



25 October 2011

Dr Vaughn Koops
Executive Officer
Law Reform Committee
Parliament House
Spring Street
East Melbourne VIC 3002

Dear Dr Koops

Donor-Conceived Inquiry: Supplementary evidence

Thank you for providing the Victorian Equal Opportunity and Human Rights Commission (Commission) with the opportunity to address the Law Reform Committee (Committee) on 10 October 2011 in relation to its inquiry into access by donor-conceived people to information about their donors (Inquiry).

I understand that our opportunity to provide supplementary evidence at this time is limited. Therefore, in the material below, therefore, I only seek to clarify and elaborate upon the Commission's submission and appearance before the Committee, and address some of the questions posed by members of the Committee.

Options for reform

Whilst the Commission's submission identified two options for reform, we consider that there are a range of alternatives to the existing regime which would better recognise and protect the rights of donor-conceived people.

My oral submissions to the Committee aimed to synthesise these two options into a single preferred model and elaborate upon some of the safeguards that would help to ensure information is collected and disclosed in a way that has the minimum possible impairment on the rights of donors, donor-conceived people and their families.

For clarity, I have briefly summarised the Commission's **preferred model** below as it differ slightly from the options identified in our written submission. This model recognises that the Charter provides a useful framework to ensure that rights are not unreasonably limited in the development of a new legal framework, rather than provide a formula to solve this complex issue:

- Subject to safeguards, all those born through donor-conception should be able to obtain some information about their donors, irrespective of when donation occurred and whether consent was obtained.
- A responsible body (authority) should be empowered to manage requests for the disclosure of information about donors and donor-conceived people.

- Upon receiving a request for information, that authority should be required to make all reasonable efforts to contact the donor and seek their consent to the release of information held (i.e. information collected at the time that the donation was made).
- If consent cannot be obtained, that authority should:
 - Release non-identifying information held (e.g. background and relevant medical information); or
 - Release identifying information that is reasonably likely to be true subject to a Contact Veto where:
 - disclosure would be in the best-interests of the donor-conceived person, and
 - counselling has been provided (similar to adoption law in NSW).
- If consent is not provided by the donor, release only non-identifying information held.
- If consent is obtained, release that information.
- That authority should have the power to seek an individual's consent to the release of existing information, and seek additional information (where adequate information was not collected).
- The collection, storage and disclosure of information would need to be subject to significant safeguards, to ensure that information is collected, stored and disclosed appropriately.
- Safeguards should include:
 - the provision of counselling prior to the collection and disclosure of information;
 - strict processes to verify an individual's identity; and
 - a limitation on the release of information to that which is reasonably likely to be true and not unreasonably disclose information relating to the personal affairs of a natural parent, relative or any other person.
- Where a donor or donor-sibling requests information about a donor-offspring or sibling respectively, identifying information about that person should only be released where the authority has been notified that the individual is aware that they are donor-conceived.
- Children should be able to apply for access to information at an age of sufficient maturity.
- Where the authority declines to disclose available information or provides only limited information, allow an individual to apply to a court or tribunal to review that decision and make orders in relation to the collection and disclosure of information.

This model provides for the release of information about donors, donor-siblings and donor-conceived people in a manner that recognises the challenges associated with disclosing information which cannot be obtained or is not reasonably likely to be true, whilst recognising the importance of disclosing information in certain circumstances.

It also recognises that section 13 of the Charter does not confer a right to privacy in absolute terms, but rather a right to be free from “unlawful or arbitrary” interference with privacy. Even if interference with privacy is legal in the sense that it is authorised by law, it may be “arbitrary” if the interference is not reasonable in the circumstances. I note that General Comment 16 of the United Nations Human Rights Committee states that the requirement of reasonableness implies that any interference with privacy must be proportional to the end sought and be necessary in the circumstances of any given case. In the Commission’s view, the model identified above provides for disclosure of information subject to safeguards and would be reasonable, proportionate, and less restrictive on the rights of donor-conceived people than the existing legal framework.

Case studies

To assist the Committee with its deliberations, the following case studies illustrate how this model might work in practice.

Case study 1

Charlie, who was conceived with gametes donated in 1986, has been on the voluntary register for six years. Charlie’s donor-parent lives with his family overseas, and is unaware of the donor register. Charlie contacts the authority and requests that they make reasonable efforts to contact his donor-parent and encourage him to consent to the release of that information. The authority obtains and reviews the donor records, and makes several unsuccessful attempts to contact the donor by phone and mail. After several months, the authority advises Charlie that it was unable to make contact with the donor but could disclose de-identified information about the donor’s background and medical history. Charlie agrees to this process and to counselling and is provided with non-identifying information.

Case study 2

Sarah, who was conceived using gametes donated in 1985, was diagnosed with cancer in 2010 and passed away in 2011. In the absence of a known family history of cancer, Sarah’s donor-sibling, Angie, contacts the authority and seeks the release of information about her donor. The authority makes contact with the donor, Jeff, and after verifying his identity, seeks his consent to the release of information held as well as additional information about his medical history. Jeff agrees to the release of the information and provides additional information so that Angie (and any other donor-siblings) have a more comprehensive family medical history. Jeff also agrees to the authority releasing his name and other identifying information subject to a contact veto, so that Angie can amend her birth certificate.

