

17 August 2007

Advisory Committee on Assisted Reproductive Technology  
PO Box 5013  
Wellington

**Advice on Aspects of Assisted Reproductive Technology: A Consultation Paper on Policy Issues**

Please find attached to this letter a submission from the Families Commission in response to the consultation paper 'Advice on Aspects of Assisted Reproductive Technology'.

If you have any queries regarding our submission please contact Janine Moss, Principal Policy and Research Analyst, phone 917-7074.

Yours sincerely

Paul J Curry  
**Chief Executive**

## **FAMILIES COMMISSION SUBMISSION**

### **ADVICE ON ASPECTS OF ASSISTED REPRODUCTIVE TECHNOLOGY: A CONSULTATION PAPER ON POLICY ISSUES**

The Families Commission has limited expertise in the field of assisted reproductive technologies (ART). What the Families Commission does have is a clear understanding of the critical role families play in New Zealand society. It is this knowledge and perspective that underpins our submission on ART.

As stated in the Families Commission Act 2003 the main function of the Families Commission is to act as an advocate for the interests of families generally (section 7). In order to perform this main function, the Commission has the following additional functions (section 8), to:

- encourage and facilitate informed debate about families
- increase public awareness and promote better understanding of matters relating to the interests of families
- encourage and facilitate the development and provision of government policies designed to promote or serve the interests of families
- consider any matter relating to the interests of families referred to us by any Minister of the Crown
- stimulate and promote research into families, for example by funding and undertaking research
- consult with, or refer matters to, other official bodies or statutory agencies.

Our vision is that “Families are the best that they can be”. One of the key outcomes contributing to this vision is focused on positive family functioning:

Families and whanau are able to carry out the functions of a strong resilient family and those with children have the capacity and resources to support their parenting role.

The family plays an important role for its members as a source of mutual support and identity and prepares them for their place in society. Families pass on knowledge, culture and values from one generation to the next and directly impact on the health, wellbeing and development of individuals. Families today experience a world which is changing on many levels. The make-up of families themselves is also changing.

The family is a powerful institution. Creating a new family and expanding an existing family is a fundamental human instinct and a strong calling for many people. Consequently, difficulties in achieving this can lead to anguish and sadness. The Families Commission understands the importance of ‘family’ and, therefore, supports the ethical use of ART and ethical research which may lead to the further development of reproductive technologies.

In performing our functions, the Families Commission needs to identify and have regard to factors that help to maintain or enhance families’ resilience and families’ strengths (section 7(3), Families Commission Act 2003). Our interest in ART is that the policies, legislation, guidelines and procedures that are developed are in the best interests of the potential families, parents and children involved. Emphasising what

is in the best interests of the family may lead to different conclusions to the application of a rights-based approach.

In responding to the questions raised in the consultation paper we are attempting to predict and forestall potential issues that may compromise positive family functioning. Of particular interest to the Families Commission are the relationships that develop between the child and their parents, their wider family and community.

As noted in our submission to ACART in March 2007, the Families Commission is of the view that the existing legal framework governing ART and the arrangements for the oversight of research is appropriate. The use of guidelines, standards and ethical review is vital, and it is important they are kept up-to-date. Given that New Zealand tends to be a rights-based society, our observation is that unless the regulations prohibit a particular activity, then almost certainly it will be allowed.

The Families Commission is of the view that, amongst other ethical considerations, the following factors should guide developments in ART:

- prohibition of commercialisation of all dimensions of human reproduction
- free and informed consent as a foundational condition
- protection of the integrity and diversity of the human genome
- recognition that human reproduction is culturally bound
- valuing and protecting cultural diversity
- recognition that the development of personal identity and a sense of belonging to parents and a family are fundamental human needs
- every person has the right to access information about their genetic identity
- recognition that there are potential implications for rights to both cultural and material assets emanating from the whanau of donors.

The legacy of the policy of closed adoption highlights the importance of actively protecting the interests of every person who is involved in ART procedures, but especially the children who are born as a result of these procedures. The demand for and availability of ART services and the rapidly developing technological nature of this field (including the potential for controversial procedures such as genetic and sex selection), heightens the importance of having a robust regulatory framework, which guides practitioners and demands ethical practice.

### **Response to the Consultation Paper Questions**

The consultation paper asks 18 questions. The Families Commission has responded to those questions that are of immediate relevance to the Commission's work: questions 1 to 7 and 9 to 14.

#### *Question 1:*

*Do you agree that the following procedures should remain subject to guidelines developed by ACART, and review by the Ethics Committee on Assisted Reproductive Technology (ECART):*

- *clinic-assisted surrogacy*
- *embryo donation for reproductive purposes*
- *donation of gametes between certain family members*

- *certain uses of preimplantation genetic diagnosis?*

The Families Commission agrees with ACART that these procedures are still relatively new in New Zealand and involve significant psycho-social issues. The ramifications for families are unknown and are potentially significant. The Families Commission supports the view that these procedures should remain subject to guidelines developed by ACART, and review by ECART. We further recommend that in developing guidelines, ACART include a “family lens” that takes account of the collective interests of families and wider implications for whanau.

*Questions 2, 3, 4, 5 and 6*

All these questions relate to the guidelines that ECART must follow when considering a range of ART applications.

The Families Commission appreciates the broad view ACART has taken in considering these guidelines, including the importance of psycho-social factors.

