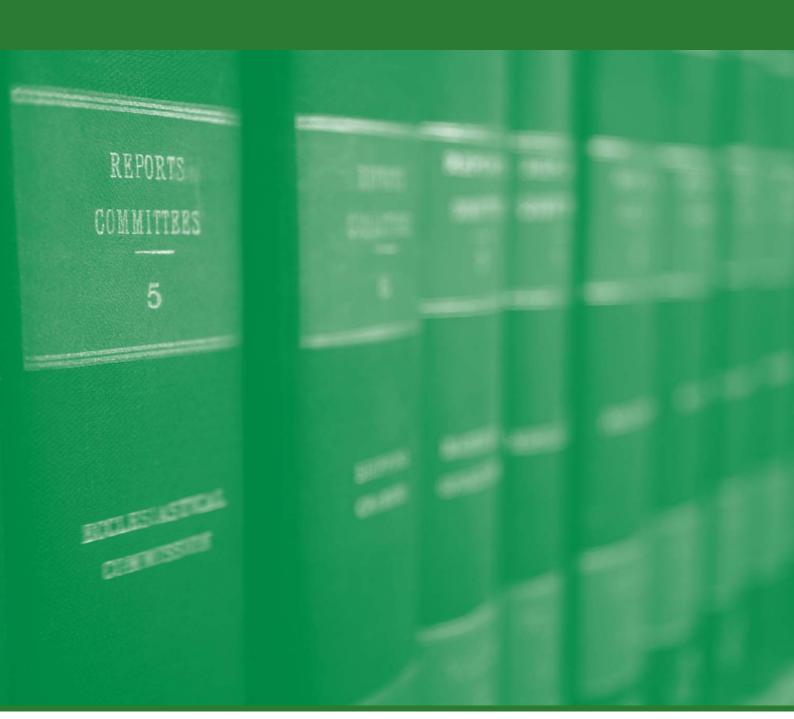


# **Committee on Law and Safety**

REPORT 1/55 - OCTOBER 2012

# INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS



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The motto of the coat of arms for the state of New South Wales is "Orta recens quam pura nites". It is written in Latin and means "newly risen, how brightly you shine".

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# Membership

CHAIR Mr John Barilaro MP, Member for Monaro

DEPUTY CHAIR Mr Jai Rowell MP, Member for Wollondilly

MEMBERS Mr Garry Edwards MP, Member for Swansea

Mr Nick Lalich MP, Member for Cabramatta Mr Guy Zangari MP, Member for Fairfield

Mr Jonathan O'Dea, Member for Davidson (from 23 February

2012 to 30 April 2012)

CONTACT DETAILS Legislative Assembly Committee on Law and Safety

Parliament House Macquarie Street Sydney NSW 2000

TELEPHONE (02) 9230 3054

FACSIMILE (02) 9230 3309

E-MAIL <u>lawsafety@parliament.nsw.gov.au</u>

URL <a href="http://www.parliament.nsw.gov.au/lawandsafety">http://www.parliament.nsw.gov.au/lawandsafety</a>

# **Terms of Reference**

That the Committee inquire into and report on whether there should be provision for the inclusion of donor details on the register of births maintained by the Registrar of Births, Deaths and Marriages.

# Chair's Foreword

The NSW Legislative Assembly Law and Safety Committee instigated this inquiry following a 2011 District Court judgment which resulted in a sperm donor's details being removed from the register of births.

The Judge had noted that, under the Family Law Act 1975, a donor conceived child that is born through artificial conception is not the legal child of the donor, and therefore the donor cannot be entered on the register of births. This led to the Judge having no other option but to accept that the donor's details should be removed from the register of births. The child's birth mother had been in a de facto relationship, and the Judge ruled that the de facto partner's details should be recorded on the register, as they were the child's legal parent.

Following public and media attention resulting from this judgment, the Committee determined that it would hold an inquiry into how donor information was recorded in New South Wales, as well as where these details should be kept. Submissions were called for and a number of witnesses attended hearings.

Throughout the inquiry it became evident that this issue was complex and that it required significant examination. The Committee struggled with a position due to either conflicting information, or the lack of information. At times the Committee also struggled with the intensely emotional and personal reflections we heard from inquiry participants.

While the Committee recognises that in the past, those that pursued donor conception arrangements either through registered clinics or through private arrangements did so on the basis of anonymity, recent legislative changes have ensured that donor conceived individuals have the ability to access information about their genetic parentage.

The Committee considers that donor conceived people have the prevailing right to know the identity of the person who contributed to their biological makeup. It is therefore important that information relating to donors is accessible and parents are encouraged to be honest with their children.

Members of the Committee favoured the principle that the rights of donor conceived people were of a greater value and paramount to that person's wellbeing in the future. It was evident that if a donor conceived person was told very early in life that they were donor conceived and that formed part of their life story, it would have positive outcomes. Unfortunately, we still live in an era of secrecy and awkwardness when it comes to this issue and thus many donor conceived people never find out, or find out later in life, with detrimental consequences.

A key issue raised during the inquiry is that donors, donor conceived people, and all those affected by donor conception should have access to comprehensive counselling and support services. The Committee has acknowledged this and we intend to further examine this issue as part of a broader review of the current system for managing donor conception information.

This inquiry also raised issues in relation to what information is recorded, how it is kept and how accessible it is to those seeking information in the future. The Committee acknowledges that this area is fragmented and more needs to be done for people who are affected by donor conception. Insufficient evidence throughout this inquiry prevented us from making a

recommendation to move the current donor information register, which is held by the Ministry of Health. We intend to examine this issue further as part of an inquiry into the management of donor conception information.

The Committee explored models for recording and accessing donor information in other states and jurisdictions and felt that the Victorian system, even though not perfect, was much more advanced than the NSW system. Under the Victorian system, donor conceived adults receive a separate page attached to their birth certificate, which alerts them to the existence of further information about their birth. They are then able to access information about their donor.

The Committee recognises that more needs to be done to ensure a consistent model for recording donor information in Australia. It is the Committee's desire to see a uniform system throughout Australia and we are keen to see this on the national agenda through the appropriate inter-governmental forums.

I would like to recognise the exceptional work of the Committee Secretariat, especially on such a complex and contentious issue. I would like to acknowledge the meticulous work performed by Carly Maxwell, Dora Oravecz, Clara Hawker and Jenny Whight. Their contribution to this report has been nothing less than exceptional.

I would also like to acknowledge my Committee colleagues, Jai Rowell MP, Garry Edwards MP, Guy Zangari MP and Nick Lalich MP for their enthusiasm, resolve and zeal on this Inquiry. Their counsel and support was invaluable. I know for all of us it has been an emotional and sobering experience.

I also would like to thank Jonathan O'Dea MP for filling in during a short term vacancy on the committee.

Although the terms of reference for this inquiry limited the scope of the Committee's recommendations, I believe our recommendations and findings are a step in the right direction. I look forward to embarking on a broader inquiry that addresses issues that we were unable to examine.

John Barilaro MP

Chair

# **Executive Summary**

#### Key issues and Inquiry outcomes

The key issues examined by the Committee during this inquiry were where donor information is stored and how it is accessed and recorded. Since 2010, a donor register has been maintained by the Ministry of Health, which contains information regarding clinical reproductive treatments involving sperm, egg, or embryo donors that resulted in a birth. For births prior to this date, which involved anonymous donors, a voluntary register was established. As donors are not legal parents, their details are not recorded on the births register maintained by the Registrar of Births, Deaths and Marriages.

Having received evidence from donor conceived people who were strongly in favour of including donor information in some form on birth documents, as well as evidence from individuals who thought that making such information available would breach privacy and create confusion about legal parents' rights and responsibilities, the Committee decided that donor information should not be included on the births register and birth certificates. The Committee considered that mandatory naming of donors on birth documents would not be an appropriate way to encourage parents to tell their donor conceived child the truth about their conception. The Committee was concerned that such a move would create confusion about the rights and responsibilities of parents and donors, and that it would be inconsistent with other jurisdictions.

The Committee has instead recommended that an addendum indicating that further information is available be attached to birth certificates that are issued to donor conceived adults. Details about the donor can then be sought by applying to the agency that manages the donor register. This model is based on Victoria's system and was widely supported by Inquiry participants as an appropriate way to encourage parental disclosure and access to information, while maintaining the privacy of donor conceived individuals.

Various options were proposed for operating a register of donor conception information, ranging from maintaining the existing register managed by the Ministry of Health; moving the register to the Registry of Births, Deaths and Marriages; or establishing an independent body to manage all aspects of maintaining such a register. After assessing the evidence, the Committee reached the view that it would be premature to alter the current system. The Committee heard evidence that the agency managing the donor register should perform more than a simple record keeping role, and should offer other relevant services to those affected by donor conception. The Committee will consider this proposal in greater detail in a subsequent inquiry.

A recurring theme identified by the Committee was the importance of parents telling their donor conceived children about the circumstances of their conception. The welfare of children is paramount and the Committee considers that parents can be supported in this process through the Government making appropriate support services available.

The details of participants in private donor conception arrangements are currently not recorded on the donor register, as they occur outside a clinical setting. The Committee is concerned that individuals conceived in these circumstances should not experience discrimination. The Committee has therefore recommended that the current system be

expanded to allow for the voluntary registration of donor details in relation to private arrangements, if the participants desire it.

#### **Future Inquiry**

Several issues emerged over the course of the inquiry, which, although outside the inquiry's terms of reference, are central to a discussion around donor conception information. Retrospective access to donor information, in relation to births occurring before 2010, was a key issue for those affected by donor conception. In considering such access, the need for the provision of other services such as counselling and support and public education became evident. The Committee found that these issues are significant and need to be examined in further detail before any recommendations for change can be made. These issues will be examined in detail by the Committee as part of an upcoming inquiry.

#### Report structure

**Chapter One** explains the background to how the inquiry was established, how it was conducted and the terms of reference that it was established under.

**Chapter Two** provides an overview of the current legislative framework in New South Wales with regard to how births are registered and the legal status of gamete donors.

**Chapter Three** compares the legislative provisions of different jurisdictions, both in Australia and overseas.

**Chapter Four** explores the viewpoints of contributors to the inquiry about whether or not donor details should be included on the births register or birth certificates, as well as options for annotating or amending birth certificates with donor conception information.

**Chapter Five** examines how donor information should be recorded and includes an outline of the current arrangements and a discussion about how such provisions could be applied to private donor conception arrangements.

**Chapter Six** outlines the evidence received around access to donor information, including the age at which such information should be accessed, issues concerning retrospective access, and the importance of having appropriate support measures, including counselling, in place.

