

# Children's Commissioner's submission to ACART on proposed Donation Guidelines

14 November 2017

Children are taonga and assisted reproductive technologies (ART) play an important role in helping people in their family formation.

The regulation of ART is important to uphold rights of children, to ensure child-centred decisions are made when treating adults, to ensure the health and wellbeing of children, and to uphold the dignity of current and future generations.

I note there is little research available on the impacts on donor-conceived children's outcomes into adulthood. This research is needed and I recommend ACART push for longitudinal research to commence as soon as possible. There is similarly little about the views and voices of children in relation to ART.

## Question 1: Rescinding the biological link policy

a) I have some real reservations about the proposal that children will intentionally be born using fertility treatment with no possibility of a genetic or gestational link with a parent. b) I note the following cultural implications of this policy change.

All children need *a sense of identity and belonging*. In New Zealand, whakapapa and inherited genetic relatedness is relevant and valued.

Genetic relatedness is important to offspring and society. This view is supported by research on donor-conceived people, research on attitudes of those who use donated gametes, or surrogates, by the interest in TV shows that report the angst individuals go through to find those genetically related to them, and the fact that some jurisdictions (e.g. Victoria Australia) invest significant public funds to help people identify their previously anonymous donor so they can make contact.

In New Zealand the whakapapa of people is central to their identity. Even in whangai arrangements, there is usually a wider genetic link between the child and their carers. Having strong connections to, and understanding of, one's whakapapa is a resilience factor for childhood wellbeing. I agree with the policy that children should be able to find out about their genetic parents, for the above cultural and psychological reasons, as well as potential health reasons.

## Question 2: Access to information held on birth certificates

I support the ability of children, at an appropriate age, to access information about their genetic parents through birth certificates, the HART register or other means.

One way this could be supported is through clinics obtaining consent for future contact with those families who express an intention to tell their children of their donor conception status. Then clinics could follow-up at 3 years and 10 years of child's age, to support families to explain to their children their birth stories in age-appropriate ways.

## Question 4: Justification to use a procedure

I agree that that ECART should be satisfied i) a donation procedure is the best or only opportunity for intending parents to have a child and ii) the intending parents are not using the procedures for social or financial convenience or gain. Considering the cultural implications of the biological link policy, children should be related to their parents if possible. Donations should only be used as a last resort.

Principles of the HART Act (section 4) that are particularly concerned with children:

(a) the health and well-being of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure:

(b) the human health, safety, and dignity of present and future generations should be preserved and promoted:

(e) donor offspring should be made aware of their genetic origins and be able to access information about those origins:

### Question 7: Limit to number of families with full genetic siblings

It is reasonable to continue the status quo and limit the number of families with full genetic siblings to **two**<sup>1</sup>, given the complexities of navigating multiple relationships among families, relatives and donor-relatives.

It is fair that children should be able to get to know their full genetic siblings in other families, e.g. in the case of embryo donation. Children have a strong sense of kinship to their siblings. This is demonstrated through the voices of siblings taken into care in different families, who desire most to see their brothers and sisters. Stories of children parted at birth who are reunited demonstrate their strong kinship feeling towards siblings.

### Question 9: Regulation of all family gamete donations *and*

### Question 13: Regulation of all clinic-assisted surrogacies by guidelines

I agree that all family gamete donations and all surrogacies should receive the same treatment<sup>2</sup> and undergo ethical review on a case-by-case basis. The process of surrogates, donors and recipients going through joint counselling provides important safeguards for subsequent children because it creates incentives to discuss future relationships. Such counselling could also reveal coercion or unhealthy relationships. Therefore, I support regulation of all these situations.

I appreciate that some family gamete donations are currently excluded from ethical review, and to include them would add costs to patients in the sector. Similarly, traditional surrogacies are currently exempted from ethical review, but are not ethically less complex than surrogacies that currently require ethical review.

The added costs of counselling (and ethics approval) are but a small portion of the costs of undergoing assisted reproductive technology, and then raising a child. The potential child and their relationships with parents and donors/surrogates should be seen as a privilege for those who would otherwise not be able to have a child. The additional cost should not be a barrier to good processes that protect future children.

### Question 14: Any other comments

#### **Embryos must not become commodities**

The loss of the biological link requirement should not be made lightly. I understand this decision stems from potential discrimination. Most people currently don't choose embryo-donation over being genetically related to their offspring where possible, yet the shift in the policy could morph into a situation in which embryos become commodities, and the rights of offspring are not central to decisions.

- I am concerned about recent ethics applications where people chose embryo donation instead of using their own gametes where they could. I think the reason 'because they *preferred* equal-non-genetic relatedness between two parents' is inadequate, and demonstrates they are not thinking from a child's point of view.
- I am concerned there is a risk that embryo donations could be used for convenience, because it is cheaper than undergoing egg stimulation and extraction, followed by IVF.
- Considering the importance placed on genetic relatedness by children and society, I encourage the wording of the guidelines to state clearly the threshold that ECART should uphold even when the biological link requirements are relinquished.

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<sup>1</sup> A family should be counted as one, however, if the children are spending time at separated parents' homes. (After all, from a child's perspective, they were one family at a point in time before the adults fell out.)

<sup>2</sup> In my view, sisters, brothers and cousins can have the same ethical challenges in donating as do donors from other 'generations'. It is currently an arbitrary distinction, e.g. the age gap between donors and recipients across different generations is not always or necessarily greater than the gap between siblings or first cousins. Surrogates who use their own eggs (traditional surrogacy) have more at stake in gestating a child to give to another family to raise. The potential child would benefit from her having gone through counselling and ethical review and discussing how the child may know his or her genetic and birth mother.