

**Submission  
No 15**

## **MANAGING INFORMATION RELATED TO DONOR CONCEPTION**

**Organisation:** Commission for Children and Young People  
**Name:** Ms Megan Mitchell  
**Position:** Commissioner  
**Date Received:** 14/02/2013

The submission supports making donor information arising from assisted reproductive technology (ART) under the NSW Assisted Reproductive Technology Act 2007 retrospective, if sufficient safeguards can be put in place to protect the rights of donors. Having access to information about biological parentage is generally in the best interests of a donor-conceived child: it can be important for the development of identity and psychological well-being and may be critical for health reasons. Currently donor information is not available prior to 2010, when the ART legislation came into effect.

The submission also supports the provision of voluntary counselling for donor-conceived people and their parents in a range of circumstances, including when requesting information and contact details for the donor.

In addition the submission argues for the provision of information to donor conceived people, their parents and the donor about the information that is held on the ART register and voluntary register, and how to obtain it. It is also argued that information should be provided about counselling and support services should these be made available for donor-conceived people and their families



Mr John Barilaro MP  
Chair  
Committee on Law and Safety  
Parliament of New South Wales  
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Dear Mr Barilaro

I write in response to your correspondence inviting the Commission for Children and Young People, (the Commission), to make a submission to the Inquiry into managing information related to donor conception in NSW. I note that the Commission made a submission to the Committee's related 2011 Inquiry into the inclusion of donor details on the register of births.

The terms of reference of the current Inquiry are to consider whether arrangements for access to donor conception information should be retrospective, that is whether people conceived by donor conception prior to January 2010 should have access to this information. In addition, the Inquiry will again consider which agency should manage donor conception information and what counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.

Donor details are currently collected on a central registry administered by the NSW Ministry of Health (the Ministry) under the *NSW Assisted Reproductive Technology (ART) Act 2007* and *Assisted Reproductive Technology Regulation 2009*. This Act came into force on 1 January 2010. NSW Health also operates a voluntary register for people who were donor-conceived prior to this date and for donors who donated before this date.

Having access to information about biological parentage is generally in the best interests of a donor-conceived child; for example it can be important for the development of identity and psychological well-being and may be critical for health reasons. Evidence from donor-conceived people provided to the previous Inquiry reinforces this. It would thus be desirable for people who were donor conceived prior to January 2010, including through private arrangements, to have access to donor information, including information that identifies the donor and any donor conceived siblings. The report of the previous Inquiry notes that principles of openness and access to information about genealogy are in line with the Convention on the Rights of the Child and NHMRC Guidelines that the interests of the child are paramount in ART.

However, as explored in the report arising from the previous Inquiry, the central problem in effecting this is that donors who donated before this date have not consented to having this information made available. In the interests of fairness to the donor, it does not seem reasonable to take this step, unless the consent of the donor is sought and obtained. Submissions to the previous Inquiry on this issue argued that to circumvent this problem, only non-identifying details of donors should be provided or that donors should be able to establish a contact veto. These proposals are reasonable. In the case of informal arrangements, due to lack of an existing system for the collection and management of donor information, it would not appear feasible to make information available retrospectively<sup>1</sup>, however donors could be voluntarily encouraged to register such information so that it could be provided in the future.

In regard to ToR b), which asks which agency should be responsible for the management and release of donor conception information, the Commission has previously argued that donor information should be held on a separate register to the Register of Births, Deaths and Marriages, but did not have a particular view whether this role should continue to be performed by the Ministry of Health or should go to the Registrar. The previous Inquiry notes that there are arguments for and against both options, but there was insufficient evidence to recommend changes to the current management of the ART Central Register.

If further consideration of this issue is warranted, the Commission is of the view that factors to consider in determining which agency should manage the ART Central Register are which agency is likely to provide better access to information for donor conceived people and related services, while at the same time adequately protecting the privacy of this information. The most appropriate agency to provide or coordinate the provision of counselling or support services and public education is also a factor.

While the Ministry does not have a direct role in providing counselling or public education, these services are provided at a local level by Local Health Districts, which are part of NSW Health. However the Registrar currently has no role in providing services of this kind, as it primarily has an information collection and management function. It is possible, as the Committee suggests in the Issues Paper prepared for this Inquiry, that it would be beneficial to establish a stand alone body to administer the donor register and perform other functions. However this is likely to be the most resource intensive option.

The Commission supports the provision of resources and materials to guide donors and donor-conceived people seeking donor information as well as access to voluntary counselling for donor-conceived people prior to the provision of this information. It is suggested that counselling be offered when a donor-conceived person makes contact with the responsible agency, seeking this information. It would need to be provided in a timely fashion, to avoid delays in the provision of donor information. It is suggested that one session of free counselling be offered, by an

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<sup>1</sup> *The previous Inquiry also considered the issue of access to information about donors who donate through private arrangements, and recommended that participants in private donor conception arrangements should be able to voluntarily register their details on the voluntary register and that availability of this information should be publicised.*

experienced government or non-government provider, funded by the NSW Government agency with responsibility for the ART Register (currently the Ministry of Health). Additional sessions, including following attempts to make contact with the donor, or meeting with the donor, may need to be self-funded. This would be similar to the arrangements around birth origin counselling that currently exist in Western Australia and Victoria, although in Victoria the counselling is entirely self-funded. It is also suggested that parents of a donor-conceived child be provided with access to counselling if they are considering telling their child that s/he is donor-conceived. A session of family counselling that includes parents and child may also be needed following the disclosure.

In regard to public education, it is important that people who are donor-conceived through ART are aware that information may be available about their donor, the type of information that is available, and the role that the Ministry of Health (or any alternative agency) can play in assisting donor conceived children to make contact with their donor. Should the collection of donor information under the ART Act be made retrospective and should information on private donor arrangements be held on the voluntary register, information would also need to be available targeting donor conceived persons explaining these changes. A communications strategy should be developed for the distribution and promotion of information resources, including publishing these on the websites of relevant government agencies and distributing printed brochures to ART providers and support groups for donor-conceived people. Promotion through the print and electronic media should also occur.

Information resources should also target donors, so that they are aware what information is held about them and by whom, and who has access to it. Provision of this information could be expected to be part of an ART provider obtaining informed consent from a donor, however as the Ministry also holds this information, it also has a responsibility to provide information to donors in this regard. Information should also be developed targeting parents of a donor conceived child, informing them of the type of information held about the birth of their child, information held on the donor and how to obtain access to it, and of the information a donor-conceived child has access to and at what age.

Information should encourage parents to disclose to a child that they are donor conceived, emphasising the benefits to the child that arise from having full details about their biological parentage and indicating that counselling is available for both the parents and the child prior to and following any disclosure. Information and resources developed for adopted people and their birth parents and siblings through Community Services and its non-government partners provide useful models to consider in this context.

I appreciate the opportunity to contribute to this Inquiry and trust that the comments provided are of assistance. [REDACTED]

Yours sincerely

[REDACTED]  
**Megan Mitchell**  
**Commissioner**

*13* February 2013