# List of Findings and Recommendations

RECOMMENDATION 1	34
That the NSW Government work with state and territory governments to develop a national consistent system for the registration, management and release of information in relation to donor conception.	
RECOMMENDATION 2	56
That the Attorney-General introduce legislation to provide that, if a birth registration statement specifies that a child was donor conceived, the Registrar of Births, Deaths and Marriages is to note that the child was donor conceived in the entry about that child's birth of the register of births.	on
RECOMMENDATION 3	56
That the Registrar of Births, Deaths and Marriages is to issue an addendum on a separate paindicating that further information is available, when a donor conceived individual aged 18 o over applies for a birth certificate.	
RECOMMENDATION 4	56
That the Registry of Births, Deaths and Marriages and the Ministry of Health inform stakeholders of the changes to birth registration statements and birth certificates, through measures including agency websites and brochures.	
RECOMMENDATION 5	56
That gamete donors' details continue to be held on a separate donor register (the ART Centr Register), and not be included on the register of births or birth certificates.	al
FINDING 1	70
There was insufficient evidence for the Committee to recommend changes to the management of the ART Central Register. The management of the Register should be examined in the context of the support services that may be required by donor conceived individuals, donors and their families. The Committee will give further consideration to these issues as part of a future inquiry.	ž
In the interim the ART Central Register should continue to be managed by the Ministry of Health.	
RECOMMENDATION 6	_76
That the Minister of Health:	
a) Implement processes to enable participants in private donor conception arrangements t voluntarily register their details on the voluntary register;	to
b) Publicise information on voluntary registration of details of participants in private arrangements on the Ministry of Health website and through public awareness material such as information brochures.	ı
FINDING 2	81

of a future inquiry.

The provisions in the <i>Assisted Reproductive Technology Act 2007</i> for disclosure of information to adult offspring born as a result of treatment using donor gametes and in the case of children, to parents or an appropriate adult, are adequate and should be retained.
FINDING 3 90
The issue of granting donor conceived individuals retrospective access to information about their donor was not covered by the Terms of Reference for the Inquiry. The Committee is therefore unable to make any recommendation for change.
The Committee will undertake a future inquiry into matters raised during this Inquiry that were not encompassed by the Terms of Reference, including retrospective access to information.
FINDING 4 95
The provision of counselling and support services and public education in relation to donor conception are important issues that require further examination. These matters should be considered as part of a broader review of the current system for managing donor conception information, and access to this information. The Committee will examine these issues as part

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# Chapter One – Introduction

### TERMS OF REFERENCE

- 1.1 On 17 October 2011, the Committee resolved to inquire into and report on whether there should be provision for the inclusion of donor details on the register of births maintained by the Registrar of Births, Deaths and Marriages. The inquiry was self referred.
- 1.2 The terms of reference were as follows:

That the Committee inquire into and report on whether there should be provision for the inclusion of donor details on the register of births maintained by the Registrar of Births, Deaths and Marriages.

# BACKGROUND TO THE INQUIRY

## District Court judgment

- 1.3 The Committee's inquiry follows a recent District Court judgment to remove a sperm donor's details from the register of births. In August 2011, Judge Walmsley of the District Court handed down a judgment in relation to an application to register the plaintiff as a parent of a child. The plaintiff was the former partner of the birth mother. The child was born to a same-sex couple following artificial insemination using sperm donated by the defendant in the case. The sperm donor opposed the application, as it meant the removal of his name from the birth register. When the child's birth was registered the father's name was left blank, however the donor's name was later added to the birth register with the agreement of the couple.
- 1.4 The Judge referred to amendments to the Status of Children Act 1996 by the Miscellaneous Acts Amendment (Same Sex Relationships) Act 2008, which enabled two women who had had a child while in a relationship to have both of their names placed on the birth register as the child's parents, and noted that the amendment to the Act was retrospective.
- 1.5 In terms of the status of sperm donors, the Judge noted that section 60H(1)(d) of the Family Law Act 1975 (Cth) provides that if a child is born through artificial conception and the mother is in a de facto relationship with another person who has consented to the procedure, and the sperm donor also consents to the procedure, the child does not become the child of the donor. In considering the application, Judge Walmsley stated that:
  - ... I consider that I must accept Ms Graycar's submission that AA's name should be placed on the Register as a parent of AB and that BB's name and his other particulars which are on the Register should be removed from it. That is because, under the provisions of the Status of Children Act ... the rebuttable presumptions in BB's favour that he is a parent, are displaced by the irrebuttable presumption that because AB was conceived through a fertilisation procedure, he is presumed not to be her parent, whereas AA is presumed to be one of her parents. The plain words of the BDMA show that only two people may be shown on the Register as a child's parents.

No doubt a provision for registration of a third parent for a situation such as this one might be a neat answer to the problem this case presents. But there might be unexpected consequences, and it is not appropriate that I speculate about them: the issue was not explored before me. Nor could it have been, given the current requirement that only two people may be registered as parents. On this issue, BB referred me to and relied on a Canadian decision, A.A. v. B.B. (2007) 83 OR (3d) 561, which concerned an application for a declaration of parentage based on the parens patriae jurisdiction of a superior court. There the sperm donor father succeeded in obtaining a declaration that the child had three parents: the birth mother and her female partner and the donor. But the jurisdiction I am exercising is not the parens patriae jurisdiction.<sup>1</sup>

- The Judge found that: the plaintiff had been in a de facto relationship with the child's birth mother at the time of the child's birth; the child was conceived through a fertilisation procedure; and the defendant was the donor of the sperm used by the couple. The Judge concluded that, based on these findings and the reasoning quoted above, the plaintiff was entitled to the orders she sought, and ordered that the name of the defendant be removed from the birth register and that the plaintiff's name be added to the register.
- 1.7 As noted above, there is no provision for registering sperm, egg or embryo donor with the NSW Registrar of Births, Deaths and Marriages, as donors are not the legal parent of a child conceived through donor conception. However, donor information has been entered on a central assisted reproductive technology register kept by the Ministry of Health since January 2010. The ART Central register was set up to assist the exchange of information on donor conceived people, with donors and offspring having the opportunity to access information about each other.
- 1.8 The Committee determined that it would conduct an inquiry to examine whether the current system for recording donor information is adequate, and whether these details should be kept by the Registrar of Births, Deaths and Marriages.

### CONDUCT OF THE INQUIRY

#### Submissions

- 1.9 The Committee made a public call for submissions by advertising in the *Sydney Morning Herald* on 26 October 2011, with a closing date of 21 December 2011. A media release announcing the inquiry and calling for submissions was placed on the Committee website and distributed to media organisations in New South Wales. The Chair of the Committee wrote to key stakeholders inviting them to make a submission to the inquiry.
- 1.10 The Committee received 32 submissions from a broad cross section of the community including; donor conceived individuals, donors, academics, government departments, consumer advocacy groups and members of the legal and medical professions. A complete list of submission makers may be found in Appendix 1.

<sup>&</sup>lt;sup>1</sup> AA v Registrar of Births Deaths and Marriages and BB [2011] NSWDC 100 at 36, http://www.caselaw.nsw.gov.au/action/PJUDG?jgmtid=154026 accessed 22 September 2011

# Public hearings and briefing

- 1.11 Two public hearings were held at Parliament House on 1 March and 5 March 2012. Evidence was taken from 15 witnesses. A list of the witnesses who appeared before the Committee may be found in Appendix 2.
- 1.12 The transcripts of evidence from the hearing may be found at the Committee's website: <a href="http://www.parliament.nsw.gov.au/lawandsafety">http://www.parliament.nsw.gov.au/lawandsafety</a>.
- 1.13 The Committee held a private briefing with representatives from the Department of Attorney-General and Justice, the Registry of Births, Deaths and Marriages and the Ministry of Health. The Committee also met privately with a donor conceived individual. The Committee thanks the organisations and individuals who participated in the inquiry.

# Visit of inspection

- 1.14 On Monday, 27 August 2012 a delegation of Committee members travelled to Melbourne, Victoria, to meet with a range of stakeholders with responsibility for different elements of the assisted reproductive technology process in Victoria.
- 1.15 A report of the visit can be found at Appendix 3.

# Chapter Two – Current legislative framework

2.1 This chapter considers the origins of the practice of registering births and the current systems for registering births and for registering gamete donors in New South Wales.

## HISTORY OF BIRTH REGISTRATION

- 2.2 The practice of recording births, deaths and marriages had its origins in England in the 1500s. Registers were kept by the church, and recorded baptisms, marriages and burials. This practice was continued by the Church of England and other denominations in the early colony days of New South Wales. Records were kept of baptisms rather than births, if a child was not baptised it was possible that no record would exist of their birth.<sup>2</sup>
- 2.3 In New South Wales, the recording of births, deaths and marriages became a civil responsibility in 1856, with the commencement of the *Registration Act 1855*. The 'General Registry for New South Wales' was established, requiring the compulsory registration of all births, deaths and marriages.
- 2.4 The purposes of birth registration were both public and private:

Providing statistical data to government and the public, and authentic legal records for proving descent and identity. It is difficult to determine which purpose was dominant.<sup>3</sup>

2.5 Particulars entered in the register upon the birth of a child included:

Name

When and where born

Sex

Father – name and surname

Rank or profession

Age

Birthplace

When and where married Issue living and deceased

Mother – name and maiden surname

Age Birthplace

<sup>&</sup>lt;sup>2</sup> State Records NSW, 'Births, Deaths and Marriages: Historical Background of Early Records', <a href="https://www.records.nsw.gov.au/state-archives/research-topics/births-deaths-and-marriages/births-deaths-marriages#historical-background-of-early">https://www.records.nsw.gov.au/state-archives/research-topics/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriages/births-deaths-and-marriage

<sup>&</sup>lt;sup>3</sup> NSW Law Reform Commission, *Names: Registration and certification of births and death*, report 61, 1988 para 3.7

2.6 The basic principles of the *Registration Act 1855*, and the practices of registration to implement them, endured with only minor administrative changes until the 1970s with the commencement of the *Registration of Births, Deaths and Marriages Act 1973*. 4

### CURRENT FRAMEWORK FOR REGISTRATION OF BIRTHS

- 2.7 In New South Wales, all births are registered with the Registry of Births, Deaths and Marriages, under the *Births, Deaths and Marriages Registration Act 1995* and the Births, Deaths and Marriages Regulation 2011. The Registry is an agency of the Department of Attorney-General and Justice NSW.
- 2.8 Regulation 5 of the Births, Deaths and Marriages Regulation 2011 specifies the particulars that are to be entered on the Register of Births, Deaths and Marriages:
  - (a) the sex and date and place of birth of the child,
  - (b) the weight of the child at birth,
  - (c) whether or not the birth was a multiple birth,
  - (d) the full name (including, if applicable, the original surname), date of birth (or age), place of birth, occupation and usual place of residence (at the time of delivery) of each parent of the child,
  - (e) the date and place of marriage of the parents of the child (if applicable),
  - (f) the full name, sex and date of birth of any other children (including deceased children) of either of the parents of the child,
  - (g) whether or not either of the parents of the child is of Aboriginal or Torres Strait Islander origin,
  - (h) if either parent of the child was born outside Australia, the period of residence in Australia of that parent.
- 2.9 Upon receipt of this information, the Registrar makes an entry about the birth in the Register. If the particulars available to the Registrar are incomplete the Registrar may register the birth on the basis of incomplete particulars.<sup>5</sup>
- 2.10 The particulars that are entered on the Register of Births, Deaths and Marriages become part of the civil records of New South Wales and are a permanent historical record. However, these records are not available for public scrutiny. Only records of births that occurred more than one hundred years ago are freely available to anyone. 6
- 2.11 Birth certificates issued by the Registry are an official certified copy of the registration data held by the Registry, and are commonly used to establish a person's identity. The Registry holds more information than that which appears

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<sup>&</sup>lt;sup>4</sup> NSW Law Reform Commission, *Names: Registration and certification of births and death*, report 61, 1988 para 3.9

