



**National Council of  
Women of New Zealand**

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Wahine O Aotearoa

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S17.15

## **Submission to the Ministry of Health on the Review of the Fertility Services Standard**

### **1. Introduction**

- 1.1. The National Council of Women of New Zealand, Te Kaunihera Wahine o Aotearoa (NCWNZ) is an umbrella group representing 258 organisations affiliated at either national level or to one of our 19 branches. In addition, about 380 people are individual members.
- 1.2. Collectively our reach is over 290,000 with many of our membership organisations representing all genders. NCWNZ's vision is a gender equal New Zealand and research shows we'll be better off socially and economically if we're gender equal. Through research, discussion and action, NCWNZ in partnership with others, seeks to realise its vision of gender equality because it is a basic human right.
- 1.3. This submission has been prepared by the NCWNZ Health and Consumer Affairs/Economics Standing Committees after consultation with the membership of NCWNZ. A significant number of individuals and members fed into this submission, indicating the high level of interest in the matter.
- 1.4. NCWNZ has previously made submissions in relation to the Fertility Services Standard and Audit Workbook, Draft guidelines for non-commercial altruistic surrogacy using IVF as treatment, Human Assisted Reproductive Technology Bill, Assisted Human Reproduction: Guidelines for Practice of Embryo Donation for Reproductive purposes, Terms of Reference for Ministerial Committee and National Ethics Committee on Assisted Reproductive Technologies and Informed Consent and Assisted Reproductive Technology.
- 1.5. There are also a number of relevant NCWNZ Resolutions relating to "Biotechnology and Assisted Human Reproduction"<sup>1</sup>

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<sup>1</sup> 9.2.1 That NCW adopt as interim policy the recommendations:

- 1) that a broad multi-disciplinary commission of enquiry be set up to look into all matters relating to artificial human reproduction, such a commission to include lay people and in particular lay women, and its terms of reference to include determining the areas of technology which should be monitored and the composition of the monitoring committee;
- 2) that a committee be set up to monitor the development and use of artificial human reproduction technology, such a committee to be multi-disciplinary and to include women, and its functions to include making recommendations about:
  - a) appropriate legislation;
  - b) the permissible scope and acceptable limits of experimentation;
  - c) the allocation of resources to these areas. 1984.

(footnote continued next page)

## 2. Executive Summary

- 2.1. NCWNZ supports this timely review of Fertility Service Standard and appreciates the opportunity to provide feedback.
- 2.2. NCWNZ however notes that amendments to the Standards should be made to reflect greater awareness of consumer rights, the changing dynamics of family structures and changing community contexts.

## 3. The Standard

- 3.1. NCWNZ believes the Services Standard seems to provide a careful framework but should be amended to account for any variations and/or loopholes which this review might expose. There is concern that there is insufficient information on male fertility to ensure the document has a gender balance. We consider the views of bioethicists should be sought and that the revised Standard documentation should then go to the Ethics Committee for their consideration.
- 3.2. It is noted that there is reference to the 'uses of gametes' and NCWNZ is concerned that this may be moving into the areas of research. There is considerable discussion required on issues such as the use of embryonic cells, stem cell research and gene manipulation. People donating for the purposes of fertility or storing embryos need to be clear on their reasons for donating and storing.
- 3.3. NCWNZ also notes that the most recent reference in the Standards appears to be 2006, even though the document was reviewed last in 2014. Hence NCWNZ would suggest that the following amendments be made:
  - Pages 8 and 82 to be updated to reflect the revised Acts of New Zealand legislation, publications and related documents.
  - Page 87 reference to the Ministry of Health guidelines be updated
  - Pages 88 and 89 website references be amended and added to as appropriate

### Part One: Consumer Rights

#### Section 1.9 Right to know one's genetic origins

- 3.5. NCWNZ believes donor offspring should have access to information and disclosure regarding their genetic origins and to have the ability to access information about their origins. This is consistent with previous NCWNZ submissions<sup>2</sup>.

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9.2.4 That NCWNZ ask the Ministers of Social Welfare, Justice and Health to expedite the establishment of national guidelines for assisted reproductive technology. 1992. Supersedes 9.2.3

9.2.5 That NCWNZ urge the Minister of Justice to refer the Report "Assisted Human Reproduction: Navigating Our Future" (Report of the Ministerial Committee on Assisted Reproductive Technology) to the Select Committee on Justice and Law Reform for public submissions in order to facilitate and expedite legislation on the vital issues involved. 1994.

9.2.6 That NCWNZ lobby Government to backdate to January 2000 funding for a second cycle of in vitro fertilisation (IVF) treatment. 2005.

