government, formalises and clarifies the role of NECAHR, putting it on a statutory basis. Sir Douglas Graham, in his address to the Institute for International Research Medico-Legal Conference in 1999, said the Bill was 'intended to provide a flexible and responsive approach to the constant advances in technology and shifting social attitudes that may be expected'. Elsewhere in his address he said:

There are numerous difficulties in trying to produce an exhaustive list of prohibited activities. For instance, shifting social attitudes may result in some activities which are currently unacceptable gaining acceptance over time. Furthermore, there are difficulties in attempting to define for all time an exhaustive list of unethical activities in an area of rapid technological advances. Accordingly, the Government has taken the view that other activities will be dealt with through the ethical decision making structures that the Bill puts in place. (p. 7)

The Bill removes some of the responsibility of decision making from NECAHR or any single Minister by imposing a procedural loop which involves the Minister of Health, the Government and NECAHR with regard to proposals that are 'new to New Zealand'.

It is interesting that both MCART and a Private Member's Bill from a Labour List Member of Parliament, the Human Assisted Reproductive Technology Bill, which was considered by the same Select Committee, proposed a regulatory body with a wider brief than that of an ethics committee. Also, Coney and Else, in their 1999 discussion document *Protecting Our Future: The Case for Greater Regulation of Assisted Reproductive Technology*, point to problems in NECAHR's role.

No ethics committee can be expected to deal with the issues involved in surrogacy in the confused, piecemeal legislative and regulatory context in which ART is currently proceeding. (p. 56)

There is an enduring awareness among committee members, seemingly although somewhat insubstantially mandated by the events leading to the formalisation of ethical review, that NECAHR makes two categories of decisions. There are those which are important for the impact they have on the kind of society ours is and will be. As well, there are those which are about process and have an impact on the way services are provided.

NECAHR's decisions may restrict individuals' private choices. Some may argue that these individuals, who, through no fault of their own, have been picked out to have their most personal and intimate wishes, intentions, and requests subjected to ethical review by government-appointed committee members, unjustly provide a yardstick for measuring both New Zealand society's level of tolerance for a particular range of rapidly developing technologies and the moral fibre of that society.

There have been contradictory perceptions of INECART/NECAHR's role in the review of surrogacy proposals and its modus operandi. One view publicly expressed early in the life of the committee was that it existed to see that clinical interventions were conducted in an ethical manner. Surrogacy per se was in this view an acceptable undertaking. INECART, however, recognised an ethical obligation to question surrogacy. And in 1993 its decision, based on committee consensus, was that ethical approval for surrogacy in principle should be declined. It was interesting at that time to note the language used by some who held a different view. INECART was accused on more than one occasion of failure to make a decision. In other words, because its decision was not what some people wanted to hear, INECART had supposedly made no decision at all. INECART was asked to reconsider. In 1994 ethical approval was again declined. This time the committee was criticised for its consistency when, as chairperson, I was privately told of disbelief that INECART could make the same decision second time around.

An outside opinion on the surrogacy proposal rejected by NECAHR was

eventually sought, and in the meantime the report, *Assisted Human Reproduction: Navigating Our Future*, was produced by IMCART. Both supported the kind of surrogacy which had been proposed. INECART itself had left the way open to review its decision at a later time by relating to a specific proposal its decision not to approve, and recommending that 'informed debate on IVF surrogacy and related issues should continue throughout New Zealand'. Three years after its 1994 decision, the committee (by this time NECAHR) accepted surrogacy as a possibility in certain circumstances, and has proceeded to delineate those circumstances and give ethical approval to proposals which fall within the parameters set. Once again, the committee was severely criticised for its decision, this time by the then Minister of Health, who, whilst acknowledging that NECAHR was operating within its terms of reference, indicated that he did not agree with the approval of surrogacy per se.

So far, I have outlined mainly events. On what did INECART/NECAHR base its decisions? How does it interpret its role? What was lacking in 1993 was any formal policy, sustained debate, widespread community consultation or purpose-designed legislation to provide a New Zealand context for ethical review. The consultation by the Canadian Royal Commission and its report, *Proceed With Care*, had they been replicated in New Zealand, could have provided a useful guide to committee members and others about ART matters. INECART members read widely across international academic literature and the popular media. Their interpretations were, of course, influenced by their personal frames of reference. The same kind of diversity evident across jurisdictions in Australia and Europe was present in individual views articulated by committee members: for example, 'surrogacy is immoral', 'New Zealand society is not ready for surrogacy', and 'in our culture surrogacy is not a problem'. What has emerged over six years of working together and several changes in membership is a modus operandi which acknowledges the positive potential of technology and change, respect for the wishes and autonomy of individuals, and caution. Informed consent is a key principle.

Currently, NECAHR's major focus is

process. Debate about whether it should be expected to carry the burden of decision making about matters as momentous as surrogacy in principle continues, as does discussion in communities and at government level about the impact of reproductive technologies on our society. Unfortunately for them, the minority of people who need to use technology to form their families do not have the time to wait for community consultation and political measures. And NECAHR is at the frontline of decision making.

