#### Submission to

## REVIEW OF THE WESTERN AUSTRALIAN HUMAN REPRODUCTIVE TECHNOLOGY ACT 1991 AND THE SURROGACY ACT 2008

Submitted by Felicity Roux

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Submitted on behalf of the L J Goody Bioethics Centre

In this Submission I outline some premises underpinning our position on human reproductive technology and surrogacy; comment on the National Health and Medical Research Council's *Ethical Guidelines* (2017); and address other issues raised in the Review Terms of Reference.

#### Who we are

The LJ Goody Bioethics Centre was founded in 1985 as an agency of the Roman Catholic Archdiocese of Perth to provide public and private consultation, education and research in ethical aspects of contemporary health care practice and public health policy for the people of Western Australia. Our services include

- a confidential ethics advisory service for members of the public, as well as for the medical and nursing professions, and members of health ethics committees;
- on-call clinical ethics consultancy to hospitals and healthcare systems in WA;
- education in general ethics, bioethics, clinical and research ethics.

Centre staff are also members of a number of clinical and research ethics committees in the public and private healthcare sectors including the Health Department of WA (HDWA) and the new Perth Children's Hospital (formerly Princess Margaret Hospital). All private and clinical consultations are offered free of charge.

#### **Premises**

- The interests of human individuals and communities are best served when our constructed physical, legal and ethical processes most closely imitate natural paradigms.
- 2 'Natural paradigms' are the structures and processes inherent in natural systems, as these have evolved biologically and socially to successfully sustain human life in all of its dimensions.
- In the natural paradigm, human life begins at the completion of fertilisation, when a single-cell zygote formed by the fusion of male and female gametes becomes a discrete organism characterised by the human genome (23 pairs of chromosomes).
- 4 Even at this very early stage a human embryo possesses a special status distinct from its composite gametes, and from an egg undergoing fertilisation. It is a discrete human being.
- Because of this special status, human embryos deserve to be protected from harm in their origin, and at every stage of their development. This includes protection from non-therapeutic research or experimentation, from damage arising from pre-implantation screening or diagnostic techniques, and from other destructive processes.
- 6 Human embryos are always subjects, never objects. Unlike gametes, they can never be reduced to commodities or treated as mere property.
- All children, however conceived, have a natural right to knowledge of and, as far as possible, contact with their genetic parents. Our laws should not facilitate the creation of children who will never have an opportunity to know their own parents.
- Parenthood, like the legal, social and moral duties inherent in it, arises from genetic, gestational and social connections with the child conceived. As far as possible our laws in the field of reproductive technology should preserve the natural paradigm and not artificially separate these aspects of parenthood.
- **Summary 1** The special status of the human embryo should be given statutory recognition in the revised HRT Act.

# NHMRC Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research (2017) (EG)

- 9 We broadly support the direction of the 2017 NHMRC *Ethical Guidelines* document, subject to the variations noted below, and propose that the HRT Act Review should seek to embed these guidelines in the revised HRT Act.
- "The interests and wellbeing of the person who may be born as a result of ART activity" (Guiding Principle 2, p20) should be held paramount in all decisions regarding the activity, because the child is the only participant in the activity who lacks a voice.
- The HRT Act should be amended to prioritise the interests and wellbeing of persons who may be born as a result of ART activity, and the Reproductive Technology Council (RTC) should be required to demonstrate how its various decisions honour that priority.

#### Clinical Practice and Reporting

The RTC should formalise the nature and extent of information that clinics are required to report to HDWA, so that clinics can better fulfil their statutory requirements.

#### **Donated Gametes**

All children born of donated gametes should have a right not only to information about their donor, but also (where possible) to have personal contact with their donor. (EG 5.6; Premise 7)

#### Sex Selection

ART procedures should never permit sex selection for non-medical purposes, since this would always represent some form of 'commodification' of the human embryo. (EG 8.14.1; Premise 6)

### Posthumous collection and use of gametes

- 14 In keeping with the natural paradigm, the death of an individual should always represent the end of their reproductive life. Regardless of personal preferences to the contrary, death means death.
- To permit the posthumous collection and use of gametes for reproductive purposes would be to separate entirely genetic parenthood from gestational and social parenthood. This would amount to an activity endorsed by the State that deprives a child of his or her rights *ab initio*. (Premise 7)

- 16 Current reliance on the *Human Tissue and Transplant Act* in WA to allow the posthumous collection and storage of gametes creates anomalies which the HRT Act could not foresee. The revised HRT Act should remove these anomalies once and for all.
- **Summary 3** The revised HRT Act should specifically forbid the posthumous collection and use of gametes for reproductive purposes.

#### Record Keeping and Date Reporting

Data sets held at HDWA should be returned to Reproductive Technology Unit control for ongoing maintenance and data linkage purposes. Current arrangements are preventing effective collection and recording of data from clinics, and consequently preventing effective use of data linkage for epidemiological research, quality control and governance purposes.

#### **Review Terms of Reference**

## Research involving human embryos

- Given the unique status of every human embryo, we submit that no excess ART embryos should be given over to research, even under NHMRC conditions. To do so would be to treat a human being as an object, not a subject with inherent rights. (Premise 4 & 5)
- For the same reason there should be no provision for the creation of human embryos specifically for research purposes. In themselves these embryos do not differ from embryos created for reproductive purposes. (Premise 4 & 5)

#### Saviour Siblings / Stem Cell Therapy

Following NHMRC *Ethical Guidelines* 8.17 the revised HRT Act should restrict 'saviour sibling' practices to the collection and use of stem cells derived from umbilical cord blood, and only when these practices protect the 'donor' child from physical harm. (Premise 5)

## Rights to Storage and Use of Gametes upon Death or Divorce

Assuming the stored gametes were originally intended for use by the couple as a couple, and that death or divorce has ended that relationship, these gametes should not be stored or used for reproductive purposes by either surviving party or by other parties.

## Rights to Storage and Use of Embryos upon Death or Divorce

Given the special status of human embryos (as distinct from gametes), every effort should be made to donate or otherwise gift these embryos to other couples for their reproductive purposes.

## **Surrogacy**

- Pursuant to Premise 6, surrogacy in WA should never be permitted for profit or otherwise than on an altruistic basis (subject to reimbursement of reasonable costs).
- In order to protect the rights of children born of surrogacy arrangements, and to maintain alignment between the *Surrogacy Act* and WA adoption practices, the extent of implications counselling as described in Regulation 4 should be maintained.

Submission tendered on 16 March 2018

Signed by Felicity Roux