<sup>2</sup> <https://www.ncwnz.org.nz/wp-content/uploads/2013/06/S15.22-Informed-Consent-and-Assisted-Reproductive-Technology.pdf>

- 3.6. This was also referred to by the Law Society when considering Parenthood Legal issues<sup>3</sup> where they stated “Clearly, donor gamete conception practices require society to find legal mechanisms to transfer legal parental responsibilities and rights from genetic parents to social parents (caregiving parents). It is evident from the hypothetical case studies that the current legal situation has the potential to leave many families and children within them, without the support of clear legal structures. This lack of clarity poses risks to donor-conceived children and their families. Besides the need to determine legal parental relationships, there is also a need for the law to take cognizance of the needs of children to know their genetic identity. Children conceived via donor sperm and eggs within heterosexual relationships, are left, under the current proposed laws, entirely dependent upon their parents to tell them their true genetic lineage. The Human Assisted Reproductive Technology Bill will require clinics to maintain a register of information for done-conceived children but will not alter this”.
- 3.7. The New Zealand Nurses Organization [NZNO] has also consistently supported transparency in all forms of assisted reproduction<sup>4</sup> which NCWNZ also supports.
- 3.8. NCWNZ notes some donors may not want to disclose such information but that it should be available if requested and disclosed in a manner that takes into account donor rights. This is especially important when considering health history and in small communities the need to mitigate against inappropriate inter family relationships.
- 3.9. This information disclosure is similar to situations involving adopted children and the importance of them being able to access birth parent information. A medical genetic and DNA history map could be supplied to the donor offspring as part of this process.

#### **What protective measures might be needed around allowing this to happen?**

- 3.11. NCWNZ believes that whatever protective measures are recognised, they need to be made known to all parties at the very outset and that guidance and counselling support should be readily available, in a manner that is culturally and age appropriate to the individual and their family.
- 3.12. NCWNZ recognises that the Privacy Act would need to be applied and the rights of the child and donor adhered to.
- 3.13. NCWNZ notes that donor consent conditions need to be taken into account when disclosing genetic origin history to donor offspring.
- 3.14. The donor may specifically request anonymity which should be upheld within the conditions of their consent giving.
- 3.15. The age of offspring and their maturity should be carefully considered along with offspring parents right to intervene when minor’s health concerns are at stake. At all times, the emotional and physical health of the off spring must be of prime concern.

<sup>3</sup> 2004: *NEW ISSUES IN LEGAL PARENTHOOD a discussion paper The Law Commission (Preliminary Paper 54) p32 3.41*

<sup>4</sup> 2016-07 ACART Ovarian tissue, 2015-09 ACART Informed consent, 2014-03 ACART import export gametes embryos, 2012-09 Amendments to Guidelines on Surrogacy Arrangements, Providers of Fertility Services and Guidelines on Donation of Eggs or Sperm between Certain Family Members. All available from our website <http://www.nzno.org.nz/resources/submissions>

### Section 1.3 Recognition of Individual Values and Beliefs

- 3.17. NCWNZ supports the current five considerations: belief and value systems, provision for interpreter or translation services, cultural or spiritual beliefs regarding the disposal of gametes and embryos are respected, culturally safe services, waste disposal processes.
- 3.18. NCWNZ believes that the Nursing Council of New Zealand's view of culture is relevant in this situation<sup>5</sup> "Culture includes, but is not restricted to age or generation, gender, sexual orientation, occupation and socioeconomic status, ethnic origin or migrant experience, religious or spiritual belief and disability".
- 3.19. An important additional consideration is the age of donors, family mental and physical health and racial and ethnic background as all these potentially impact on the overall wellbeing of the resulting child.
- 3.20. NCWNZ notes that standard 1.11.1 states it is the donor's responsibility if a child is disabled as a result of failure to disclose defects. This factor requires implicit and clear emphasis well in advance of granting consent, along with some clarity on how that liability is addressed.
- 3.21. NCWNZ believes that clarity on the timeframes for storage of embryos would need to be conveyed to all parties. And in line with the view NZNO has advocated previously NCWNZ believes that in the event of opposing views with regard to disposal /retention of embryos, the wishes of the mother must take precedence since women are most affected by reproductive choices.

## 4. Conclusion

- 4.1. NCWNZ supports this timely review of Fertility Services Standards by the Ministry of Health, but wishes to see amendments as outlined above, to reflect ethics, consumer rights and awareness and cultural respect.

Vanisa Dhiru,  
National President

Rae Duff  
Immediate Past  
National President

Pip Jamieson, Convener,  
Economics and Consumer Affairs  
Standing Committee

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<sup>5</sup> *Guidelines for Cultural Safety, the Treaty of Waitangi and Maori Health in Nursing Education and Practice / Nursing Council of New Zealand*