With regard to surrogacy (question 2), the Families Commission notes that ACART is not proposing to change the prohibition on commercial surrogacy or any of the provisions in the Human Assisted Reproduction Act 2004 relating to surrogacy. The Families Commission agrees that, with the exception of parenthood laws, these provisions are adequate. The Families Commission supports the recommendation made by the Law Commission<sup>1</sup> that specific mechanisms be enacted for transferring legal parenthood to implement surrogacy arrangements. We also note that the Government agreed with the Law Commission’s recommendation.

*Question 7:*

*What are your views on whether the use of preimplantation genetic diagnosis (PGD) should be extended to allow the testing of embryos solely for tissue typing for an existing child with a disease?*

The Families Commission does not have a specific view on whether testing embryos solely for tissue typing for the benefit of an existing sick child should be allowed in New Zealand. Obviously this is a complex and value laden decision where there are many competing interests, rights and responsibilities.

The Families Commission suggests that when considering this issue, amongst other ethical considerations, ACART and the Minister take into account the following points:

- Allowing this procedure will inevitably have further future ramifications. As much as possible, these need to be identified and the implications worked through. For example, what about the case of an IVF child with leukaemia?
- Consider the principle of ‘first do no harm’.
- Informed consent cannot be gained from the second child. Their parents are consenting on their behalf, first that they are born with this purpose in mind, and subsequently to medical procedures. As these parents are in a situation where their objectivity is compromised, the best interests of the second child need to be carefully considered and protected.
- Timeliness of the various interventions, including taking into account a child’s sense of time. For example, how old will the second child need to be before

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<sup>1</sup> Law Commission. (2005) *New Issues in Legal Parenthood*, Report 88, recommendation R15, p95.

undertaking a bone marrow transplant operation and what is the optimal timing for the child with leukaemia?

- Is this procedure contrary to the principle of protecting the integrity and diversity of the human genome?

*Question 9:*

*What are your views on whether an embryo for reproductive purposes should be allowed to be created using a donated egg and donated sperm?*

The concerns and issues raised by ACART with respect to this question are valid and potentially significant. In particular, the psychological impact and long term effects on a person of gaining information about two donor parents could be considerable. If this change were allowed, the legal implications would need to be considered.

We wonder whether a distinction should be made between donations by strangers and donations by people with a genetic link to the person or partners wanting a child. The impact of this distinction could be significant. The potential psycho-social issues could be less where the donors have a genetic link with the person or partners wanting a child.

*Question 10:*

*Do you agree that embryo splitting requires no specific recommendation to the Minister of Health (which will mean that it is unable to proceed, although it will not be prohibited)?*

The Families Commission supports ACART's suggestion that it will only provide advice to the Minister of Health when embryo splitting becomes a procedure fertility clinics are interested in using.

*Question 11:*

*Do you agree that the import and export of donated in vitro embryos and gametes should be allowed, provided that the prohibitions and principles of the HART Act are met?*

This question does not accurately reflect the discussion on page 16 which specifically refers to the import or export of donated gametes and embryos where they have been donated in order that subsequent IVF children can be genetically related.

The Families Commission agrees that if the import and export of donated in vitro embryos and gametes were allowed, the prohibitions and principles of the HART Act should be met, and that this should be restricted to situations where people want to have another child and complete their family and their donated gametes and embryos may be in another country.

The Families Commission suggests that this allowance could also potentially be extended to include the import and export of donated in vitro gametes and embryos where they are donated by family members living overseas, in order that their children can be genetically related to their parent(s).

Allowing exceptions to a blanket prohibition on the import and export of donated in vitro embryos and gametes risks opening up the possibility of other exceptions. As a general principle, it is not desirable to encourage the trading of genetic material. It would be difficult to be assured that the methods of collection and the use of embryos and gametes complied with New Zealand standards. It could be difficult to establish

whether informed consent had been gained. There are also risks associated with demand being driven by wealthier countries, leading to the exploitation of people in poorer countries.

If this exception were allowed, protocols for the exchange of in vitro embryos and gametes between countries would need to be developed, managed and monitored.

The Families Commission can, however, see benefits in allowing families to expand and be genetically related.

*Question 12:*

*Do you agree that requirements for the import and export of donated in vitro embryos or gametes should be set out in guidelines developed by ACART, rather than regulations?*

The Families Commission notes that guidelines do not have the benefit of the parliamentary process that is required for the development of regulations. Guidelines are, therefore, arguably less rigorous. The requirement for a parliamentary process signals the significance of these issues.

*Question 13:*

*Do you agree that it is necessary to prescribe requirements for informed consent in regulations?*

Given the potential risks and psycho-social impacts associated with ART procedures, the Families Commission considers that free and informed consent is a foundational condition. We also note that there is potential for a wide and varied interpretation of informed consent.

In our last submission to ACART, the Families Commission noted with interest the requirements the UK Human Fertilisation and Embryology Authority (HFEA) has relating to the consent that must be obtained from those who donate embryos for research. We wondered whether these could be usefully adapted for use in New Zealand.

*Question 14:*

*What specific requirements for informed consent would you like to see?*

The Families Commission notes that ART procedures typically involve a number of individuals all of whom would need to give informed consent at a variety of stages. We also are aware that different cultures have different concepts of whom and how informed consent should be gained and given. For example, for Maori the concept of whanaungatanga is important in relation to gaining informed consent.

In the Commission's opinion, consent has a family dimension which is not entirely met by simply obtaining consent from individuals. Again, our view is that the application of a family/whanau lens to all ART procedures is consistent with the notion of families as foundational units within society.