



Our ref: PCC/ELCSC/HRC/FLC/MLLC:PWeh:1405508

17 November 2017

Ms Gemma Broderick
Principal Legal Officer
Legal and Regulatory Services – Legal Branch
NSW Ministry of Health
Locked Bag No. 961
North Sydney NSW 2059

By email: legalmail@doh.health.nsw.gov.au

Dear Ms Broderick,

Statutory review of Part 3A of the Assisted Reproductive Technology Act 2007 (NSW)

Thank you for the opportunity to provide comments to the Ministry of Health on the statutory review of Part 3A of the *Assisted Reproductive Technology Act 2007* (“Act”). The Law Society’s Privacy and Communications, Elder Law, Capacity and Succession and Human Rights Committees have contributed to this submission. The Family Law and Medico-Legal Liaison Committees support this submission.

1. Background

The Act commenced on 1 January 2010. Relevantly, it aims to ensure that persons who are donor conceived after 1 January 2010 have a right to access both identifying and non-identifying information about the donor. To facilitate this, information about donors is placed on a Central Register maintained by the NSW Ministry of Health. The Act does not operate retrospectively.

In 2016 the Act was amended to insert Part 3A. This provides for a person who had been conceived by use of a gamete donation prior to 2010 to access non-identifying information about their donor, referred to under the Act as “accessible information”.¹ Accessible information includes information about:

- the ethnicity and physical characteristics of the donor;
- the relevant medical history of the donor; and
- the sex and year of birth of each offspring of the donor

but only to the extent that that the information is non-identifying information.²

Applications for accessible information can be made by a donor conceived person to either the Secretary of the NSW Ministry of Health or directly to the Assisted Reproductive Technology (ART) provider.³ When an ART provider gives the donor conceived person the

¹ *Assisted Reproductive Technology Act 2007* (NSW) s 41T(1).

² *Ibid* s 41S.

³ *Ibid* s 41T(2).

accessible information the provider must also give the Secretary of the Ministry of Health a copy of the accessible information as well as any information that the ART provider has about the identity of the donor, identifying information about each woman who has undergone ART treatment using a gamete donated by the donor and each offspring born as a result of that ART treatment.⁴ The accessible and identifying information about the donor is then placed on the Central Register so that other offspring of the donor can access the accessible information.⁵

Identifying information about a person who donated gametes prior to 1 January 2010 can only be disclosed with the consent of the donor.

When Part 3A was inserted into the Act there was discussion as to whether there should be a central collation of pre-2010 donor records. Ultimately, no provision to that effect was included in Part 3A but a clause was inserted to review the operation of Part 3A after 12 months.

The Ministry of Health has now called for submissions on whether Part 3A of the Act is adequate in ensuring that pre-2010 records are appropriately kept and non-identifying records are made available to pre-2010 donor conceived individuals or whether the Act should require a central collation of all pre-2010 ART records relating to donor conceived individuals.

2. Previous submissions by the Law Society

In 2013 the Law Society made two submissions in response to a review of the Act. This was prior to the inclusion of Part 3A. Both of these submissions emphasised that the best interests of the child are the paramount consideration and expressed the view that the Central Register should include information on donors who donated gametes prior to 1 January 2010 to ensure that the donor information is held securely and available in the future if required. Copies of these submissions are attached.

3. Current position

The Law Society recognises that the best interests of the child are the primary consideration when developing policy in this area.⁶ A further guiding consideration is the right of a child to know his or her parents.⁷ However, the privacy rights of donors are also highly relevant. We set out below an analysis of some of the relevant benefits of having a Central Register, as well as the privacy considerations that must inform any proposal for further reform.

3.1. Benefits

If the Government introduces legislative amendment requiring ART providers to send all pre-2010 information to the Ministry of Health for inclusion on a Central Register, the Law Society notes that there would be a number of advantages. It would ensure that if an ART provider was to close, or their records be destroyed, the records could still be accessed via the Central Registry.⁸

⁴ Ibid s 41U; *Assisted Reproductive Technology Regulation 2014* (NSW) reg 23C.

