

## **Notes of ACART Hui**

**22 August 2012**

**Wellington Airport Conference Centre**

### **Present**

Dr John Angus, Chair, ACART

Associate Professor Andrew Shelling, Deputy Chair, ACART

Cilla Henry, ACART

Professor Khyla Russell

Dr Kuni Jenkins

Tu Williams

### **In attendance**

Betty-Ann Kelly, ACART Secretariat

Chris Wilson, ACART Secretariat

Stella Li, ACART Secretariat

### **Apologies**

Moe Milne

The points below reflect comments by one or more attendees, and do not reflect formal agreement by the hui as a whole.

### **Introduction and background**

The Chair opened the hui by welcoming those attending. He acknowledged the work of the late Hone Kaa as the Chair of Te Mana Ririki Trust. He briefly explained the role of ACART, and noted the hui would assist ACART to understand Māori perspectives on ACART's work.

Cilla Henry reported that she had attended the recent Koroneihana at Turangawaewae marae, and the Rangitahi Forum presented Te Tupuranga 2050 and what the future would look like for Māori. Attendees at that Forum included several young women without children who were not aware of the possibilities of storing their eggs at the life stage of optimum fertility. She said that there was a great deal of interest in the possibilities made available through assisted reproduction.

The Deputy Chair noted:

- the main causes of infertility are obesity, smoking, age and sexually transmitted diseases
- currently, Māori women are protected from the impacts of age because they are having children earlier on average than women in the whole New Zealand population

- however, there is an increasing trend for younger Māori women to focus on their education and career pathways, and to delay child rearing. This means assisted reproductive technology and fertility issues are likely to become increasingly relevant for Māori in the future

He also noted recent New Zealand research that investigated university students' knowledge of fertility issues. The research found that students generally overestimated the timespan for which women are fertile, and overestimated the capacity of assisted reproduction technologies to assist where people experience difficulties in creating a family.

Attendees commented on other aspects of the broader environment with implications for Māori now and potentially in the future.

- Many Māori cannot afford the cost of assisted reproductive treatment. A number of arrangements are "under the radar". Whāngai is another option chosen by whānau where people are unable to have a child themselves.
- The rollout of much faster broadband would contribute to changes in how education and information were delivered, and how learning would happen.
- Māori who are gay or lesbian have greater confidence now in talking about their sexuality.

Attendees noted the importance of whakapapa.

- Establishing and preserving whakapapa will always be a primary interest for a Māori person, regardless of assisted reproductive technology. Whakapapa is inherited only through genetic links.
- Whakapapa is extremely important and valuable for an individual, their whānau and their future whānau. Whakapapa is extensive and expansive.
- To be Māori, it is fundamental to hold the knowledge of who you are and where you come from. Knowledge of whakapapa is empowering because it gives a person security and confidence about where they belong.
- It is desirable to be able to trace one's whakapapa as far back as possible to the original ancestor. Whakapapa determines a person's inheritance and right of access to resources (e.g. mutton birding in the Titi Islands, treaty settlement resources), including whether access rights can pass to subsequent generations. Such rights can be very geographically specific.
- There is a large Māori population in Australia. Attendees discussed what was being done to ensure Australian Māori children remain linked to their whakapapa.

Many tribal groups have official registers, which depend on parents or grandparents registering a child born in another country. Many young Māori do return to be registered, because they want to maintain those links. Online electronic registration helps to preserve the younger generation's whakapapa.

- The customary practice of whāngai usually occurs between relatives. In most cases this means whakapapa is maintained and known.
- Reasons for whāngai arrangements can include giving a child from a large family to someone who could not have their own children. Whāngai may also involve grandparents raising grandchildren.
- Most whāngai arrangements are open, and are discussed with the child from an early age. However, secrecy may be part of some arrangements.

***Proposed amendments to *Guidelines on Surrogacy Arrangements Involving Providers of Fertility Services* and *Guidelines on Donation of Eggs or Sperm between Certain Family Members****

- The attendees appeared to agree with all proposed amendments to the surrogacy guidelines and family eggs or sperm donation guidelines.
- They agreed with ACART's conclusion that the current surrogacy guidelines discriminated on the basis of sex and sexual orientation, because the language of the eligibility criteria "intended mother" and "medical condition" inherently excluded men from entering surrogacy arrangements.
- However, it was noted that while the HART Act enables children born from donations to access identifying information about a donor from the age of 18 years (assuming they know that a donor played a role in their creation), this was too late for children to know about their origins.
- Given that whakapapa can determine one's rights to inherit and access resources, it is important children are not disadvantaged because they cannot establish their whakapapa connections.
- In gestational surrogacy arrangements, there is no direct genetic link between a surrogate and the child (though there may be whakapapa links where the surrogate is from the same whānau as an intending parent).
- Attendees endorsed ACART's view that surrogacy should not be used for reasons of convenience.

- Surrogacy is the only available option for male couples to have a child who is genetically related to one of the couple. Many enter into “under the radar” arrangements. The security of the child and the parties involved are safeguarded by including whānau in discussion about the arrangement. Gay men are likely to look to whānau for assistance where they wish to enter a surrogacy arrangement in order to become parents.
- Sperm donation may also take place outside a clinic setting.
- The attendees agreed with ACART’s proposal that single men and male couples applying to ECART to enter a surrogacy arrangement should also be able to apply to use eggs donated by a family member.
- The attendees agreed with ACART’s proposal that single women and lesbian couples should be able to apply to ECART to use sperm donated by a family member without needing medical justification.

#### **Import and export of sperm, eggs and embryos**

- The Chair explained that a common scenario reported to ACART is for couples to go overseas, have treatment using donated eggs, have a child, and then be unable to use surplus *in vitro* embryos in New Zealand because the embryos were created using commercially sourced eggs. Women therefore sometimes return from overseas with multiple embryos replaced in order to save the cost of subsequent trips, thereby increasing the probability of a multiple birth. Multiple pregnancies and births risk the health and wellbeing of women and children, and have resourcing impacts on New Zealand’s health system.
- For attendees, the key concern is that a child’s whakapapa and other family links may be lost where a child is born overseas or is born in New Zealand from unknown overseas donors.

#### **Principle (f) of the Human Assisted Reproductive Technology Act 2004 and its articulation in ACART’s ethical framework.**

- The ethical framework is not about moral judgement. The attendees considered it as a guiding mechanism to facilitate the articulation of Māori views.

#### **Other comments by attendees**

- Younger Māori are well-educated, better informed, and have greater openness when engaging with whānau and iwi about issues involving parenting arrangements or assisted reproductive technology. This means the cultural consequences can be considered. If discussion of infertility becomes more normalised and open, there is potential for a positive ripple effect in understanding about what is possible and the implications.

- Given the reality of a multicultural society (in New Zealand, and globally), there will be increasing cultural diversity in Māori heritage. This may challenge the preservation of whakapapa.
- The participants were satisfied with the level of Māori input into ACART.
- A Māori perspective is not narrowly or individually based: the individual is always considered in a wider context. Māori live in diverse realities. For example, a sperm donor is not just an individual donor. Where a donor is Māori, to pass on genetic material is to pass on whakapapa. Therefore, the decision to donate sperm or eggs has impacts that go beyond the particular donor.
- Looking to the past helps to face the challenges of the future.
- Assisted reproductive technology is about forming a family. One attendee noted the link to the story of Tane and the creation of his children with different female elements. In today's world, the Tane story is a useful analogy to understand assisted reproduction and the implications for children.
- The cost of assisted reproductive treatments is a barrier to equity of access.