<sup>&</sup>lt;sup>5</sup> Births, Deaths and Marriages Registration Act 2005, section 17

<sup>&</sup>lt;sup>6</sup> NSW Registry of Births, Deaths and Marriages, <u>www.bdm.nsw.gov.au</u>

on a birth certificate. All birth certificates issued are for births or adoptions that occurred in New South Wales. Persons able to apply for a birth certificate include:

- the person named on the birth certificate
- a parent of the person named on the birth certificate
- · persons authorised in writing by the person named on the certificate
- a solicitor acting on behalf of the person named on the birth certificate
- a legal guardian of the person named on the birth certificate
- a person with power of attorney for the person named on the birth certificate.<sup>8</sup>

### BIRTH REGISTRATION AND DONOR CONCEPTION

- 2.12 At the time that the *Registration Act 1855* was passed, the only way of conceiving a child was by natural reproduction. Parents recorded in the register were assumed to be the biological and legal parents of the child.
- 2.13 The advent of assisted reproductive technology (ART) to conceive a child using donated gametes (that is ova, sperm or embryos) and the increasingly diverse forms of family mean that the legal parents of a child are not necessarily the biological parents.
- 2.14 In 1983, the Family Law Amendment Act no 72 (Cth) created the assumption that, for the increasing number of babies born each year as a result of using donated gametes, the woman who bore the child was legally recognised as the child's mother and her husband or de facto partner as the child's father creating a socially and legally recognised parent-child relationship between two adults and a child who may or may not have a biological relationship.
- 2.15 Section 60H of the Family Law Act 1975 Act provides that a child born as a result of an artificial conception procedure is the child of the woman who received the treatment, and of their de facto partner (or other intended parent), regardless of whether the child is their biological child. The person who provided genetic material is not a parent of the child. The donor and the recipients of the genetic material must have consented to the procedure.
- 2.16 The Status of Children Act 1996 brought NSW legislation into conformity with Commonwealth legislation regarding presumptions of parentage. The Attorney General, the Hon Jeff Shaw MLC, stated in his second reading speech that the purpose of the Bill was to improve the system for determining a child's parentage, including where a child was born as a result of a fertilisation procedure:

... by bringing provisions ... relating to parentage presumptions and parentage testing procedures into conformity with the Family Law Act 1975, by bringing those

<sup>&</sup>lt;sup>7</sup> Submission no 31, NSW Government

<sup>&</sup>lt;sup>8</sup> NSW Registry of Births, Deaths and Marriages, <u>www.bdm.nsw.gov.au</u>

# INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS CURRENT LEGISLATIVE FRAMEWORK

parentage presumptions which apply in relation to children born as a result of artificial conception procedures up to date with current medical technology ...

Where the child has been conceived as a result of sperm or ovum donation with the consent of a woman's husband or defacto spouse, the woman and her husband or defacto spouse are presumed conclusively to be the parents of that child. Presumptions made in this situation are irrebuttable - that is, they are not able to be refuted or disproved.<sup>9</sup>

- 2.17 Section 14(1) of the *Status of Children Act 1996* provides that a woman who becomes pregnant as the result of a fertilisation procedure and her husband are presumed to be the parents of the child regardless of whether it was their genetic material used or not. This also applies to women in same sex relationships, who are presumed to be the mother and parent of the chid. Husbands and de facto partners must have consented to the procedure in order to be presumed to be the child's parent.
- 2.18 In New South Wales the legal parents, rather than the biological parents, of a child are recorded in the Register of Births, Deaths and Marriages. A child may have only two legal parents. The legal parents of a child have certain rights and responsibilities for the child that biological parents do not necessarily have, including:
  - Provision of food, clothing, a home, financial support and protection from harm;
  - Power to make decisions and give consent in relation to a child's health, education and religion;
  - Entitlement to Paid Parental Leave and access to the Family Tax Benefit;
  - If parents separate, the parent who does not have primary custody has an obligation to make child support payments;
  - Upon the death of their parents, legal children have rights of inheritance on the estate.<sup>10</sup>
- 2.19 Section 18 of the *Births, Deaths and Marriages Registration Act 2005* governs the registration of parent details:

The Registrar must not include registrable information about the identity of a child's parent in the Register unless:

- (a) both parents of the child make a joint application for the inclusion of the information, or
- (b) one parent of the child makes an application for the inclusion of the information and the other parent cannot join in the application because he or she is dead or cannot be found, or for some other reason, or

<sup>&</sup>lt;sup>9</sup> The Hon JW Shaw MLC, Legislative Council Hansard, 29 May 1996, page 1641

<sup>&</sup>lt;sup>10</sup> Victorian Law Reform Commission, *Assisted Reproductive Technology and Adoption: Final Report*, February 2007, p 113

- (c) one parent of the child makes an application for the inclusion of the information and the Registrar is satisfied that the other parent does not dispute the correctness of that information, or
- (d) a court orders the inclusion of the information in the Register, or
- (e) a court makes a finding that a particular person is a parent of the child, or
- (f) the Registrar is entitled under any law (including a law of another State or the Commonwealth) to make a presumption as to the identity of the child's parent, or
- (g) the regulations authorise the Registrar to include the information.

#### Recent amendments

- The Miscellaneous Acts Amendment (Same Sex Relationships) Act 2008 amended the Births, Deaths and Marriages Registration Act 2005 and the Status of Children Act 1996 with the aim of ensuring that people in same sex relationships had the same rights and responsibilities as people in other relationships. The amendments enabled both same-sex parents of a child conceived as the result of a fertilisation procedure to be recorded as the legal parents in the Register of Births, Deaths and Marriages and noted on the birth certificate. Previously, only the birth mother could be registered.
- 2.21 Section 21 of the *Status of Children Act 1996* allows for a person to apply to the Supreme Court for a declaration of parentage if a parent/child relationship exists between themselves and a child. If a declaration of parentage is made, the declaration is to be immediately transmitted to the Registrar of Births, Deaths and Marriages to be dealt with under the *Births, Deaths and Marriages Registration Act 2005*.

### LEGAL STATUS OF GAMETE DONORS

- 2.22 Under both Commonwealth and New South Wales law, gamete donors are not legal parents of children conceived using their gametes. This is reflected in the Commonwealth *Family Law Act 1975* (see paragraph 1.15) and the *Status of Children Act 1996* (NSW).
- 2.23 Section 14 of the Status of Children Act 1996 reads:
  - (2) If a woman (whether married or unmarried) becomes pregnant by means of a fertilisation procedure using any sperm obtained from a man who is not her husband, that man is presumed not to be the father of any child born as a result of the pregnancy.
  - (3) 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.

### THE CENTRAL REGISTER

- 2.24 Prior to 1 January 2010 in New South Wales, there was no central system of registration for gamete donors and donors could remain anonymous.
- 2.25 Many donor conceived individuals could not identify their biological parent/s or biological siblings, leading to a lack of information about genetic heritage and background and, in some cases, 'genealogical bewilderment' a sense of lost identity and desire to know more about their donor. 11
- 2.26 The Assisted Reproductive Technology Act 2007 and the Assisted Reproductive Technology Regulation 2009 addressed this issue through the establishment of a Central Register, to reside with and be managed by, NSW Health.
- 2.27 The Central Register includes information about children conceived through:
  - Surrogacy arrangements
  - Conceptions involving donated gametes that take place in clinics run by registered ART providers.
- 2.28 People who do not use registered ART providers, but rather make private arrangements to use donor sperm, cannot record the event on the Central Register. Thus the donor details may not be recorded anywhere and children born as the result of private arrangements may not have access to information on their donor parent.
- 2.29 In the second reading speech on the Bill, the Hon Tony Kelly MLC outlined the principles of the bill:

The third and most important underlying principle in the bill is the recognition of the rights of the children born as a result of ART procedures and the importance of acting in their best interests.

A fundamental aspect of this right is the availability of and access to information about their biological parents and siblings.

... The ability of donor-conceived children to obtain information about their genetic background is a matter that is of vital importance to those children and in many cases their parents.

The registers both mandatory and voluntary will help those children to fill what many consider to be a major gap in their lives.

... This bill clarifies and protects the rights and obligations of people involved in ART treatment.

It provides a strong regulatory framework for the ethical and social issues raised by these technologies in a manner that is sensitive to and achieves an appropriate

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<sup>&</sup>lt;sup>11</sup> Submission 13, Dr Sonia Allan, p 18

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balance between the diverse needs of donor-conceived children, parents, donors and providers.  $^{12}$ 

- 2.30 Provision of information to the Central Register by ART providers is mandatory. The ART Act is not retrospective, only donations made after 1 January 2010 need to be disclosed to the Central Register. It is, however, possible for donor conceived people or donors who made donations prior to 1 January 2010 to place information on the Central Register voluntarily.
- 2.31 ART providers must collect and store information about both donors and recipients (women undergoing ART treatment) and provide this information to the Central Register following the birth of a child.
- 2.32 The Assisted Reproductive Technology Regulation 2009 specifies the particulars entered into the Central Register following the birth of a child using donated gametes.

### For donors of gametes:

- (a) the full name of the donor,
- (b) the residential address of the donor,
- (c) the date and place of birth of the donor,
- (d) the ethnicity and physical characteristics of the donor,
- (e) any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - (i) a person undergoing ART treatment involving the use of the donated gamete, or
  - (ii) any offspring born as a result of that treatment, or
  - (iii) any descendent of any such offspring,
- (f) the name of each ART provider who has previously obtained a donated gamete from the donor and the date on which the gamete was obtained,
- (g) the sex and year of birth of each offspring of the donor.
- (h) the gamete provider's consent.

#### For the birth

- (a) the full name, sex and date of birth of a child born as a result of ART treatment using donated gametes, and
- (b) the name of the woman who gave birth to the offspring, and
- (c) the full name and date and place of birth of the donor of the gamete.

 $<sup>^{12}</sup>$  The Hon Tony Kelly MLC, Legislative Council Hansard, 27 November 2007 p 4382

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2.33 From September 2010 to March 2012, 296 births were recorded in the Central Register, approximately 200 births each year. Nine donors and two donor conceived offspring had registered voluntarily. 13

# Access to information on the Central Register

2.34 The following people can access information on the Central Register: 14

Adult donor conceived individuals will have access to:

- (a) The full name of the donor,
- (b) The residential address of the donor,
- (c) The date and place of birth of the donor,
- (d) The ethnicity and physical characteristics of the donor,
- (e) Any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - i. A person undergoing ART treatment involving the use of the donated gamete, or
  - ii. Any offspring born as a result of that treatment, or
  - iii. Any descendent of any such offspring,
- (a) The name of the ART provider who provided the above information, and
- (b) The sex and year of birth of each other offspring of the donor,

Other adult offspring of a donor (not through donation) will have access to the sex and year of birth of each other offspring of the donor.