⁵ Above n 1, ss 41N, 41W.

⁶ Convention on the Rights of the Child, opened for signature 20 November 1989, 44 NUTS 25 (2 September 1990) art 3.

⁷ Ibid, art 7; See also, National Health and Medical Research Council, *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*, available at https://www.nhmrc.gov.au/files/nhmrc/file/guidelines/ethics/16506_nhmrc_-_ethical_guidelines_on_the_use_of_assisted_reproductive_technology-web.pdf 5.6.

⁸ We note that the new s 41O now requires any pre-2010 record within an ART provider's control to be in a readily accessible form during the retention period for the record, which is generally 75 years from the day the most recent ART service was provided.

Additionally, we note that inclusion on the Central Register may assist access to non-identifying information. The Discussion Paper states that donor conceived individuals from gamete donations made prior to 2010, who wish to access non-identifying information about their donor, currently have to apply to either the ART provider or the Secretary for that information. If the application is made to the ART provider they must respond to the individual and provide a copy of the information to the Secretary. If the application is made to the Secretary, the Secretary must liaise with ART providers to locate the information and provide it to the individual, as well as updating the Central Register. Storing all donor information on the Central Register would reduce the time to respond to requests for non-identifying information. It would also assist to avoid duplication of resources and possible delays in accessing counselling services that can result from the Secretary having to constantly liaise with ART providers individually holding the records.

3.2. Concerns

However, we also note that a number of competing issues arise if ART providers are asked to disclose information about individuals who donated gametes prior to 1 January 2010 to the Ministry of Health for collation on the Central Register.

As recognised in the Discussion Paper prepared by the Ministry of Health, individuals who donated gametes prior to 1 January 2010 made their donation on the understanding that they would remain anonymous.⁹ We understand that ART providers may have made assurances to donors that their personal information would remain private and confidential. At that time it was not open to donor conceived individuals to request any information, either identifying or non-identifying, about their donor. The proposal to include this information on the Central Register would require the Ministry of Health to collect and store identifying information about donors that was not intended to be disclosed or disclosable at the time of collection and is not required to be disclosed at present.

Australian Privacy Principle ("APP") 2, contained in the *Privacy Act 1988* (Cth) ("Privacy Act"), states that individuals must have the option of not identifying themselves, or of using a pseudonym, when dealing with an APP entity in relation to a particular matter.¹⁰ While that requirement does not apply if the APP entity is required or authorised by or under Australian law to deal with the individuals who have identified themselves,¹¹ those who donated gametes prior to 1 January 2010 made that donation on the basis of complete anonymity, pursuant to contemporary legislation. This raises questions about the operation of APP 2. Similarly, we note the operation of APP 6, which provides that an APP entity can only use or disclose personal information for a purpose for which it was collected unless provided for by an exception, including where the disclosure is required by, or authorised under, an Australian law. Those who donated gametes prior to 1 January 2010 may not have anticipated disclosure of their personal information for the purpose of centralised record keeping.

The Discussion Paper states that including all information on donors prior to 2010 in the Central Register will still not allow the disclosure of identifying information without the consent of the donor.¹² As a practical matter, we note that including the pre-2010 records in the Central Register would require the existing measures in place to be reviewed to ensure that there are adequate safeguards to protect identifying information from disclosure. Having both accessible and identifying information on the same database creates a risk that identifying

⁹ Ministry of Health, "Assisted Reproductive Technology Act 2007, Part 3A Statutory Review: Discussion Paper", 3, 8.

¹⁰ *Privacy Act 1988* (Cth) Sch 1, cl 2.

¹¹ *Ibid* Sch 1, cl 2(2).

¹² Above n 9, 8.

information may be inadvertently disclosed in the event of a security breach of the Central Register or any other privacy breach due to malice or human error.

