Submission No 37

# MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Ms Clara Hawker The Committee Manager Legislative Assembly Committee on Law & Safety Parliament House Macquarie Street SYDNEY NSW 2000

Dear Ms Hawker,

#### Issues Paper: Managing information related to donor conception

Thank you for the opportunity to provide a submission to this consultation.

The Elder Law and Succession Committee of the Law Society of NSW (ESLC) represents the Law Society in the areas of elder and succession law as they relate to the legal needs of people in NSW. The Family Issues Committee (FIC) represents the Law Society in the area of family law as it relates to the legal needs of people in NSW (together referred to as the "Committees"). The Committees include experts in these areas drawn from the ranks of the Law Society's membership.

The ELSC recently made a submission to a NSW Government inquiry into the inclusion of donor details on the register of births, as well as to a NSW Registry of Births Deaths and Marriages ("BDM Registry") Review of Birth Certificates. In these submissions, the ELSC noted its view that the Registrar of BDM should keep a register that encompasses all of the parents that a child can have, however defined. These details should include donor details. The ELSC's view is also that the details kept on this register do not need to appear on the official birth certificate, but a birth certificate should be issued noting the person's current parents.

The Committees' position is informed by the considerations set out below.

#### A. The best interests of the child is the paramount consideration

The FIC notes that the United Nations Convention on the Rights of a Child ("Convention") recognises that the principle underpinning any consideration in relation to children is that 'the best interests of the child shall be the primary consideration' (Article 3). This is the principle that informs these submissions.

#### B. Child's right to know parents

The ELSC notes that Article 7 of the Convention states that a child shall have, as far as possible, "the right to know and be cared for by his or her parents".





The National Health and Medical Research Council *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* at paragraph 6.1 states "persons conceived using ART [assisted reproductive technology] procedures are entitled to know their genetic parents".

#### C. Who is a parent

The ESLC notes that persons will be presumed to be parents of a donor-conceived child where any of the following circumstances apply:

- 1. The presumption arising from a birth resulting from a fertilisation procedure pursuant to section 14 of the *Status of Children Act 1996* (NSW) ("*Status of Children Act*"):
  - '(1) When a married woman has undergone a fertilisation procedure as a result of which she becomes pregnant:
    - (a) her husband is presumed to be the father of any child born as a result of the pregnancy even if he did not provide any or all of the sperm used in the procedure, but only if he consented to the procedure, and
    - (b) the woman is presumed to be the mother of any child born as a result of the pregnancy even if she did not provide the ovum used in the procedure.
  - (1A) When a woman who is the de facto partner of another woman has undergone a fertilisation procedure as a result of which she becomes pregnant:
    - (a) the other woman is presumed to be a parent of any child born as a result of the pregnancy, but only if the other woman consented to the procedure, and
    - (b) the woman who has become pregnant is presumed to be the mother of any child born as a result of the pregnancy even if she did not provide the ovum used in the procedure.

Note. "De facto partner" is defined in section 21C of the Interpretation Act 1987.

- (2) If a woman (whether married or unmarried) becomes pregnant by means of a fertilisation procedure using an ovum obtained from another woman, that other woman is presumed not to be the mother of any child born as a result of the pregnancy. This subsection does not affect the presumption arising under subsection (1A) (a).
- 2. A child born as a result of assisted reproduction technology treatment under the Assisted Reproduction Technology Act 2007 (NSW) ("Assisted Reproduction Technology Act").
- 3. A child born as a result of artificial conception procedure under section 60H of the Family Law Act 1975 (Cth) ("Family Law Act").

The ELSC notes that biological parents are not legal parents:

1. By reason of sperm donation to a woman (married or unmarried) who becomes pregnant from a man who is not her husband and the presumption is the donor is not the father (section 14(2) Status of Children Act and section 60 H(1)(d) Family Law Act). This child will be offspring under the Assisted Reproduction Technology Act.

2. If they donated an ovum resulting in a pregnancy, the donor is presumed not to be the mother of the child (section 14(3) *Status of Children Act* and section 60H(1)(d) *Family Law Act*). This child will be offspring under the *Assisted Reproduction Technology Act*.

### D. Importance for a child to know parents

The National Health and Medical Research Council acknowledged the importance of a child knowing their parents in its report *Ethical guidelines on the use of assisted reproductive practice and research.* The report points out at paragraph 5.7 that "Good record keeping is an essential component of clinical practice and vital for ART because of the long-term consequences of procedures involving ART on the health and psychosocial wellbeing of the persons who are born and on the participants in ART procedures themselves (and their spouses and partners, if any)."

The Victorian Parliament Law Reform Committee in its *Inquiry into access by donor-conceived people to information about donors* also noted the importance to children in knowing who their parents are.

### E. Risks of consanguinity

There is a public interest in allowing easy identification of one's parents. This may be for a range of reasons, such as to eliminate the risk of consanguinity for such things as marriage or having a sexual relationship. It would also allow for a person to trace their ancestry for reasons of genetic health.

Section 27(1) of the Assisted Reproductive Technology Act states that: "An ART provider must not provide ART treatment using a donated gamete if the treatment is likely to result in offspring of the donor being born, whether or not as a result of ART treatment, to more than five women...". This limits a specific ART provider to five women (but not to the treatments per woman), but does not prevent a donor going to different ART providers. This limitation is extended in Victoria as the relevant Act in that State provides that treatment cannot be provided to more than ten women.

It is possible for a donor to provide gametes to more than one ART provider on more than one occasion. The ELSC's view is that the possibility of having multiple children should not be underestimated and the risks of consanguinity are magnified by the potential number of children.