Parents of a child born through donation will have access to:

- (a) The ethnicity and physical characteristics of the donor,
- (b) Any medical history or genetic test results of the donor or the donor's family that are relevant to the future health of:
  - i. A person undergoing ART treatment involving the use of the donated gamete, or
  - ii. Any offspring born as a result of that treatment, or
  - iii. Any descendent of any such offspring,
- (c) Sex and year of birth of each other offspring of the donor

<u>The donor</u> will have access to the sex and year of birth of each offspring of the donor.

http://www.health.nsw.gov.au/resources/art/pdf/central\_art\_donor\_registe.pdf accessed 4 July 2012

<sup>&</sup>lt;sup>13</sup> Mr Greg McAllan, Associate Director, Legal and Regulatory Services, NSW Ministry of Health, Transcript of evidence, 1 March 2012, p.14

evidence, 1 March 2012, p 14

NSW Health, *The Central ART donor register*,

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The information on the Register will only reflect the circumstances of the donor, and any offspring of the donor, as at the time the donor donated his or her gametes, unless the donor or offspring provides updated information to the Register.

# Chapter Three – Other jurisdictions

In this chapter, the Committee outlines the framework operating in Australian and selected international jurisdictions with respect to donor conception, focussing on issues including regulation of donor identification, legal parentage and registers of donor details. The Committee also examines the national guidelines for the use of assisted reproductive technology as well as providing current statistics on the use of assisted reproduction in Australia and New Zealand.

## **AUSTRALIA**

- The Australian Institute of Health and Welfare describes assisted reproductive technology as 'a group of procedures that involves the in vitro (outside of body) handling of human oocytes (eggs) and sperm or embryos for the purposes of establishing a pregnancy', with an ART treatment cycle involving the fertilisation of a woman's eggs and transfer of one or more fresh embryos into the uterus in order for a pregnancy to occur. <sup>15</sup>
- Treatment can also be undertaken using donor eggs from a woman to create embryos for transfer to another (recipient) woman.
- 3.4 Other fertility treatments undertaken in Australia and New Zealand include artificial insemination, whereby sperm are placed into the female genital tract, either with controlled ovarian hyperstimulation or in a natural cycle. Artificial insemination can be undertaken using a partner's sperm or donated sperm. 16

# Egg and embryo donation

3.5 According to Australian Institute of Health and Welfare data, in 2009 egg and embryo donation and recipient cycles made up 4.1% (3,172) of all treatment cycles in Australia and New Zealand. 1,037 cycles were initiated with the aim of donating eggs: 901 cycles from Australia and 136 from New Zealand. 2,135 cycles were initiated for women with the aim of receiving donated eggs or embryos: 1,868 cycles in Australia and 267 cycles in New Zealand. It is relevant to note that an individual woman may undergo more than one treatment cycle in a year, or experience more than one pregnancy. There were 340 live births resulting from cycles using donated eggs and 36 from cycles using donated embryos. <sup>17</sup>

<sup>&</sup>lt;sup>15</sup> Australian Government, Australian Institute of Health and Welfare, *Assisted reproductive technology in Australia and New Zealand 2009*, Assisted reproductive technology series no 15, November 2011, Canberra, p 1

<sup>&</sup>lt;sup>16</sup> AIHW, Assisted reproductive technology in Australia and New Zealand 2009, November 2011, pp 1-2

<sup>&</sup>lt;sup>17</sup> AIHW, Assisted reproductive technology in Australia and New Zealand 2009, November 2011, pp 26-27. The AIHW defines a donation cycle as an ART treatment cycle in which a woman intends to donate, or donates her eggs to another woman. This may result in the donation of either eggs or embryos. A recipient cycle is defined as a treatment cycle where a woman receives eggs or embryos from another woman. The use of donor sperm does not change the donor status of the cycle.

# Donor sperm insemination

3.6 According to Australian Institute of Health and Welfare data, 2,556 donor sperm insemination cycles were reported by clinics in Australia and New Zealand in 2009, resulting in 349 clinical pregnancies and 272 live births. 18

# National framework for regulation of ART

- 3.7 There is no national legislation regulating ART in Australia as it is regulated at a state level. However there is a national framework consisting of the Fertility Society of Australia's Reproductive Technology Accreditation Committee Code of Practice which includes accreditation standards for clinics undertaking ART. The National Health and Medical Research Council (NHMRC) also provides ethical guidelines on the use of assisted reproductive technology in clinical practice and research.
- 3.8 Victoria, South Australia, New South Wales and Western Australia have introduced legislation to regulate ART. This reflects a trend towards statutory regulation of ART with a focus on the welfare of children born out of this practice rather than reliance on the national ethical guidelines, as noted by Western Australia's Reproductive Technology Council:

... a number of other States have made significant enactments. The developments ... continue a trend towards more prescriptive legislation rather than relying on NHMRC guidelines. The developments also reflect a shift towards more child-centred legislation. For example, ART legislation in South Australia will include a provision that the welfare of any child born through ART is of paramount importance and is the fundamental principle of the Act. The child focus is also apparent from the increased regulation of ART donor registers and the disclosure of information to gamete donors, donor offspring and the parents of donor offspring. <sup>19</sup>

Each of these pieces of legislation established a state regulatory body which issues licences to clinics that provide ART services. When there are anomalies between the state acts and the Code of Practice, the state acts have precedence. <sup>20</sup>

3.9 Where state legislation is in place, it overrides national regulations and guidelines (such as the NHMRC guidelines). There is no legislation regulating ART in Queensland, Tasmania, the ACT, or the Northern Territory. In these states the national regulatory framework applies.

#### National Health and Medical Research Council Guidelines

3.10 The National Health and Medical Research Council (NHMRC) is an independent statutory agency whose role includes fostering consideration of ethical issues

<sup>&</sup>lt;sup>18</sup> AIHW, *Assisted reproductive technology in Australia and New Zealand 2009*, November 2011, p 43. The data does not include insemination undertaken outside of the clinical setting.

<sup>&</sup>lt;sup>19</sup> Western Australian Reproductive Technology Council, *Annual Report 2009-2010*, p 29

<sup>&</sup>lt;sup>20</sup> National Health and Medical Research Council, 'Assisted Reproductive Technology', http://www.nhmrc.gov.au/health-ethics/australian-health-ethics-committee-ahec/assisted-reproductive-technology-art/assisted-accessed 14 December 2011

<sup>&</sup>lt;sup>21</sup> Fertility Society of Australia, Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, October 2010, p 6 <a href="http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf">http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf</a>

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relating to health. NHMRC guidelines are non-mandatory rules or principles developed to achieve best practice in specific fields. <sup>22</sup> The NHMRC updated its ethical guidelines in use of assisted reproductive technology in clinical practice and research in 2007. In outlining the ethical dimension and issues relevant to ART that were taken into account in preparing the guidelines, the guidelines state that 'AHEC has recognised that the welfare of people who may be born as a result of the use of ART is paramount. <sup>23</sup>

### Donation of gametes

- In terms of the donation of gametes, the guidelines state that ART clinics should uphold the right to knowledge of genetic parents and siblings. Specifically that:
  - Donors should understand and accept the biological connection they have with the donor conceived child, and that the child has a right to knowledge about them;
  - Recipients should be understand the biological connection they child has with the donor and be encouraged to tell their child of their origins;
  - Public forums be used to encourage donors who were previously anonymous to consider registering their details; and
  - That clinics should not use genetic material collected prior to the introduction of these guidelines without the consent of the donor.<sup>24</sup>

#### Entitlement to information

- The guidelines state that clinics should provide donor conceived persons with the following information about their donor on request, once the person has reached 18 or is sufficiently mature to understand the significance of the request:
  - all medical and family history information
  - identifying information about the gamete donor
  - the number and sex of persons conceived using gametes provided by the same gamete donor, the number of families involved, and any identifying information that these siblings have consented to being released.<sup>25</sup>
- 3.13 The information should be provided by a medical practitioner, or a health professional with appropriate qualifications.

<sup>&</sup>lt;sup>22</sup> National Health and Medical Research Council, 'How NHMRC develops its guidelines', <a href="http://www.nhmrc.gov.au/guidelines/how-nhmrc-develops-its-guidelines">http://www.nhmrc.gov.au/guidelines/how-nhmrc-develops-its-guidelines</a> accessed 14 December 2011

<sup>&</sup>lt;sup>23</sup> Australian Government, National Health and Medical Research Council, *Ethical guidelines in use of assisted reproductive technology in clinical practice and research*, June 2007, p 9 <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="http://www.nhmrc.gov.au/">nhmrc/publications/attachments/e78.pdf</a> accessed 10 January 2012. The NHMRC's Australian Health Ethics Committee (AHEC) develops its human research guidelines.

<sup>&</sup>lt;sup>24</sup> NHMRC, Ethical guidelines in use of assisted reproductive technology in clinical practice and research, June 2007, pp 25-26 <a href="http://www.nhmrc.gov.au/\_files\_nhmrc/publications/attachments/e78.pdf">http://www.nhmrc.gov.au/\_files\_nhmrc/publications/attachments/e78.pdf</a> accessed 10 January 2012

<sup>&</sup>lt;sup>25</sup> NHMRC, Ethical guidelines in use of assisted reproductive technology in clinical practice and research, June 2007, p 29 http://www.nhmrc.gov.au/ files nhmrc/publications/attachments/e78.pdf accessed 10 January 2012

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- The guidelines state that gamete donors are entitled to some information about the recipients of their gametes and the offspring born (in particular, to prepare them for future approaches by their genetic offspring) which may include non-identifying information about gamete recipients, including the number and sex of persons born.<sup>26</sup>
- 3.15 The guidelines state that the principles outlined above should also apply to the use of donated embryos.<sup>27</sup>
- 3.16 In terms of clinics' provision of professional counselling for participants in gamete or embryo donation, the guidelines note that discussion of the issues relating to donation should include 'the right of persons born to have identifying information about their genetic parents and information about the possibility that they will make contact in the future.<sup>128</sup>
- 3.17 The guidelines also contain requirements for obtaining informed consent from participants, including for the use of identifying information, and recommended record keeping practices to record and facilitate the exchange of information between donors, recipients and donor conceived persons. The following information should be collected from donors:
  - name, any previous name, date of birth and most recent address;
  - details of past medical history, family history, and any genetic test results that are relevant to the future health of the person conceived by gamete donation (or any subsequent offspring of that person) or the recipient of the donation; and
  - details of physical characteristics.<sup>29</sup>

# Reproductive Technology Accreditation Committee Code of Practice

- 3.18 ART clinics and providers in Australia must obtain accreditation by the Fertility Society of Australia's Reproductive Technology Accreditation Committee (RTAC). The RTAC produces a Code of Practice for ART, and compliance with the Code is compulsory for ART providers.<sup>30</sup> As part of the Code, providers are required to demonstrate that they have certain policies and processes in place including:
  - support of the offspring's right to know their genetic origins;
  - retaining records about donors and recipients;

<sup>&</sup>lt;sup>26</sup> NHMRC, Ethical guidelines in use of assisted reproductive technology in clinical practice and research, June 2007, p 29 <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="http://www.nhmrc.gov.au/">nhmrc/publications/attachments/e78.pdf</a> accessed 10 January 2012

<sup>&</sup>lt;sup>27</sup> NHMRC, Ethical guidelines in use of assisted reproductive technology in clinical practice and research, June 2007, p 33 <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="https://www.nhmrc.gov.au/">https://www.nhmrc.gov.au/</a> files <a href="https://www.nhmrc.gov.au/">nhmrc/publications/attachments/e78.pdf</a> accessed 10 January 2012

NHMRC, Ethical guidelines in use of assisted reproductive technology in clinical practice and research, June 2007, p 44 <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="https://www.nhmrc.gov.au/">nhmrc/publications/attachments/e78.pdf</a> accessed 10 January 2012