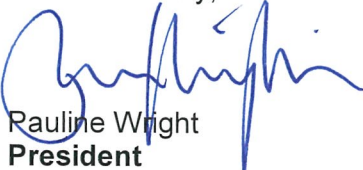
We note that to an extent this is already a live issue for the Ministry of Health. When ART providers are required to give accessible information about a donor to the Secretary after a request from a donor-conceived person, the provider is also required to provide any information that they have about the identity of the donor.¹³ The Discussion Paper states that all information provided to the Secretary, including identifying information, is included on the Central Register.¹⁴ We understand that the rationale for this is to ensure that the records obtained under Part 3A can be collected, stored or matched with any future application made by another offspring of the donor and to allow accessible information to be disclosed straight from the Central Register when requested rather than having to go back to the ART provider. For the reasons set out above, the Law Society would be grateful for further information about what safeguards are currently in place to protect the identifying information of pre-2010 donors on the Central Register.

We also note that the central collation of all donor information may make it much easier for the legislation to be changed in the future to allow access to identifying information about donors prior to 2010. The Law Society opposes any incremental removal of protections that have been previously given or promised to individuals without proper consideration of the cumulative long term effect. In our previous submission on the Act, the Law Society noted that donations dropped dramatically after legislation was passed requiring that donors be identifiable.¹⁵ If identifying information from prior to 2010 is released, this may undermine public confidence in such donation schemes and in the government's commitment to ensuring the privacy of individuals. If the Ministry of Health wishes to pursue the collection of all donor information on the Central Register, the Law Society suggests that this should only be done with a public commitment that the legislation will not be amended to allow for identifying information of pre-2010 donors to be released without the consent of the donors.

As a final matter, if ART providers are required to provide donor information to the Central Register, there is a risk that donors will be less likely to provide up to date information if necessary. APP 13 allows an APP entity to update an individual's information if requested by the individual or if the entity is satisfied that the information is inaccurate, out of date, incomplete, irrelevant or misleading.¹⁶ As noted in the Discussion Paper, a central collation of records may make donors less likely to provide up to date information. If information on pre-2010 donors is to be held in the Central Register we suggest that the Ministry of Health will need to consider the most effective ways to inform donors about updating their information on the Central Register.

Should you have any queries, please contact Ella Howard, Policy Lawyer, on (02) 9926 0252 or at ella.howard@lawsociety.com.au.

Yours sincerely,



Rauline Wright
President
Encl.

¹⁶ Above n 10, Sch 1, cl 13.



THE LAW SOCIETY
OF NEW SOUTH WALES

Our ref: FIC/ELSCJDeI762469

21 August 2013

Ms Gemma Broderick
Senior Legal Officer
Legal & Regulatory Services
NSW Ministry of Health
Locked Bag No. 961
NORTH SYDNEY NSW 2059

By email: legalmail@doh.health.nsw.gov.au

Dear Ms Broderick,

Discussion Paper: Review of the Assisted Reproductive Technology Act 2007

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 Committees recently made a submission to a NSW Government inquiry into the management of information related to donor conception (attached). In this submission, the Committees stressed the importance of the right of a child to know his or her parents and that there are a number of reasons why it is in the public interest to allow a child to easily identify his or her parents.

The Committees' overarching view is that the questions of law and policy in relation to donor-conceived children should be approached in a similar way to adopted children.

While the Committees note that the *Assisted Reproductive Technology Act 2007* (NSW) ("ART Act") provides for a central register managed by the Ministry of Health, the Committees' view expressed in its previous submission is that information relating to donor conception should be centrally administered by the Registry of Births, Deaths and Marriages.

Further, the Committees' view is that information held by ART providers in relation to donor-conceived children prior to 1 January 2010 should be included in the Register. The Committees also submit that the regulatory requirements should extend to private arrangements and information about donor conceived children from private arrangements should be included in the register.