Some Current Issues in Ethical Review

An adequate legal framework

Safeguarding the rights and interests of a child who may result from surrogacy arrangements is of primary ethical concern. Sometimes the best safeguard lies in appropriate legislation. In its report accounting for its 1994 decision to decline ethical approval for surrogacy, INECART pointed to a legal vacuum in the area of surrogacy and the need for a clearly defined pathway through existing legislation which had some bearing on surrogacy arrangements although not written specifically to meet their needs. Atkin and Reid in their report, *Assisted Human Reproduction: Navigating Our Future*, wrote that some review of the law in relation to adoption procedures might be necessary 'if surrogacy became a commonly accepted practice', although they claimed that 'under current circumstances ... the present law functions satisfactorily for the few cases which arise' (p. 117).

The 1999 Law Commission *Preliminary Paper 38 Adoption Options for Reform* asks 'whether adoption is the appropriate forum in which to regularise the outcome of a surrogacy arrangement' (p.92). The Commission's tentative view is that:

The current adoption legislation is a clumsy means of regularising the status of a child who is born pursuant to a successful surrogacy arrangement. It would appear that the current requirements may discourage commissioning parents from applying to adopt the child, for fear that the statutory criteria might be applied stringently or the courts will reverse their previous position. If status is not determined, the legal position of the child within its 'social' family is not secure. This is an untenable situation. (p.96)

The report also confirms that:

Surrogacy arrangements exist in a legal vacuum in New Zealand. When such arrangements do occur, the legal status and obligations of each participant and any resulting child must be determined in accordance with a range of family legislation that was not drafted with surrogacy in mind. (p.93)

In the meantime, NECAHR faces problems arising from interpretations and practices which relate to adoption legislation, specifically over the need for police checks on adoptive parents – these are currently carried out by the Adoption Service of the Child, Youth and Family Service in the Ministry of Social Services; the contact adoptive parents have with the child immediately after birth; and payments made to the birth mother for costs incurred during the pregnancy.

Informed consent

Medically assisted surrogacy in New Zealand's society in 2000 is a complex undertaking. There are sophisticated and rapidly developing medical technologies, substantial commercial interests, a legal maze, and psychosocial uncertainties about identities, roles and relationships. It is of ethical concern to NECAHR that parties proposing to involve themselves in surrogacy arrangements have the knowledge, understanding and freedom to make informed choices and decisions.

In seeking to assure itself that parties are able to proceed in this manner, NECAHR requires reports from professionals – clinicians, lawyers and counsellors – who have the knowledge and expertise to inform, advise and counsel their clients. These reports should indicate an adequate level of understanding for informed decision making. In some of these areas, NECAHR continues to find inadequacies. It is for this reason that the committee still regards surrogacy as 'innovative' and therefore continuing to need ethical review on a case-by-case basis. Once the knowledge and expertise are in place to allow informed choice and decision making, case-by-case review of surrogacy proposals which meet NECAHR's criteria should not be necessary. NECAHR will shortly release guidelines for non-commercial surrogacy using IVF as treatment. It does not see a role for itself in educating professionals, but rather in pointing out the gaps.

Cultural diversity

In its ethical reviews NECAHR is acutely aware of diversity, and the tension between this and concepts of community and society. It is aware of the multi-faceted racial and cultural components of New Zealand's society.

For some time New Zealand stood out as one of the few countries which insisted on information about biological origins being recorded and made accessible to children resulting from the application of reproductive technologies. This practice is possibly attributable to the influence of whakapapa in Maori culture. Certainly, for some members of NECAHR, concepts of family were challenged and expanded by Maori members' explanations of whangai.

In particular, NECAHR has an ethical concern about how to safeguard choice through knowledge about and access to identity and cultural heritage for children who may be born as the result of surrogacy arrangements which involve men and women of Maori origin who have chosen to distance themselves from traditional Maori values and practices. This concern is relevant specifically in the case of gamete donation in surrogacy.

The Future of Ethical Review of Surrogacy and Ethical Review More Generally

This paper has identified three areas where decisions may be made about the use and implications of assisted reproductive technologies. These are politics, the law, and ethics. Many of the problems encountered by INECART and now NECAHR derive from confusion about the interfaces between these areas and where responsibility should lie.

In regard to politics, the prevalent view suggested minimum intervention and maximum exercise of autonomy. At the same time, individual ministers and the Government claimed a role for themselves to a greater or lesser extent. In regard to the law, two Bills were eventually drafted and have been to a Select Committee but nothing has come before the House. A crucial difference in approach between the two is the role of an ethics committee. There is a raft of relevant but non-specific legislation already in place which has some bearing on the rights of individuals

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Similar thinking has informed some countries' decisions to outlaw surrogacy, especially commercial surrogacy, on the grounds that it involves the commodification of children, and that this is not in their best interests.