Case study 3

Peter, who was conceived with gametes donated in 1982, contacts the authority and seeks the release of information about his donor-parent. The authority retrieves the records held, some of which have faded significantly and do not verify the donor’s name or contact information. The authority advises Peter that it will not disclose any of the information held. Peter applies to a court/tribunal to review the authority’s decision to withhold the information. The court/tribunal reviews the information held and makes orders for the disclosure of non-identifying information which can be ascertained from the records and is reasonably likely to be true.

Case study 4

Laura contacts the authority at age 17 and seeks the release of information about her donor-parent and donor-siblings, due to concerns about consanguinity and a desire to amend her birth certificate. The authority meets with Laura and finds that she has sufficient maturity and autonomy to appreciate earlier disclosure without parental consent.

The authority retrieves the records held and contacts the donor to obtain consent to the release of information so that Laura's birth certificate can be amended to accurately identify her biological and custodial parents. The donor is provided with counselling but does not consent to release of information or further contact. The authority assesses whether disclosure of the identifying information held would be in Laura's best interests, and finds that whilst disclosure would prevent further emotional and psychological harm, identifying information should not be released until Laura is 18 when she can be held accountable for signing a statutory declaration agreeing not to make contact with the donor-parent. In the interim, the authority provides Laura with non-identifying information about her donor-parent.

The authority reviews the register and identifies that two of Laura's five donor-siblings have consented to the release of identifying information and for contact to be made. In the absence of being able to verify that the remaining three siblings are aware that they are donor-conceived, the authority provides Laura with identifying information about the two donor-siblings noted on the register and agrees to contact her if the remaining siblings register interest with the authority.

Case study 5

Tom, a donor, contacts the authority to seek information about his donor-offspring conceived around 1984. The authority reviews reasonably available data as well as the register and finds that only three of Tom's eight donor offspring have contacted the authority and consented to the release of information. In the absence of direct knowledge that the remaining offspring are aware that they are donor-conceived, the authority provides counselling to the donor and three donor-offspring and releases information about the three donor offspring and donor respectively.

Release of information to donors and donor-siblings

During the hearing, the Committee asked questions about the rights of donors and donor-siblings to access information about donor-offspring and donor-siblings. For clarity, the right to privacy under the *Charter of Rights and Responsibilities Act 2006* (Charter) provides protection from arbitrary or unjustified interference with person, and social individuality and identity. In the context of donor-conception, the right to privacy applies to donors, donor-offspring and donor-siblings equally and provides a right to information about one's donor-offspring and donor-siblings as information directly relevant to one's individuality and identity. The words "arbitrary" and "unjustified" indicate that the right to privacy is not absolute, and is subject to internal limitations. In addition, these rights may be subject to reasonable limitations in accordance with section 7(2) of the Charter.

The fact that a donor-conceived person may not know that they are donor-conceived would be an important factor in considering whether limitations on the right to

privacy would be reasonable, and should be given significant weight by the authority when deciding whether to release identifying information about a donor-offspring or donor-sibling.

Right to an accurate birth certificate

On balance, international law supports the presumption in favour of the right to have an accurate birth certificate. General Comment 16 on the right to privacy under the *International Covenant on Civil and Political Rights* provides that in order to have effective protection of one's private life, all individuals have the right to ascertain in an intelligible form whether personal data is stored. If files are incorrect, as is the case with many birth certificates of donor-conceived people, the individual should have the right to request rectification. As an important record of personal information, birth certificates should be able to be corrected where they do not accurately reflect an individual's biological or birth parents.

Status of the Authority under the Charter

As I indicated in oral submissions, whilst I do not have a firm view on what organisation might be appropriate to act as the authority, it will be important for the relevant authority to be a public authority with obligations under section 38 of the Charter. Section 38(1) provides that:

...it is unlawful for a public authority to act in a way that is incompatible with a human right or, in making a decision, to fail to give proper consideration to a relevant human right.

The Supreme Court of Victoria has provided some useful guidance about the scope and character of the obligation placed on public authorities under the Charter in *Sabet v Medical Practitioners Board of Victoria* [2008] VSC 346. The Court identified three distinct concepts of relevance:

1. *Engagement*: whether or not a particular decision or course of conduct actually or potentially impacts upon one of the rights protected under the Charter
2. *Limitation*: whether that impact is such as to restrict full realisation of the relevant rights, and
3. *Justification*: an analysis of whether an identified limitation is reasonable and therefore permissible in accordance with the framework specified in section 7 of the Charter.

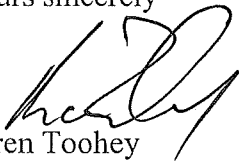
Accordingly, the Authority will have to:

- conduct itself in accordance with the Charter in a procedural sense.
- consider relevant human rights in the Charter in the course of engaging with donors and donor-conceived people, and collecting and disclosing information.
- consider relevant human rights in a substantive sense in the context of making decisions.

It will be important that the relevant authority is appraised of the types of human rights issues that can arise in the context of regulating donor-conception, and the collection and disclosure of information.

The Commission would be happy to provide any further assistance the Committee considers appropriate. I can be contacted on 9032 3470 or Karen.Toohey@veohrc.vic.gov.au.

Yours sincerely



Karen Toohey
Acting Commissioner