<sup>&</sup>lt;sup>29</sup> NHMRC, Ethical guidelines in use of assisted reproductive technology in clinical practice and research, June 2007, pp 44-45, 50-51 <a href="http://www.nhmrc.gov.au/files\_nhmrc/publications/attachments/e78.pdf">http://www.nhmrc.gov.au/files\_nhmrc/publications/attachments/e78.pdf</a> accessed 10 January 2012

<sup>&</sup>lt;sup>30</sup> Fertility Society of Australia, Reproductive Technology Accreditation Committee, *Code of practice for assisted reproductive technology units*, October 2010, p 4 <a href="http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf">http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf</a>

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- the organisation explains the provisions, responsibilities and obligations associated with linking between donors, recipients and offspring;
- the legislation defining the legal status of children born as a result of the procedure;
- the information that service providers collect and the extent to which that information may be disclosed to people born as a result of the donation; and
- the process for the disclosure of identifying information.<sup>31</sup>

## Senate inquiry into donor conception practices

- 3.19 The Senate's Legal and Constitutional Affairs References Committee conducted an inquiry into donor conception practices in Australia, which reported in February 2011. The relevant recommendations are summarised below.
- 3.20 <u>National legislation</u> that the Australian Government work to ensure that nationally consistent legislation relating to donor conception be developed as a matter of priority. The Committee recommended that the legislation include:
  - a prohibition on donor anonymity
  - a limit on the number of families a donor is able to assist
  - rights of access by donor conceived individuals to identifying and non identifying information about their donor and siblings
  - protection for the welfare and interests of donor conceived children.
- 3.21 National register that the Australian Government, through the Standing Committee of Attorneys General, establish a national register of donors and donor conceived individuals. This should include a clear articulation of the role of the body administering the register.
- 3.22 The Committee recommended that if a national donor conception register is not established, that each state and territory should establish their own centralised register in such a way that will ensure a consistent approach to the granting of access to information held on the registers.
- 3.23 <u>Principles for registers' operation</u> the following principles should be adhered to in developing any register:
  - donor conceived individuals should be able to access identifying information about their donor once they reach 18 years of age, or a younger age as agreed by all states and territories

<sup>&</sup>lt;sup>31</sup> Fertility Society of Australia, RTAC, *Code of practice for assisted reproductive technology units*, October 2010, Appendix 2, p 23-24 <a href="http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf">http://www.fertilitysociety.com.au/wp-content/uploads/201011201-final-rtac-cop.pdf</a>

- donors should be able to access identifying information about individuals conceived as a result of their donation only with the consent of the donor conceived person
- donor conceived individuals should be able to access identifying information about their siblings only with the consent of those siblings
- donors, donor conceived individuals and recipient parents, and close relatives of donors or donor conceived individuals, should be able to access non-identifying information about the donor or donor conceived person, as applicable (provided that where a donor conceived individual seeks information, the person is at least 16 years of age, or a younger age as agreed by all states and territories).
- 3.24 Retrospectivity if state and territory registers will not be retrospective, a national voluntary register or separate register in each state and territory should be established to allow donors who donated anonymously to agree to have their information recorded and disclosed to any individuals conceived as a result of their donation.
- 3.25 <u>Private arrangements</u> donors in private arrangements be encouraged to have their information recorded and disclosed to any individuals conceived as a result of their donation on a national voluntary register or separate register, if such registers are established in each state and territory.
- 3.26 <u>Voluntary registers</u> any voluntary registers include a DNA databank, to enable donors and donor conceived individuals to place their details on the register for possible matching, in circumstances where records relating to their identities have been destroyed.
- 3.27 <u>Publicity campaign</u> that the states and territories jointly fund a campaign to publicise the establishment of either a national voluntary register or separate voluntary registers in each state and territory.
- 3.28 Notation of birth certificates states and territories that have not already done so should notate birth certificates of donor conceived children so that when they apply for a birth certificate over the age of 18, they can be provided with additional information about their conception, if they choose. 32
- The Federal Government's response to the report was tabled in August 2012. In the response, the Government expressed support for protecting the interests of donor conceived individuals, while noting the Commonwealth's lack of power under the Constitution to enact legislation regulating donor conception practices. The Government referred to the role played by the NHMRC's ethical guidelines in helping to protect the interests of donors, donor recipients and donor conceived children, and noted that the guidelines were consistent with many of the Senate Committee's recommendations. The Government's response stated that the guidelines 'provide a nationally consistent basis upon which other States and Territories may wish to develop regulation in this area'. The Government also

<sup>&</sup>lt;sup>32</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, pp xi-xvii

referred to the development of the RTAC's national accreditation scheme, which requires compliance with the RTAC Code of Practice and the NHMRC's ethical guidelines.

3.30 The Government expressed support for nationally consistent legislation and stated that 'the Australian Government encourages States and Territories, who have not already done so, to implement a legislative framework that will mandate compliance with the established accreditation and regulatory scheme.<sup>133</sup>

# Standing Council on Law and Justice project

- 3.31 The Standing Council on Law and Justice (previously the Standing Committee of Attorneys-General) is undertaking a project in relation to a national model for the harmonisation of donor conception registers. The Council's website states that 'There is currently no national consistency in the regulatory framework for the registration and record-keeping practices relating to information about conception donors or the manner and form in which information is made available to donor conceived individuals.'
- 3.32 The relevant Ministers are working with Health and Community Services Ministers to develop a discussion paper on a national model.<sup>34</sup>

#### Victoria

### Regulation of assisted reproductive technology

- 3.33 The use of assisted reproductive technology in Victoria is governed by the Assisted Reproductive Treatment Act 2008 (Vic) (ART Act). This legislation implemented many of the recommendations made by the Victorian Law Reform Commission in its 2007 report on ART and adoption.
- 3.34 Victoria was the first Australian jurisdiction to introduce legislation for ART, and the first to establish a register containing information about people connected with donor conception births.
- 3.35 The purposes of the ART Act include: regulating the use of ART and artificial insemination (other than self-insemination); regulating access to information about treatment procedures covered by the Act; establishing the Victorian Assisted Reproductive Treatment Authority; and providing for the keeping of a Voluntary Register and a Central Register by the Registrar of Births, Deaths and Marriages.<sup>35</sup>
- 3.36 The guiding principles in the Act include that:

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<sup>&</sup>lt;sup>33</sup> Australian Government, *Government Response to the Senate Legal and Constitutional Affairs References Committee Report: Donor Conception Practices in Australia*, August 2012, <a href="http://www.aph.gov.au/Parliamentary Business/Committees/Senate Committees?url=legcon ctte/donor conception/Government Response/govt response.pdf">http://www.aph.gov.au/Parliamentary Business/Committees/Senate Committees?url=legcon ctte/donor conception/Government Response/govt response.pdf</a> accessed 10 September 2012

<sup>&</sup>lt;sup>34</sup> Standing Council on Law and Justice, Current projects and achievements <a href="http://www.scag.gov.au/lawlink/SCAG/II">http://www.scag.gov.au/lawlink/SCAG/II</a> scag.nsf/pages/scag achievements#Donor%20registers accessed 22 March 2012

<sup>35</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 1

- the welfare and interests of persons born or to be born as a result of treatment procedures are paramount;
- children born as the result of the use of donated gametes have a right to information about their genetic parents; ... <sup>36</sup>
- 3.37 In March 2012, Victorian's Law Reform Committee tabled a report on access by donor conceived people to information about donors. The Committee recommended changes to Victoria's system to improve access to information and support for donor conceived individuals. The recommendations included enabling retrospective access to donors' identifying details, returning responsibility for managing the donor registers to the Victorian Assisted Reproductive Treatment Authority (VARTA), and improved counselling and support services.

### Consent and disclosure of information

- 3.38 The ART Act contains eligibility and consent provisions, as well as specifying the information those involved in ART treatment must disclose and how that information is maintained and accessed. In terms of donors, the Act provides that they must specify the types of treatment procedures that their gametes or embryo may be used for, and the number of women who may receive such treatment. Donors must have received counselling before they provide consent. At the time they give consent, donors also provide the information that is required to be recorded in the registers created under the Act. <sup>37</sup>
- 3.39 The legislation stipulates that donors must be given written advice about their own and future children's rights under the Act and the nature of information stored on the Register. 38
- 3.40 Those receiving treatment must undergo counselling which must provide advice on the rights of the donor and the child as well as the recipients and the type of information stored on the Register. 39

### Registers of information

3.41 Under the Act, ART providers and doctors carrying out artificial insemination are required to keep registers containing information on donors of gametes and embryos that are kept or stored; destruction or disposal of gametes and embryos; women on whom treatment procedures are carried out; transfer of gametes and embryos between providers; treatment procedures carried out, including particulars of pregnancies, miscarriages and births. 40

<sup>&</sup>lt;sup>36</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 5

<sup>&</sup>lt;sup>37</sup> Assisted Reproductive Treatment Act 2008 (Vic) ss 16 to 21. Consent may be withdrawn at any time before a procedure is carried out. Consent lapses after 10 years, or any specified lesser period.

<sup>&</sup>lt;sup>38</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 19

<sup>&</sup>lt;sup>39</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 25

<sup>&</sup>lt;sup>40</sup> Assisted Reproductive Treatment Act 2008 (Vic) ss 49 and 50

- 3.42 Each financial year, ART providers and doctors must give the Registrar of Births, Deaths and Marriages specified information about births, pregnancies and treatments and procedures they carried out in the preceding year. 41
- 3.43 The Registrar keeps a Central Register, which contains the information given by ART providers; for each donor, the number of persons born as a result of a procedure or insemination using their gametes; and prescribed information. <sup>42</sup> The Register contains information about children born as a result of a treatment procedure; women who received a treatment procedure; and about sperm and egg donors (where applicable). Information on the register includes names and dates of birth, and further details such as a donor's physical attributes, for example hair and eye colour, blood group. <sup>43</sup>

### Access to information on registers

- 3.44 The Act provides for applications for disclosure of information recorded on the Central Register, which may be made by the donor, the donor conceived person or their descendent, or the parent of a donor conceived person.<sup>44</sup>
- 3.45 The Registrar must disclose identifying information to donor conceived persons if they are an adult, or in the case that they are a child, their parent or guardian has consented to the making of the application, or a counsellor has given them counselling and advised the Registrar in writing that they are sufficiently mature to understand the consequences of the disclosure.
- In addition, applicants must have been conceived using gametes donated after 31 December 1997; or for those conceived using gametes donated between 1 July 1988 and 31 December 1997, the donor has given consent to the disclosure.<sup>45</sup>
- 3.47 The Registrar may only disclosure identifying information to an applicant if they are satisfied the person has received counselling about the possible consequences of the disclosure. In terms of non-identifying information, applicants must have been offered counselling by the Registrar. The Registrar is also required to make all reasonable efforts to give notice of an intended disclosure of identifying information, to the person to whom the information relates. 46
- The Registrar must also keep a separate, Voluntary Register containing information on donors and persons born out of donor treatment procedures. The Register contains the names and addresses of persons who have requested this information to be entered on the Register. They may also indicate their wishes in relation to obtaining information about another person on the Register, and the release of information about them to another person on the Register. The

<sup>&</sup>lt;sup>41</sup> Assisted Reproductive Treatment Act 2008 (Vic) ss 51 and 52

