Submission
No 21

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Organisation:	NSW Committee on Adoption and Permanent Care Inc
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NSW COMMITTEE ON ADOPTION AND PERMANENT CARE INC

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Legislative Assembly Committee on Law and Safety
Parliament House
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Thank you for the opportunity to make comment on the issues raised in the Issues Paper: Managing Information Related to Donor Conception.

The NSW Committee on Adoption and Permanent Care Inc ("the Committee") is a non-profit organisation, with membership comprising government and non-government agencies, support groups and individuals interested in, involved in. or affected by adoption and permanent care or related issues. The Committee is also interested in the issues faced by some donor conceived people and the many similarities they share with adoptees, especially in regards to issues about identity and their right to information. In fact as written in our Committee's Constitution we believe that children born through assisted reproductive technology have the same right to know their origins as children who have been adopted or are in permanent care.

This submission has been prepared by the Committee's Legislative Review Sub-Committee on behalf of the Committee. In our submission, we will not be citing individual cases, nor will we be representing individuals or individual agencies, but will broadly comment as a group of key agencies and support groups on the basis of our shared knowledge pertaining to this Discussion Paper.

ACCESS TO INFORMATION

Question 1: Should donor-conceived adults have retrospective access to donors' identifying details?
Question 2: If retrospective access were granted what conditions should apply?
Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?

The Committee notes that, for many individuals conceived prior to 2010, there is no guaranteed access to information or, indeed any guarantee that the individual knows the details of their conception. We strongly believe that donor-conceived adults should have retrospective access to donors' identifying information as it is a basic human right for people to know their origins and have a sense of their identity. Equally important is their access to their donor's medical information. However, we also acknowledge the impact on the donor who could receive unwanted requests for contact by numerous offspring; therefore we believe that provisions, such as a contact veto used in adoption practice, should be put in place, especially in the initial stages, for donor conception prior to 2010. It is important to stress that such a contact veto would not, however, prevent the release of the identifying information of the donor.

The situation is very similar to that of adoption, where contact vetos were introduced for adoptions finalised prior to 1990 and where the provision for this has later been removed. In fact, many original vetos were later removed as a consequence of mediation between the person applying for information and the person placing the veto. While there was an initial opposition to the release of retrospective information, the Committee notes that there have been no known significant adverse impacts of this legislation.

The Committee does not support the implementation of the Advance Notice Register, noting that this has not been greatly utilised in the adoption arena. In addition, we believe this provides an opportunity for parents of a donor-conceived person to defer provision of this information and does not encourage the parents to be honest to their child about the circumstances of their conception.

We strongly believe that counselling and support services are required; hence the fact that the NSW government currently funds 4 major agencies to provide post-adoption support services. NSW has post-adoption support services who offer a valuable search, mediation, counselling and contact service to those impacted by adoption. We believe that, given the potential number of children conceived from the one donor, a similar service would be extremely valuable.

It is difficult to propose a particular model, when the only known model is the Victorian one, which we are aware has some issues. However, we would argue that agencies which may best be able to deal with such situations would be a non-government agency that currently has experience in working with post-adoption issues, such as identity, grief and loss, relationship, reunion and contact services.

We do not believe that such counselling should be mandatory as we believe that this goes against the principle that the person is entitled to their own information, could impose unnecessary barriers and prevent a person from seeking this information. Individuals who seek such counselling should, however, be able to access this free of charge as is the case in the NSW post adoption support services.

We have further addressed issues in this section under the section on "Access to Information".

MANAGEMENT OF DONOR REGISTERS

Question 4: Which agency is best placed to manage the register of donor conception information (donor register)? Is the current management of the register adequate?

Question 5: Should a standalone body be established to manage the register? What other areas could it have responsibility for?

The Committee believes the Ministry of Health is not the most appropriate agency to manage this register. The primary issues here are not to do with the medical issues related to the conception of the child; rather they are to do with the relationship, identity and emotional needs of the persons born through assisted reproductive technology. Births, Deaths and Marriages (BDM) has great knowledge and experience in the provision of ethical, standardised record keeping and is the holder of substantial information about each registered birth. We believe that BDM is the most appropriate body to manage the records and any additional information and could then refer to a relevant accredited support service, which would provide a range of services as required.