THE LAW SOCIETY OF NEW SOUTH WALES

170 Phillip Street, Sydney NSW 2000, DX 362 Sydney T +61 2 9926 0333 F +61 2 9231 5809
ACN 000 000 699 ABN 98 696 304 966 www.lawsociety.com.au



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

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

The Committees note 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 Committees note 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 Committees note 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 ART 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 Committees note 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 ART 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 ART 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 ART 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 Committees' 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 – Are the objectives of the ART Act still valid?

In general terms, the Committees consider that the stated objectives remain appropriate.

Question 2 – Should any further objectives be included in the ART Act?

Consistent with the guiding principle that the legislation should be guided by the paramount consideration of the best interests of the child, it is the Committees' view that a further objective of promoting as well as protecting the interests of a person born as a result of ART treatment should be included in the ART Act.

Question 3 – Is the current information required to be collected on donors and held on the Register appropriate?

Yes. The Committees are of the view that the current information collected and held on the Register is appropriate. In addition, the Committees submit that the current information collected about donors and held by the Register should be expanded. The Register should also include information on assisted reproduction prior to the 1 January 2010 to ensure that this information is held securely and is available in the future if required. The Committees note that ART providers are not required to keep the pre-2010 information for any extended period of time.¹ Should the ART provider close, or destroy their information, then there is no way for this information to be retrieved in the future. The Committees submit also that given its position that all pre-2010 information should be included in the register, its view is that the transitional arrangements for the 2010-2015 period are not necessary.²

The Committees note also that the Reunion and Information Register currently in existence for adoption would also be appropriate for matters of ART. This register allows people to register their details and willingness of contact of members of the birth family including parents and siblings.

¹ The *Human Tissue Regulation 1995* (although now superseded by the *Human Tissue Regulation 2000*) would have regulated arrangements that took place between 1995 and 2000. That Regulation required clinics to maintain records in respect of each sperm donation for a period of 10 years where the donor is aged 20 years or over, or until the donor reaches the age of 30 where the donor is younger than 30 years at the time of donation.

² While ART providers are required under s 31 of the ART Act to keep records for 50 years, Regulation 13(3) of the ART Regulation 2009 provides for transitional arrangements:

- (3) An ART provider is not required to keep records under section 31 of the Act, in relation to the following gametes or embryos:
 - (a) an embryo that was created using a donated gamete before the commencement of that section if the embryo is used to provide ART treatment to a woman within 5 years after that commencement, or
 - (b) a donated gamete that was obtained from a donor before the commencement of that section if the gamete is used to provide ART treatment to a woman within 5 years after that commencement and the woman has, before that commencement, already conceived an offspring as a result of ART treatment using a donated gamete from the donor.

Question 4 – Should the provisions in the ART Regulation setting out the information that is collected and held on the Register be moved to the Act?

Yes. The Committees are of the view that the legislative provisions setting out the information that is collected and held on the Register should be moved to the Act as this will ensure a greater degree of ongoing certainty about the information to be collected and recorded. The Committees further submit that the facility that exists via the ART Regulation for adding to the categories of information to be collected should be preserved.

Question 5 – Should the ART Act be amended to allow information about private arrangements to be held by the Register?

It is the Committees' view that information about private arrangements should be held on the Register as this is in the best interests of a donor-conceived child and it consistent with their Convention rights.

The Committees note that it is clear that once a private arrangement has been entered into, issues can arise to the potential detriment of children when there is later conflict between the donor and the recipient. The Committees note that in *AA v Registrar of Births Deaths and Marriages and BB* [2011] NSW DC 100 the donor father was originally recorded on the child's Birth Certificate. The mother's partner wanted to be registered on the birth certificate as a parent and, therefore, the father was removed.

The Committees' view is that the same information required from ART providers (where applicable) should also be required in relation to private arrangements. The Committees' view is that a regulatory approach that is consistent for both private arrangements and ART providers would be best positioned to protect the best interests of all donor-conceived children.

Question 6 – Is the 5 year limit on the transitional arrangements appropriate?