Other forms of ART that could be banned as not in the best interests of the child include:

- births to postmenopausal women using donated ova;
- large, multiple pregnancies;
- multiple use of gametes from one donor;
- using donated embryos from one couple for a number of recipients;
- inter-racial gametes donation;
- inter-generational gametes donation;
- births to parents with severe disabilities.

The proposed Assisted Human Reproduction Bill outlaws cloning and animal/human hybrids, but other practices, such as the use of eggs from dead women or fetuses and those listed above are not included as prohibited practices.

A case can be made for prohibiting some forms of ART on the grounds that it is not in the child's interests to exist. If there is a strong likelihood that the child's welfare will be seriously jeop-

ardised because an adequate upbringing cannot be provided, or if the manner of the child's conception deviates extremely from the norm, these could be grounds for prohibiting such conceptions. Alternatively, a legal process might be required to ensure that the potential child's interests are represented and adequately considered.

At the very least there should be some criteria and/or processes which override the strict application of the Human Rights Act.

The Assisted Human Reproduction Bill fails to grapple with this issue. Instead it reinforces adults' rights but is silent on the matter of the interests of the child. The drafting of more comprehensive legislation would provide a process of debate about what procedures should or should not be allowed and who can have access to them. This would provide the opportunity for the rights of the child and the interests of the child to be defined and receive statutory protection.

An extended version of this paper is contained in the publication *Protecting Our Future: The case for greater regulation of assisted reproductive technology*, edited by Sandra Coney and Anne Else, and available from Women's Health Action, PO Box 9947, Newmarket, Auckland at a cost of \$20. Email mckayl@womens-health.org.nz

References

- Human Fertilisation and Embryology Authority (HFEA) (1995). *Code of Practice* [UK].
- Marcus S.F., Marcus N.K., Brinsden P.R. (1996). 'Astonishing fertility from a single oocyte recovery'. *Human Reproduction*, 11(10): pp. 2136-37
- Ministerial Committee on Assisted Reproductive Technologies (MCART) (1994). *Assisted Human Reproduction: Navigating Our Future*. Tribunals Division, Department of Justice.
- Officials Committee (1995). *Assisted Human Reproduction: A commentary on the report of the Ministerial Committee on Assisted Reproductive Technologies*. Department of Justice.
- Shanner, L. (1995). 'The right to procreate: Where rights claims have gone wrong.' *McGill Law Journal*, 40: pp. 823-74

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involved in surrogacy arrangements and any child. The Law Commission's discussion paper asks important questions about ensuring the legal status of children born of a surrogacy arrangement.

However, there are bigger questions. Who is responsible for making decisions about matters as momentous as surrogacy? Is what is involved really any more than ensuring the safe and agreed-to applications of technology which compensate for inadequacies in the functioning of a human body, comparable, for example, to kidney dialysis or organ transplant or the dispensing of a new drug? Should we dismiss the present mix of political monitoring and intervention, non-specific legislation, professional self-regulation, ethical review, and law making because it is 'confused', 'piecemeal', and often demand-driven and reactive? Should we view the current approach as enlightened, flexible and enabling,

and justly advancing the wishes of individuals in a diverse and dynamic society? And what can we learn from these experiences of the last six years to apply to other situations where technological developments are outstripping foresight and the traditional means of ensuring scrutiny and, where appropriate, regulation and control?

References

- Assisted Human Reproduction: Navigating Our Future Report of the Ministerial Committee on Assisted Reproductive Technologies*. Wellington. Tribunals Division, 1994.
- Code of Practice for Units Using In Vitro Fertilisation and Related Reproductive Technologies*. Australia. The Fertility Society of Australia Reproductive Technology Accreditation Committee, 1992.
- Coney, Sandra & Else, Anne, (Eds), (1999). *Protecting Our Future: The case for greater regulation of assisted reproductive technology*. Auckland. Women's Health Action Trust.

- Department of Health (1992). *Draft National Standard for Ethics Committees*. Wellington. Department of Health.
- Graham, Rt Hon Sir Douglas. *Current Medico-Legal Issues Speech Notes*. Auckland. Institute for International Research 7th Annual New Zealand Medico-Legal Conference, February 1999.
- Law Commission (1999). *Preliminary Paper 38. Adoption Options for Reform: A discussion paper*. Wellington.
- Ministry of Health. *Minutes of 10th Meeting of NECAHR 30 July 1997*. Wellington. Ministry of Health.
- Ministry of Health (1995). *Non-Commercial Surrogacy by Means of In Vitro Fertilisation Report of the Interim National Ethics Committee on Assisted Reproductive Technology*. Wellington. Ministry of Health.
- Royal Commission on New Reproductive Technologies, *Proceed with Care: Final report of the Royal Commission*. Canada. 1993.
- Ministry of Health (1993). *Terms of Reference for the Interim National Ethics Committee on Assisted Reproductive Technology*. Wellington: Ministry of Health.