<sup>&</sup>lt;sup>42</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 53

<sup>&</sup>lt;sup>43</sup> Births, Deaths, Marriages Victoria, 'ART FAQs' <a href="http://online.justice.vic.gov.au/CA2574F700805DE7/page/Births-Births+FAQs-ART+FAQs-QpenDocument&1=10-Births-&2=70-Births+FAQs-&3=10-ART+FAQs-" accessed 8 December 2011 and Assisted Reproductive Treatment Regulations 2009 (Vic) Sch 5

<sup>&</sup>lt;sup>44</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 56

<sup>&</sup>lt;sup>45</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 59

<sup>&</sup>lt;sup>46</sup> Assisted Reproductive Treatment Act 2008 (Vic) ss 61, 62

Registrar may only disclose information about a person from the Register if it is in accordance with the person's wishes. Identifying information may be released to a person only if the Registrar is satisfied they have received counselling about the potential consequences of the disclosure. In the case of non-identifying information, the Registrar must have offered the person counselling.<sup>47</sup>

### Role of Registrar of Births, Deaths and Marriages

- 3.49 The *Births, Deaths and Marriages Act 1996* (BDM Act) provides that the general functions of the Registrar include performing functions given to the Registrar by the ART Act. 48
- 3.50 The ART Act amended the BDM Act to transfer responsibility for the Central and Voluntary Registers from the Infertility Treatment Authority to the Registrar of Births, Deaths and Marriages. In the second reading speech on the Bill, the Minister for Health outlined the reasons for transferring the registers:

The VLRC [Victorian Law Reform Commission] recommended moving the management of the central and voluntary registers to a service with specialist expertise in information management. This bill provides that the registrar of births, deaths and marriages will be responsible for these registers. Counselling associated with applications to the registers will be provided by Adoption Family Records Services or by ART clinic counsellors. This expands the number of counsellors available to provide the counselling, thus providing greater choice and access.

The movement of responsibility for the registers to the registrar of births, deaths and marriages is consistent with government policy of, wherever possible, centralising records that relate to parentage with one agency. The registry has extensive expertise in data collection and records management. In this way, any person seeking information about their identity will approach births, deaths and marriages thus normalising the process for donor-conceived persons and separating their genetic identity from the treatments received by their parents. <sup>49</sup>

#### Birth certificates

- 3.51 Under section 17(2) of the *BDM Act*, birth certificates issued when donor conceived persons born from 2010 reach adulthood will indicate that further information is available about their birth through an addendum that is attached to the certificate.
- 3.52 This provision in relation to birth certificates was among the amendments contained in the 2008 ART Act. In the second reading speech on the Bill the Minister for Health made the following comments on recording donor details on birth certificates, which focussed on the privacy rights of donor conceived children:

The information in relation to donor conception will not be recorded on the birth certificate and there is no mandatory requirement on parents to tell donor-conceived children of the manner in which they were conceived. On the one hand, recording such information on the birth certificate would interfere with privacy

<sup>&</sup>lt;sup>47</sup> Assisted Reproductive Treatment Act 2008 (Vic) s 71 to 73

<sup>&</sup>lt;sup>48</sup> Births, Deaths and Marriages Registration Act 1996 (Vic) s 6(bb)

<sup>&</sup>lt;sup>49</sup> Parliament of Victoria, Legislative Assembly Hansard, Wednesday, 10 September 2008, p 3454

# INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS OTHER JURISDICTIONS

rights because it would involve public disclosure of personal information. On the other hand, it may be argued to be a reasonable interference as it gives effect to a child's right to access information about their identity-genetic information.

While there is no requirement to tell a child they are donor conceived, where the donation was made after 1 January 1998, once the child turns 18 it is possible for Victorian Assisted Reproductive Treatment Authority (VARTA) to write directly to the child at a donor's request and advise that the donor wishes to make contact. This provides a strong incentive for parents to tell a donor-conceived child about the manner in which they were conceived. In addition, VARTA provides significant support and encouragement for parents to tell, through the 'Time to tell' campaign.

Placing such information in a public document such as a birth certificate is a significant interference with the right to privacy and does not have the same protections for ensuring that children have access to such information only when they are sufficiently mature to deal with it. In the circumstances, it is considered that it is not appropriate to record such information on a birth certificate or mandate telling children of the manner of their conception. This is better achieved through non-legislative means. <sup>50</sup>

3.53 The addendum can only be issued to the person conceived by a donor treatment procedure that is named in the entry on the births register.

### Western Australia

### Regulation of assisted reproductive technology

The *Human Reproductive Technology Act 1991* (HRT Act) governs artificial conception procedures in Western Australia. The Act regulates the use of treatments and research involving the creation and storage of embryos, as well as the storage of donated eggs and sperm. It also establishes a licensing system and obligations for practitioners who undertake reproductive technology procedures, and provides for the establishment of the Reproductive Technology Council. The Commissioner issues Directions that set standards of practice under the Act, based on the Council's advice. The Directions cover matters including: record keeping and reporting; consent requirements; information; storage and use of gametes and embryos; eligibility and assessment; and assistance with decision making and counselling. <sup>51</sup>

### Consent and disclosure of information

3.55 The Directions state that information must be given to participants before they give effective consent for the use or donation of reproductive material, including on: the effect of the *Artificial Conception Act 1985*; information that is included on registers in relation to the donated material, its use and the biological parentage of any child born as a result of the use; and rights of donors,

<sup>&</sup>lt;sup>50</sup> Parliament of Victoria, Legislative Assembly Hansard, Wednesday, 10 September 2008, p 3439

<sup>&</sup>lt;sup>51</sup> Western Australian Government Gazette, No 201, 30 November 2004, *Human Reproductive Technology Act 1991* Directions, p 5422,

http://www.slp.wa.gov.au/gazette/GAZETTE.NSF/gazlist/28FA432BECED857B48256F58002444B8/\$file/gg201.pdf accessed 12 December 2011

participants and children born as a result of the donation to access identifying and non-identifying information in accordance with the Act. 52

- 3.56 The HRT Act contains provisions for the registration of information on participants in donor conception. It requires licensed providers of artificial fertilisation procedures to keep records including: the identity and consent details of gamete, egg and embryo donors; collection and storage details; and recipient details. In terms of fertilisation procedures undertaken, record keeping requirements under the Act include: the identity and consent details of each participant; the nature and outcomes of the procedures; and identifying details of any children born as a result of the procedure.<sup>53</sup>
- 3.57 The Department of Health is required to keep a register containing information provided by licensed providers of artificial fertilisation, including:
  - (i) the identity of participants;
  - (ii) the outcome of procedures, showing the genetic origin of the human gametes, human egg undergoing fertilisation or human embryo used;
  - (iii) the identity of children born as a result of an artificial fertilisation procedure, including the identity of each biological parent; and
  - (iv) such relevant demographic and clinical information,

as may have been required to be supplied under this Act;  $\dots$  54

### Reproductive Technology Register

3.58 The Reproductive Technology Register was set up in 1993. According to the WA Reproductive Technology Council, the Register:

... allows ongoing monitoring of ART practices, provides a significant data resource for epidemiological research in ART in WA and also ensures that information relating to the identity and outcomes of ART treatment cycles are recorded in a central and secure location. This is of particular importance when ART treatments have involved the use of donated reproductive material, as the RT Register provides a record of identifying information relating to donation and birth outcomes that have resulted from those donations (though it should be noted that licensees must also indefinitely retain the original records). <sup>55</sup>

3.59 Participants in HRT procedures have been entitled to access identifying information obtained under the HRT Act since 2004. Frior to this date, participants' access was limited to non-identifying information.

http://www.slp.wa.gov.au/gazette/GAZETTE.NSF/gazlist/28FA432BECED857B48256F58002444B8/\$file/gg201.pdf accessed 12 December 2011

<sup>&</sup>lt;sup>52</sup> Western Australian Government Gazette, No 201, 30 November 2004, *Human Reproductive Technology Act 1991* Directions, p 5430,

<sup>&</sup>lt;sup>53</sup> Human Reproductive Technology Act 1991 (WA) s 44

<sup>&</sup>lt;sup>54</sup> Human Reproductive Technology Act 1991 (WA) s 45

<sup>&</sup>lt;sup>55</sup> Western Australian Reproductive Technology Council, *Annual Report 2009-2010*, p 25

<sup>&</sup>lt;sup>56</sup> Human Reproductive Technology Act 1991 (WA) s 49(2)(d)

- 3.60 A Legislative Assembly Select Committee inquiry into the HRT Act recommended making donor identifying information available on request to donor offspring when they reach 16 years of age and amendments to the legislation in 2004 provided for this, on condition that the donor conceived person received counselling.<sup>57</sup> The amendments were not retrospective and did not apply to donations made without consent being given for identifying information to be provided.<sup>58</sup>.
- 3.61 In addition, the 2004 amendments enabled sharing of identifying information where children are under 16 years, with both parental and donor consent. <sup>59</sup> Information sharing is also conditional on counselling approved by the Director General of the Department of Health, which addresses the best interests of the child. <sup>60</sup>

### Voluntary Register

- The WA Department of Health also maintains a Voluntary Register for donor conceived adults, recipients, and donors who want to access their donor and/or recipient information. This includes people born from donor assisted conception before 2004, when there was no provision for accessing information identifying a donor. Non-identifying information may be provided, and identifying donor information may be given to a donor conceived person who is over 18 years of age. Information is only released subject to consent and after professional counselling. <sup>61</sup>
- 3.63 The Voluntary Register was a recommendation of the Select Committee, which considered that although identifying information should not be accessible retrospectively, 'a compromise was required and ... a retrospective voluntary register [should] be established based on the mutual consent between donor and offspring and that donors are to be encouraged to place their names on the register.<sup>162</sup>
- 3.64 Donor participants lodging an application with the Voluntary Register have a number of options: to register their name; access non-identifying information; access identifying information (with written consent); seek information about the existence of half-siblings; and notification of serious hereditary medical conditions. They may also indicate their wishes in relation to information sharing. Links between participants can be made based on the information received, with

<sup>&</sup>lt;sup>57</sup> Legislative Assembly of Western Australia, *Select Committee on the Human Reproductive Technology Act 1991*, Report, April 1999, p 197

Western Australia Department of Health, Reproductive Technology Council, *Questions and answers about the donation of human reproductive material*, 2011, pp 24-25 <a href="http://www.rtc.org.au/publications/docs/Q&A.pdf">http://www.rtc.org.au/publications/docs/Q&A.pdf</a> accessed 13 December 2011 and *Human Reproductive Technology Act 1991* (WA) ss 46, 49(2e)

<sup>&</sup>lt;sup>59</sup> Human Reproductive Technology Act 1991 (WA) s 49(2a) (2d)

<sup>&</sup>lt;sup>60</sup> Western Australia Department of Health, RTC, *Questions and answers about the donation of human reproductive material*, 2011, p 25 http://www.rtc.org.au/publications/docs/Q&A.pdf accessed 13 December 2011

<sup>&</sup>lt;sup>61</sup> Western Australian Reproductive Technology Council, *Annual Report 2010-11*, p 20

<sup>&</sup>lt;sup>62</sup> Legislative Assembly of Western Australia, *Select Committee on the Human Reproductive Technology Act 1991*, Report, April 1999, p 202

identifying details only being released to a participant with the relevant person's written consent. 63

3.65 The WA Reproductive Technology Council's 2010-11 Annual Report states that since 2002, a total of 154 Voluntary Register applications have been made: 16 applications having been received from donor conceived adults, 82 from recipients and 56 from donors. The following table shows matches and contact made through the WA Voluntary Register:

Table: Matches from Western Australia's Voluntary Register<sup>64</sup>

Donor participants	Matched	Made contact
Parent recipient and donor	6	4
Half siblings	7	3
Total	13	7

#### Birth certificates

3.66 The WA Department of Health's submission to this inquiry stated that birth certificates do not indicate the use of donor conception, nor do they include the donor's name:

There is no requirement to state the method of conception on the birth certificate of the child. In the eyes of the law, the recipient(s) has the rights and duties of responsibility as if the child was their natural child. ... a sperm or ova donor, or embryo donors, including a known donor, has/have no parental rights or responsibilities in respect of a resulting child.