The Committees note that if their recommendations are accepted, then the five year limit will be superfluous as all previous information will have been collected. In any event, the Committees agree with the Ministry's preliminary view that the current transitional period of five years is not appropriate.

Question 7 – If not, what time limit, if any, should be set for women falling within the transitional arrangements?

The Committee rely on the response set out to Question 6.

Question 8 – Is the 5 women limit still appropriate?

Yes. The Committees are of the view that the five women limit is appropriate as this reduces the risk of consanguinity.

Question 9 – Should the 5 women limit be changed to a 5 family limit?

No. The Committees are of the view that the five women limit should not be changed to a five family limit as this would pose a greater risk of consanguinity.

Question 10 – Should the 5 women limit be changed to a 10 women limit?

No. The Committees are of the view that the five women limit should not be changed to a 10 women limit as this would pose a greater risk of consanguinity.

Question 11 – Should there be a limit on the use and storage of donated gametes and embryos created using donated gametes?

The Committees' view is that other bodies are better placed to respond.

Question 12 – If so, what limit should apply? The current 10 year limit or another time period?

The Committees' view is that other bodies are better placed to respond.

Question 13 – If a limit is applied, should there continue to be a process for exemption? How should this occur?

The Committees' view is that other bodies are better placed to respond.

Question 14 – Should the ban on the use of gametes after death except with the written consent of the gamete provider remain in the ART Act?

The Committees note that this is essentially a policy question which involves the often competing rights of donor offspring, donors and parents.

The Committees acknowledge that the removal and use of gametes after death with or without the consent of the gamete provider involves complex ethical, moral and legal issues which may require case-by-case consideration.

The Committees submit that the relevant principle underpinning any consideration in relation to children is that "the best interests of the child shall be the primary consideration". This principle should also be applied when considering the creation of children through the use of gametes after death.

The Committees note that the discussion paper suggests that the ART Act could be amended to allow for the use of gametes after death where there is no express consent. The paper also suggests that an external arbitrator could be an appropriate mechanism to allow for the posthumous use of gametes. If the Act were amended to allow an external arbitrator to determine the posthumous use of gametes, it is the Committees' view that the appropriate arbitrator would be an independent body such as a tribunal (for example the Administrative Decisions Tribunal or its equivalent division in the consolidated NSW Civil and Administrative Tribunal) or the Supreme Court of NSW.

The Committees note in particular that the following issues will require closer attention:

- The question of legal "parents" of any child conceived using a gamete used after the death of the donor.

- Rights of inheritance of any child conceived. The ELSC notes that the *Succession Act 2006* (NSW) states at s 107 that:

Survivorship

(1) A person will not be regarded as having survived an intestate unless:

- (a) the person is born before the intestate's death and survives the intestate by at least 30 days, or
- (b) the person is born after the intestate's death after a period of gestation in the uterus that commenced before the intestate's death and survives the intestate for at least 30 days after birth.

- Property rights that have arisen in recent case law in relation to the possession and use of gametes (cf *Jocelyn Edwards; Re the estate of the late Mark Edwards* [2011] NSWSC 478 and *Re H, AE (No 2)* [2012] SASC 177).

Question 15 – If not, in what circumstances should the use of gametes after death occur where there is no written consent?

The Committees refer to its response to Question 14.

Thank you once again for the opportunity to provide comments.

Yours sincerely,



John Dobson
President

Submission
No 37

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Organisation: The Law Society of New South Wales
Name: Mr John Dobson
Position: President
Date Received: 22/02/2013



THE LAW SOCIETY
OF NEW SOUTH WALES

Our ref: ElderLaw:JD.VK:683680

20 February 2013

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 (ELSC) 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 LAW SOCIETY OF NEW SOUTH WALES
170 Phillip Street, Sydney NSW 2000, DX 362 Sydney t +61 2 9926 0333 f +61 2 9231 5809
ACN 000 000 699 ABN 98 696 304 966 www.lawsociety.com.au



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.

Yours sincerely,



John Dobson
President