



Office of the Information Commissioner
Queensland

**Submission to the Legal and Constitutional
Affairs Reference Committee's inquiry into
the past and present practices of donor
conception in Australia**
(July 2010)

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Overview

Thank you for the opportunity to make a submission to the Legal and Constitutional Affairs Reference Committee's inquiry into the past and present practices of donor conception in Australia (**the inquiry**).

The Office of the Information Commissioner Queensland (**OIC**) has, under the *Information Privacy Act 2009* (Qld) (**IP Act**), a role in providing public comment on any matter which relates to public sector privacy. As part of that role, the OIC has identified a number of issues which involve the privacy of those involved in the donor conception process which, the OIC believes, should be considered as part of the inquiry.

The OIC would be pleased to offer further assistance or expand on any of the points raised in this submission should the inquiry request it.

1. Privacy interests

The privacy interests involved in any consideration of donor conception go beyond those of the social parents or the child. The OIC has identified the following privacy interests which should be examined as part of the inquiry:

- The donors, whether of egg or sperm
- The surrogate, where the embryo is carried to term by someone other than the social parent or the donor(s)
- The child
- The social parents
- Donor-related siblings of the child: other children conceived from the same donor but raised by different social parents

2. Competing rights, competing interests

There are a number of different privacy interests at play in any discussion of donor conceived offspring and their right to know information about their genetic history. It is important that those competing privacy interests be considered fairly and balanced appropriately. The OIC believes the inquiry should identify each privacy interest and engage in a balancing exercise between them, including identifying the positives and negatives in overriding any given privacy interest and the risks involved, taking into account public interest factors.

3. Retrospectivity

The OIC does not support any attempt to apply new rules about the provision of information to those involved in the donor conception process retrospectively. For example, if donors provided sperm or eggs on the understanding that their identities would remain confidential, that should not be overridden by new laws without evidence that the presumptions of benefit are shown to be erroneous or that any detriment that is shown to arise overrides the benefits of the policy to an extent where it becomes desirable to change the rules.

The OIC supports a campaign of education and encouragement to encourage such donors to come forward and consent to the provision of information about them to children conceived from their donations.

4. Obligations on donors

The OIC recognises the strong interest donor conceived children have in knowing their genetic history. To that end, the OIC would recommend that, as part of the inquiry, the feasibility of requiring donors to provide a social and medical history to form a dossier which can be provided to the donor conceived child upon request. While requiring donors to consent to having information about them provided to the child, or to allow the child to contact them, will provide a mechanism to allow the child to learn his or her genetic history, it will not be successful where the donor has become unlocatable or uncontactable, or has died. A dossier of this kind will allow the donor conceived child to know their genetic history regardless of intervening action which would prevent them from learning this information from the donor.

The OIC raises no objection to making consent to be contacted or to have identifying information provided to the donor conceived offspring a pre-requisite to donation, so long as the obligations are clearly explained to the donor and they are provided with an opportunity to receive appropriate advice, whether legal or from a counsellor.

5. Obligations on social parents

As noted above, the OIC acknowledges that the donor conceived child has a strong interest in knowing his or her genetic history. However, exercising this interest is dependant solely on the social parents informing the child of the circumstances surrounding his or her conception.

The OIC would support a legislative requirement for a social parent to inform a donor conceived child that he or she is donor conceived, only if there is evidence to support that this practice would be in the best interests of the child. Irrespective of the approach taken, the OIC support, however, intervention at an early stage to educate and inform social parents of the benefits of informing their children, and ensuring that social parents are provided with education and support around this issue, including the opportunity to discuss the issue with other social parents.

6. Information management: collection, retention, responsibility, register, access management

As it currently stands, there is no central register in Australia of donors and no central authority responsible for maintaining and managing records related to donor conception. This means that when, for example, a fertility clinic closes down, unless those records are passed to another responsible body, that information may be lost, destroyed or difficult to locate. Donors might be quite willing to have their details provided to their donor conceived children, but if the repository of that information is gone, the donor conceived child may never be able to find them.

The OIC recommends that the inquiry consider the specific record keeping requirements on entities supplying this service that recognise possible future needs to access such information and the appropriateness of creating a central authority with responsibility for retaining records relating to donor conceptions, and managing access to those records by donor conceived children. If the right of the donor conceived child to know their genetic history is viewed as of paramount importance, then it will be necessary to ensure that the records of that information are stored securely, managed appropriately and able to be accessed as and when required.

The OIC would also recommend the inquiry consider the feasibility of developing a list of required information that must be provided by potential donors, so that each clinic or doctor knows what they are required to collect about each donor and donors know what information they will be required to provide, wherever they are in Australia. This will ensure that donor process has transparency, and the decision as to what is 'necessary information' is not left to each clinic or Doctor to make.