Accordingly, it is not the practice in WA to have a donor of reproductive material named on the birth certificate of a child born from use of the donor material.<sup>65</sup>

### South Australia

#### Regulation of assisted reproductive technology

- 3.67 Assisted reproductive treatment in South Australia is regulated by the Assisted Reproductive Treatment Act 1988 (ART Act), which provides for the registration and record keeping requirements applying to providers of assisted reproductive treatment. The Act states that: 'The welfare of any child to be born as a consequence of the provision of assisted reproductive treatment in accordance with this Act must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of this Act.<sup>166</sup>
- 3.68 The confidentiality provisions of the Act provide that the identity of a donor of human reproductive material must not be disclosed, except as required or

<sup>&</sup>lt;sup>63</sup> Western Australian Reproductive Technology Council, *Annual Report 2010-2011*, p 20

<sup>&</sup>lt;sup>64</sup> Western Australian Reproductive Technology Council, *Annual Report 2010-2011*, pp 20-21

<sup>&</sup>lt;sup>65</sup> Submission 30, WA Department of Health, p 3

<sup>&</sup>lt;sup>66</sup> Assisted Reproductive Treatment Act 1988 (SA), s 4A

- authorised under the Act; or in order to provide ART treatment; or with the consent of the donor. <sup>67</sup>
- 3.69 One of the conditions of registration that South Australian providers must meet is compliance with the NHMRC's ethical guidelines on the use of ART. The guidelines specify that suitable records must be kept to ensure donor conceived children can access information about their genetic heritage.<sup>68</sup>

### Donor conception register

- 3.70 Under the ART Act, the Minister for Health may keep a donor conception register, which is required to contain the following details for each donor:
  - (a) the donor's full name and nominated contact address; and
  - (b) the full name and nominated contact address of the person to whom assisted reproductive treatment using the donor's human reproductive material was provided; and
  - (c) the full name of any child born as a consequence of such assisted reproductive treatment (if known); and
  - (d) any other information required by the regulations, and may include any other information that the Minister thinks fit.  $^{69}$
- 3.71 The provisions in relation to the donor conception register do not apply to ART treatment that was provided before the commencement of the section. 70
- 3.72 A donor conception register has not yet been established under this legislation.

#### Parentage of donor conceived children

- 3.73 Both Victoria and South Australia have enacted retrospective legislation which ensures the rights of single women, women with male partners, and women with female partners to be recognised as legal parents for children born as a result of a fertilisation procedure.
- 3.74 Western Australian legislation also presumes the woman and her partner, either male or female, to be the legal parents of a child born through ART.
- 3.75 In addition to defining the legal parents, legislation in all three states also explicitly extinguishes any parental rights or responsibilities on the part of the egg or sperm donor.

<sup>&</sup>lt;sup>67</sup> Assisted Reproductive Treatment Act 1988 (SA), s 18

<sup>&</sup>lt;sup>68</sup> Assisted Reproductive Treatment Regulations 2010 r 8 and South Australia Department of Health, *Fact sheet 3:* Assisted insemination, the law and you,

http://www.sahealth.sa.gov.au/wps/wcm/connect/6c9cad8043a63c5ba6b4eeed1a914d95/ART+FS3-Approval+for+Al-sahealth-2011.pdf?MOD=AJPERES&CACHEID=6c9cad8043a63c5ba6b4eeed1a914d95 accessed 19 December 2011

 $<sup>^{69}</sup>$  Assisted Reproductive Treatment Act 1988 (SA), s 15

<sup>&</sup>lt;sup>70</sup> The section was inserted by the *Reproductive Technology (Clinical Practices) (Miscellaneous) Amendment Act 2009*, which commenced on 1 September 2010.

#### **NEW ZEALAND**

3.76 The *Human Assisted Reproductive Technology Act 2004* (HART Act) regulates ART in New Zealand. Its purposes include providing framework to regulate and guide the performance of assisted reproductive procedures and research; prohibiting unacceptable procedures and research; prohibiting certain commercial transactions relating to human reproduction; and establishing 'a comprehensive information-keeping regime to ensure that people born from donated embryos or donated cells can find out about their genetic origins.' The Act outlines certain principles to be followed by persons in performing functions under the Act, including that 'donor offspring should be made aware of their genetic origins and be able to access information about those origins.'<sup>71</sup>

### **Human Assisted Reproductive Technology Register**

- 3.77 The HART Act requires the Registrar of Births, Deaths and Marriages to maintain information on donors and donor offspring. The Human Assisted Reproductive Technology (HART) Register has been in operation since August 2005. It contains information on egg, sperm and embryo donors, donor offspring and their guardians involved in fertility treatment using donor gametes or embryos. The information held by Births, Deaths and Marriages about donors may include their personal details, family history, ethnicity and cultural affiliation as well as Māori affiliations, if applicable.
- 3.78 Placing information on the register does not result in any change to the details on a person's birth certificate.<sup>72</sup>
- 3.79 For donations made before August 2005 registration is voluntary, with information provided to Births, Deaths and Marriages on a voluntary basis by donors and donor offspring. Registration of information in relation to donations after August 2005 that result in a birth is mandatory. Fertility clinics must provide the required details to Births, Deaths and Marriages to register the birth of donor offspring after this date.
- 3.80 Fertility clinics initially provide Births, Deaths and Marriages with the donor's name, address and date and place of birth; the offspring's name, gender and date and place of birth; and the guardian's name and address. However clinics also hold more detailed information about donors, offspring and guardians, which they provide to Births, Deaths and Marriages after 50 years have passed.
- 3.81 Donor offspring can provide their details to Births, Deaths and Marriages for inclusion on the register once they turn 18, or if they are 16 or 17 and have obtained the Family Court's approval. In addition, guardians of donor offspring under 18 can provide their details for inclusion on the register.

<sup>&</sup>lt;sup>71</sup> Human Assisted Reproductive Technology Act 2004 (NZ) ss 3(f), 4(e)

<sup>&</sup>lt;sup>72</sup> Human Assisted Reproductive Technology Act 2004 (NZ) Part 3 and New Zealand Department of Internal Affairs, 'Human Assisted Reproductive Technology (HART) Register',

http://www.dia.govt.nz/diawebsite.nsf/wpg\_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument accessed 18 January 2012

#### Accessing information on the register

- 3.82 In terms of accessing the information, only people named on the register can obtain any information held on the register. Donor offspring can access information once they turn 18, or if they are 16 or 17 and have obtained the Family Court's approval. Guardians can obtain information on behalf of donor offspring under 18.
- 3.83 Donors and offspring born as a result of donations made before August 2005 who voluntarily register their details can place restrictions on the release of their information. For donations after this date that result in a birth, identifying information about donor offspring cannot be released to a donor or other donor offspring without the donor offspring's consent. However, donors cannot restrict the release of identifying information about them to donor offspring. They are notified when information about them is accessed.
- 3.84 In terms of matching donors and offspring, for births occurring after August 2005 donors and offspring can be linked based on the information provided by clinics. For donations made before this date, matching depends on the information available to Births, Deaths and Marriages for donations where both parties have registered voluntarily. Where a match is made, all parties are advised in writing and may apply to obtain information from Births, Deaths and Marriages, or a clinic.<sup>73</sup>
- 3.85 The Births, Deaths and Marriages website notes that counselling is recommended for people accessing donor conception information. The Registry does not fund the cost of counselling and DNA testing that may be sought by people accessing donor information.<sup>74</sup>

### Parentage of donor conceived children

- 3.86 Parentage provisions for children born out of ART procedures are contained in the *Status of Children Act 1969*. The Act provides that a woman who becomes pregnant through ART, as a result of using an ovum donated by another woman, is the mother of any child born of the pregnancy. A non-donor partner is a parent of any child of a pregnancy where a partnered woman becomes pregnant through ART using donor semen or donor ovum not from her partner.<sup>75</sup>
- 3.87 The Act also contains provisions extinguishing donors' parentage.<sup>76</sup>

<sup>&</sup>lt;sup>73</sup> New Zealand Department of Internal Affairs, 'Human Assisted Reproductive Technology (HART) Register', <a href="http://www.dia.govt.nz/diawebsite.nsf/wpg\_url/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument">http://www.dia.govt.nz/diawebsite.nsf/wpg\_url/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument</a> accessed 18 January 2012 and New Zealand Department of Internal Affairs, 'What is the HART Register?',

http://www.dia.govt.nz/pubforms.nsf/URL/HARTbrochure.pdf/\$file/HARTbrochure.pdf accessed 18 January 2012

<sup>&</sup>lt;sup>74</sup> New Zealand Department of Internal Affairs, 'Human Assisted Reproductive Technology (HART) Register', <a href="http://www.dia.govt.nz/diawebsite.nsf/wpg\_url/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register?OpenDocument#seven accessed 22 March 2012</a>

<sup>&</sup>lt;sup>75</sup> Status of Children Act 1969 (NZ) ss 17, 18

<sup>&</sup>lt;sup>76</sup> Status of Children Act 1969 (NZ) ss 19, 20, 21, 22

#### **UNITED KINGDOM**

- 3.88 In the UK, approximately 2,000 children have been born each year after treatment using donated eggs, sperm or embryos since 1991. In 2010, 1,985 women had donor insemination treatment. These women had 3,878 cycles of treatment, an increase of 0.8% compared with the previous year.<sup>77</sup>
- The *Human Fertilisation and Embryology Act 2008* regulates assisted reproduction in the United Kingdom. The Act established the Human Fertilisation and Embryology Authority (HFEA) as the regulator of treatment using eggs and sperm, and treatment and research involving embryos. The Authority sets standards and issues licences to fertility centres, and monitors their operations. It also holds information about fertility treatments in the UK.<sup>78</sup>

## Human Fertilisation and Embryology Authority Register

- 3.90 The Human Fertilisation and Embryology Authority Register has been in operation since 1991. It contains the details of regulated fertility treatments occurring since that date, including the children born as a result of treatment and information about donors where donated gametes were used as part of the treatment. Clinics provide required information to the HFEA about fertility treatments they provide and the outcomes of the treatment.<sup>79</sup>
- 3.91 Information recorded on the register includes a physical description of the donor, their ethnicity as well as any further information they provided, such as their occupation. For donors who donated after April 2005, when anonymity ceased, their name and address is also recorded on the register. Donors who donated before April 2005 can elect to voluntarily remove their anonymity by reregistering with HFEA. They then become an identifiable donor. 80
- 3.92 From July 2004 the HFEA collected the following information about donors, and made it available to donor conceived individuals:
  - the donor's parents' ethnic group
  - whether they were adopted
  - their marital status
  - how many children they already had and the children's gender (if applicable)
  - details of donor screening tests and medical history
  - a goodwill message