### F. Responses to questions set out in the Issues Paper

The Committees set out below responses to some of the questions posed in the Issues Paper. The Committees have not provided responses to questions where they consider other stakeholders better placed to do so.

### Question 1 – Should donor-conceived adults conceived before 2010 have retrospective access to donors' identifying details?

The Committees believe that a person should have access to some of the donor's identifying details no matter when the child was conceived, for the reasons stated above.

It is important that any considerations are made in a manner consistent with Australia's international obligations under the Convention. While the Committees acknowledge that the donor's privacy issues should be considered, they are of the view that providing the donor-conceived child access to information related to their conception is in that child's best interests, and consistent with their Convention rights.

The issue of whether information which identifies the donor should be included has to be considered in the context of the competing interests at play. The FIC's view is that the following matters are relevant in answering this question:

- Research shows that donations dropped dramatically after legislation was passed requiring that donors be identifiable. Prior to January 2010 donors were assured that identifying information would not be made available. If identifiable information from prior to 2010 is made available, this may undermine public confidence in donation schemes that might apply in other areas.
- Research has shown that it is important for children to have information about their genetic makeup. The need that many donor-conceived children express to know about their biological family is analogous to that of adopted children. This need to know does not necessarily extend to wanting to meet their biological family.
- The adults raising a child conceived through surrogacy did so in a known legal environment at the time.
- Consent is an important consideration to determining whether the donors should be identified.

### Question 2: If retrospective access were granted what conditions should apply?

At the outset, the FIC notes that reference to donors should include reference to sperm donors and to egg donors as the same principles apply. The FIC submits that the information made available retrospectively should include information about ethnicity, genetic and medical history.

The FIC's view is that if the decision was made to make available donor-identifying information, donors should be contacted before any information is released and be given the opportunity to express any concerns. Alternatively, the identity of the donors should not be released without their consent.

If the conditions were applied on the release of identifying information without consent, the FIC also sees some benefits to the release of information about siblings such as date of birth and gender. This would address the associated risks of consanguinity referred to earlier.

# Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for the information be managed? Would counselling and support services be required?

The FIC's view is that counselling support should be made available. Government funding should be provided for donor-conceived children at least on a means-tested basis as these children have had no control over the circumstances of their birth.

The FIC notes that consideration should also be given to the impact on the donors. Prior to their involvement in the ART, they may have received advice which may no longer be accurate if a decision were made retrospectively. Facilitating referrals and access to legal advice (on issues such as parental responsibility, maintenance obligations and testate issues) might assist.

# 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?

The Committees note that the information is currently held in the NSW Central Health Register, operated by NSW Health. The Committees note also that information available on the relevant website recommends that people applying for information held on the register, or seeking to register their own details seek counselling first.

However, the Committees note that in practical terms, a person applying for a birth certificate would apply to the BDM Registry. If that person also wished to find out about their conception history, then the Registrar of BDM would have to refer that person to NSW Health. If the person applying for the birth certificate has no prior knowledge of their conception history, they may not know to ask about the NSW Central Health Register.

In the Committees' view, it would be preferable for all of the information relating to the birth and parentage of a child to be held in one agency to avoid duplication of resources, loss of efficiencies and delays accessing counselling services. The BDM Registry should already have the appropriate privacy and confidentiality measures in place and the Committees are of the view that the information related to donor conception should be held in a register administered by the BDM Registry. The Committees note that the relevant counselling information and referral service could also be provided to the person by the BDM Registry, both prior to and following the provision of the information, if required.

Further, the Committees note that it is preferable for a Government agency to be responsible for keeping these records rather than a private agency such as an ART provider as this information could be lost if that ART provider were to close.

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

As noted in the response to question 4, the Committees are of the view that it is not necessary to establish a standalone body to manage the Register. Rather, the BDM Registry staff should be appropriately trained and the Registry resourced to both manage the register, and to provide referral information about counselling services available. The BDM Registry already has expertise in collecting, storing and providing sensitive and confidential information to clients and would provide a centralised and streamlined service where people would naturally look to find family information.

Similarly as noted in the response to question 4, in the Committees' experience, if individuals are seeking information about their parents, they apply to the BDM for a birth certificate. The BDM Registry should have appropriate notations in their records which should then alert any donor-conceived people to the further information that is available, and which should also alert the BDM Registry staff to the possible need for counselling services.

A donor-conceived person, if allowed to access information about their parents, should be able to discover the information without unnecessary bureaucratic barriers.

If it is the case that the register of donor conception information will continue to be held by a separate organisation, as is the case of the NSW Central Health Register, a donor-conceived person who is unaware of his or her conception history may not discover that there was further information available. In the Committees' view, this arrangement is not

one that best fulfils the right to know one's parents and may not be in the best interests of the child.

### Question 6 – Should counselling and support services be offered to those seeking donor conception information from the donor register?

Yes. The FIC's view is that counselling services should be available to donors and parents of donor-conceived children so they can gain assistance with various issues. The matter of *Re Evelyn* (1998) FLC 92-807 is a classic case in point. It is impossible to know how, for example, a person who has given birth is going to feel about the child regardless of whether or not the child contains any of that person's genetic material. The risks are even greater when the donor believed that their details would not be made available. It therefore is important that expert counselling services are made available to all involved.

## Question 8 – How would support services be funded? By Government, the individual seeking service, or by assisted reproductive technology clinics?

The Committees believe that Government-funded support services should be available to donor-conceived people who would not otherwise be able to access these services. Donor-conceived people are not donor-conceived by choice. They occasionally have limited means, and they should not be disadvantaged due to their circumstances.

Thank you once again for the opportunity to provide comments.