7. Information: access rights and limitations

The OIC recommends the inquiry consider who is to have as of right access to information about donors and donor conceived children. It is clear that there is a strong interest in donor conceived children having access to their genetic history, and so to information about their donors. However there are other access issues that may arise, for example:

- Access by donors to information about their donor conceived offspring, and whether such information would include indentifying information.
- Access by donor conceived children to information about their siblings: other children conceived from the same donor.
- Access by guardians or other persons legally responsible for a donor conceived child in the event that one or both social parents has died.

The OIC recommends that the inquiry consider who, beyond the donor conceived child, should have access to information and in what circumstances.

8. Birth certificates

As it currently stands, birth certificates of donor conceived children in Australia list the social parents as mother and father. The OIC notes that there is concern in the literature regarding how such a practice interferes with a donor conceived child's interest in knowing their genetic history. A number of approaches to resolving this issue have been suggested, including the use of special notations on birth certificates, which indicate that the person was conceived by donor, and that the social parents listed are not the genetic parents, or the production of a second birth certificate, available only to the donor conceived child, which lists the genetic parents and the social parents.

The OIC recognises that, given that the OIC does not support placing a legal obligation on social parents to inform children that they are conceived by donor, a birth certificate which sets out that the child is donor conceived may be the only opportunity a child has to discover this fact.

However, the OIC does not believe that it is appropriate to notate the standard birth certificate in a way that indicates the person is donor conceived. There are many situations in which a child's birth certificate has to be or is likely to be produced which have nothing to do with the child's conception and to so notate the birth certificate would be to reveal the fact that the child was donor conceived to anyone to whom the birth certificate is provided. If the inquiry is to consider birth certificates, the OIC would urge the inquiry to strongly consider an approach which will not mark the child as donor conceived upon presentation of the standard birth certificate.

9. Informal donation: obligations on maternal parent

It will not always be the case that a woman who conceives a child using donor sperm will do so through a formal process involving a clinic. Arrangements may be made informally with a friend or a privately sourced donor. The OIC believes the inquiry should address this issue, and examine how it relates to the interest of the donor conceived child discovering his or her genetic history. It should be noted that the OIC does not support any penalties or sanctions being applied to a woman who elects not to name a child's father.

10. The Convention on the Rights of the Child

Article 8 of the Convention on the Rights of the Child states:

1. *States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.*
2. *Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.*

As the identity of the biological parent and the fact of donor conception have been recognised as a fundamental building block of the identity of a child, the OIC recommends that the inquiry consider the extent to which the rights set out in Article 8 apply to:

- a donor conceived child's right to know their genetic and biological heritage
- the identity of the donor being provided to the donor-conceived child
- the right of the donor conceived child to know information about the extended family of the donor
- the right of donor conceived children to know of the existence and the identities of donor-siblings, that is children conceived from the same donor with different social parents.

The OIC also recommends that the inquiry consider how, and to what extent, these rights should be given effect in Australia, and whether they should be implemented by way of Australian legislation.

References

- *Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes* Gottlieb, Claes et al Human Reproduction Vol.15, No.9, pp.20552-2056, 2000
- *Embryo donation families: mothers' decisions regarding disclosure of donor conception* MacCallum, Fiona and Golombok, Susan Human Reproduction Vol.22, No.11, pp 2888-2895, 2007
- *Telling the story: parents' scripts for donor offspring* Rumball, Anna and Adair, Vivienne Human reproduction Vol.14, No.5, pp1392-1399, 1999
- *Sharing information with donor insemination offspring: A child-conception versus a family-building approach* Daniels, KR and Thorn, P Human Reproduction Vol.16, No.9, pp 1792-1796, 2001
- *The controversy surrounding privacy or disclosure among donor gamete recipients* Golombok, Susan Journal of Assisted Reproduction and Genetics, Vol.14, No.7, 1997
- *Knowing where you come from: the rights of donor-conceived individuals and the meaning of genetic relatedness* Minnesota Journal of Law Science and Technology, 2010, 11(2), pp 655-684
- Victorian Law Reform Commission, Assisted Reproductive Technology & Adoption: Final report June 2007
- New South Wales Law Reform Commission, Discussion paper 11 (1984): Human Artificial Insemination, Chapter 12 – Record Keeping in AID
- Four Corners, Australian Broadcast Corporation, Transcript of Janine Cohen's report *Secrets of the Fathers* broadcast date 24 October 2005
- New Zealand Law Commission, Preliminary Paper 54 New Legal Issues in Parenthood March 2004