This also normalises the situation for donor-conceived adults seeking information about their birth as every individual approaches BDM with enquiries about their birth record.

COUNSELLING AND SUPPORT SERVICES

Question 6: Should counselling and support services be offered to those seeking donor conception information from the donor register?
Question 7: Are there other types of support that could be offered?
Question 8: How would support services be funded? By the government, the individual seeking the service, or by ART clinics?
Question 9: How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?

It is imperative that a specialised counseling and support service is established to meet the growing need of donor conceived people accessing their information. It is important to note that the primary issues donor conceived people will face when accessing their information are to do with identity, relationships, grief and loss and contact – they are not medical issues and therefore the counseling and support should not be provided by a health service. We believe that an agency experienced in post adoption issues should deliver the specialised support service as it is the closest equivalent professional field to work with clients facing these issues. We know both donor conceived people and adoptees can yearn for knowledge about their biological family and medical history and need to connect with people to whom they are biologically related.

The Issues Paper notes that in NSW, couples undergo counselling when they begin ART. We are aware that NSW legislation requires that an ART provider must ensure that counselling is available to any woman who seeks treatment from the provider, the woman's spouse/partner and any person proposing to provide a gamete. However, this counselling is voluntary and there are no legislative requirements as to what is addressed in the counselling. The Committee would like to suggest that attendance at counselling be made mandatory for all persons when they begin ART. The experience in the adoption area is that counselling is extraordinarily beneficial as an opportunity to gain insight into the type of parenting being embarked upon and the specific issues of adoption. We can extrapolate that in ART, counselling would also serve this function, particularly in relation to the parents' understanding of the child's need to know about their genetic origins, the importance of open communication with the child about his or her origins and the long-term implications for the donor.

The Committee believes that such counselling should be provided by a suitably qualified welfare trained professional, similar to provisions for a Registered Counsellor under the Adoption Act 2000, and must cover the areas outlined above, which should be prescribed by legislation. This counselling should be available where the ART treatment is offered but referral to suitable independent counsellors or agencies should also be considered. In addition, the specialist service provider, referred to previously, could provide group information sessions, which could be attended by interested parties at any stage in the process as well as public information and resources.

We note that there has been very little financial assistance, if any, to support groups in this area, with the main one in NSW being the Donor Conception Support Group run by a group of volunteers; therefore the Committee believes that this needs to be urgently addressed. We are aware that accessing support and mediation services is becoming a major issue for those born through donor conception and we are aware they are currently beginning to access adoption support services. This is an area of need that will only continue to grow and attention must be given now to financial and operational assistance to specialised support groups, to assist them in the provision of much needed services, including counselling, search, mediation and reunion services.

RECORD KEEPING

Question 10: How long should ART clinics be required to retain records?
Question 11: What should happen to records if a clinic closes?
Question 12: How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.

The Committee supports the NHMRC guidelines that records should be kept indefinitely. This is based on our considerable shared experience of matters relating to adoption records and the recognition that biological information relates not only to the donor-conceived person but subsequent generations. The Committee brings attention to the Adoption Regulations 2003 Clause 73 (3), which states, "The case records are not to be destroyed". There are many adopted people and their children who, when they seek information in later adult years, are extremely distressed to learn that their records have been destroyed.

The Committee believes that the ART clinics must retain these records. However, should a clinic close, records must be transferred to BDM to be stored at the Office of State Records for safe keeping. State Records can then release information to an accredited specialist service provider, upon request from BDM.

The Committee would recommend that legislation be enacted that prohibits the tampering with, or destruction of, any records relating to donor conception information.

We thank you for the opportunity to contribute to this consultation. Please do not hesitate to contact me if you require further information.

Yours sincerely

[redacted]

Damon Martin
Chairperson
NSW Committee on Adoption and Permanent Care Inc

In consultation with the Committee's Legislative Review Sub-committee:

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