<sup>&</sup>lt;sup>77</sup> United Kingdom Human Fertilisation and Embryology Authority (HFEA), Donor conception – births, <a href="http://www.hfea.gov.uk/donor-conception-births.html">http://www.hfea.gov.uk/donor-conception-births.html</a> and Latest UK donor insemination figures – 2009 and 2010, <a href="http://www.hfea.gov.uk/1270.html">http://www.hfea.gov.uk/1270.html</a> accessed 19 January 2012

<sup>78</sup> HFEA, What we do, http://www.hfea.gov.uk/133.html accessed 19 January 2012

<sup>&</sup>lt;sup>79</sup> HFEA, Our role as an improved information provider, <a href="http://www.hfea.gov.uk/5443.html">http://www.hfea.gov.uk/5443.html</a> accessed 19 January 2012

<sup>&</sup>lt;sup>80</sup> HFEA, Can you be anonymous as a sperm, egg or embryo donor, <a href="http://www.hfea.gov.uk/1973.html">http://www.hfea.gov.uk/1973.html</a> accessed 22 March 2012 and Summary of access rights, <a href="http://www.hfea.gov.uk/docs/Summary">http://www.hfea.gov.uk/docs/Summary</a> of Access Rights.pdf

• a description of themselves as a person. 81

### Accessing information

- 3.93 Individuals born after 1991 may contact HFEA to find out if they are donor conceived. For donations made after April 2005 (or where the donor has removed their anonymity), donor conceived children are able to access information about the identity of their donor when they reach 18. For donations that occurred under condition of anonymity, donor conceived individuals who are 18 may access anonymous information about their donor. The HFEA can only comply with a request for information from a donor conceived individual if the applicant has been provided with an opportunity for proper counselling about the implications of their request.
- 3.94 From 2009, information access was widened to enable 16 year old donor conceived individuals to access non-identifying information about both their donor and donor conceived genetic siblings, and 18 year old donor conceived individuals were able to access identifying information about donor conceived genetic siblings, if both parties consented. In addition, people intending to marry or enter a civil partnership could jointly apply to the HFEA to establish whether they were genetically related.
- 3.95 Donor conceived individuals who want to share or receive contact details of their genetic siblings can apply to the HFEA to join the Donor Sibling Link. Applicants choose how their contact details are shared with potential siblings and whether they wish to receive sibling's contact details. Applicants are required to be given the opportunity to receive counselling about the implications of disclosure.
- 3.96 Donors have the statutory right to access the following anonymous information about children born as a result of their donation: the number of offspring born, their sex, and year of birth. The HFEA is required to contact donors to advise them that a donor conceived individual has requested identifying information about them, but it may not disclose any information about the applicant to the donor. Donors do not have a legal right to contact their donor conceived offspring.
- 3.97 In addition to the statutory access rights outlined above, the HFEA grants discretionary access to parents of donor conceived children, to anonymous information about their donor and the number, sex and year of birth of other children with the same donor.<sup>82</sup>

### Voluntary register

3.98 A voluntary information exchange and contact register for donor conception that occurred before 1991, when the Human Embryology Act came into force, is maintained by UK DonorLink. The register enables donor conceived people over 18, donors and half-siblings to exchange information and, if they wish, to contact each other.

<sup>&</sup>lt;sup>81</sup> HFEA, Summary of access rights, <a href="http://www.hfea.gov.uk/docs/Summary\_of\_Access\_Rights.pdf">http://www.hfea.gov.uk/docs/Summary\_of\_Access\_Rights.pdf</a> accessed 26 March 2012

<sup>&</sup>lt;sup>82</sup> HFEA, Summary of access rights, <a href="http://www.hfea.gov.uk/docs/Summary\_of\_Access\_Rights.pdf">http://www.hfea.gov.uk/docs/Summary\_of\_Access\_Rights.pdf</a> and Donor Sibling Link, <a href="http://www.hfea.gov.uk/donor-sibling-link.html">http://www.hfea.gov.uk/donor-sibling-link.html</a> accessed 26 March 2012

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- 3.99 UK DonorLink is funded by the Department of Health and managed by a registered charity called After Adoption Yorkshire, which has experience in providing information and counselling to people affected by adoption, as well as with donor conception issues. According to the UK DonorLink website, the government had indicated that it would cease funding the register, which was originally set up as a pilot project, however it has agreed to provide transitional funding until December 2012. But the provide transitional funding until December 2012.
- 3.100 By 30 June 2010, around 317 people had registered with UK DonorLink, or were in the process of registering and the register had enabled 26 links between half siblings and identified 2 donors. In addition, 2 links have been made between donors and donor conceived adults.<sup>85</sup>

### Parentage of donor conceived children

- 3.101 Under the HFE Act, a woman who carries a child following assisted reproduction is the child's mother. The husband of a married woman who conceives a child using donor sperm is treated as the child's father, unless he did not consent to the treatment. In the case of unmarried couples receiving treatment, the man is treated as the father of the child if he and the woman have each given written consent to him being treated as the father of any child resulting from the treatment. No other person is able to be treated as the father of the child. 86
- 3.102 For women with female civil partners, the woman giving birth to the child as a result of donor insemination is the mother of the child and her civil partner is treated as the child's other parent (if they consented to the treatment). Both parties are required to have given written consent for the other woman to be treated as the child's parent. No man is to be treated as the father of the child.<sup>87</sup>
- 3.103 Donors who donate through licensed clinics in the UK are not the legal parent of a child born as a result of their donation, and they have no legal obligations or rights over the child.<sup>88</sup>
- 3.104 The HFE Act does not cover donations made through private arrangements and unlicensed companies. Therefore, 'if an unmarried couple carry out self-insemination with donor sperm at home or elsewhere, not as part of licensed treatment, the male partner would not be the legal parent. He would have to take steps to acquire formal parental responsibility, for example by adopting the child.'89

<sup>&</sup>lt;sup>83</sup> UK DonorLink, Annual report 2009-10, <a href="http://www.ukdonorlink.org.uk/UKDL%20Annual%20Report%202009-10.pdf">http://www.ukdonorlink.org.uk/UKDL%20Annual%20Report%202009-10.pdf</a> p 2

<sup>&</sup>lt;sup>84</sup> UK DonorLink, <a href="http://www.ukdonorlink.org.uk/">http://www.ukdonorlink.org.uk/</a> accessed 10 September 2012

<sup>&</sup>lt;sup>85</sup> UK DonorLink, Annual report 2009-10, p 6

<sup>&</sup>lt;sup>86</sup> Human Fertilisation and Embryology Act 2008 (UK), ss 33 to 41

 $<sup>^{87}</sup>$  Human Fertilisation and Embryology Act 2008 (UK), ss 42 to 47

<sup>&</sup>lt;sup>88</sup> Human Fertilisation and Embryology Act 2008 (UK), ss 41 and 47. HFEA, Your legal responsibilities as a sperm, egg or embryo donor, <a href="http://www.hfea.gov.uk/1972.html">http://www.hfea.gov.uk/1972.html</a> accessed 22 March 2012

<sup>89</sup> Human Fertilisation and Embryology Act 2008 Explanatory Notes,

http://www.legislation.gov.uk/ukpga/2008/22/notes/division/6/2 para 174, accessed 26 March 2012

3.105 The HFEA's website states that donors planning to donate outside of a licensed clinic should seek legal advice, noting that 'where fresh donated sperm is used outside of an HFEA licensed clinic, the donor is considered by law to be the child's legal father, with all the responsibilities and rights that involves.<sup>190</sup>

#### Birth certificates

Donors are not named on birth certificates. <sup>91</sup> The inclusion of donor conception on birth certificates was considered by a Joint Committee report on the 2008 Bill that amended the legislation for assisted reproduction. The Committee noted the arguments for and against registering donor conception on birth certificates and recommended that the government consider the issue as a priority. The Government's response stated that its 'position to date is that it is preferable that parents are educated about the benefits of telling children that they were donor-conceived rather than forcing the issue through the annotation of birth certificates'. However the response also stated that the Government recognised the importance of giving donor conceived people access to information about their genetic background, and that it would keep the matter under review. <sup>92</sup>

#### NATIONAL CONSISTENCY

- 3.107 The Committee received evidence regarding national consistency in relation to registers of information on donor conception. Inquiry participants' comments focussed on the desirability of links between state donor registers and consistency across jurisdictions; 93 the lack of Commonwealth powers to regulate in this area; and concern that a nationalisation process could 'actually restrict people's options and choices rather than giving them assistance. 194
- 3.108 The Senate Committee recommended that state and territory governments establish a centralised register to ensure a consistent approach to access to information held on donor conception registers. The Senate Committee expressed concern at inconsistent regulation of donor conception between jurisdictions, noting that it had received evidence indicating that:
  - anonymous donations are still being used or accepted in clinics, in breach of the NHMRC Guidelines;
  - without a nationally consistent coding system, donors can donate in a number of states and territories without any tracking of every jurisdiction in which they have donated;
  - sperm and oocytes can be imported into Australia without any similar crosschecking occurring;

<sup>&</sup>lt;sup>90</sup> HFEA, Your legal responsibilities as a sperm, egg or embryo donor, <a href="http://www.hfea.gov.uk/1972.html">http://www.hfea.gov.uk/1972.html</a> accessed 22 March 2012

<sup>&</sup>lt;sup>91</sup> HFEA, Your legal responsibilities as a sperm, egg or embryo donor, <a href="http://www.hfea.gov.uk/1972.html">http://www.hfea.gov.uk/1972.html</a> accessed 22 March 2012

<sup>&</sup>lt;sup>92</sup> UK House of Commons Library, *Human Fertilisation and Embryology Bill Research paper*, No 08/42, May 2008, pp 56-57

<sup>&</sup>lt;sup>93</sup> Dr Sonia Allan, Transcript of evidence, 5 March 2012, p 5; Mr Daniel Stubbs, Director, Inner City Legal Centre, Transcript of evidence, 5 March 2012, p 17

<sup>&</sup>lt;sup>94</sup> Professor Jenni Millbank, Transcript of evidence, 5 March 2012, p 24

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- there are no consistent limits on the numbers of families a donor is able to assist; and
- there are no consistent rights of access by donor conceived people to identifying and non-identifying information about their donor and siblings.

### Committee comment

- 3.109 The Committee considers that it is important that Australian governments work to develop a nationally consistent framework for registration and record-keeping practices relating to information about donors and the way in which this information is made available to donor conceived individuals. Inconsistency between states creates confusion for donors and donor conceived individuals and their families. As noted by the Senate Committee, it also means that different rights of access to information apply, depending on where the treatment occurred. The Committee considers that this is inequitable for donor conceived individuals.
- 3.110 The Committee is recommending that the NSW Government work with other states and territories to build a consistent system for registering and accessing information in relation to donor conception.

#### **RECOMMENDATION 1**

That the NSW Government work with state and territory governments to develop a nationally consistent system for the registration, management and release of information in relation to donor conception.

<sup>&</sup>lt;sup>95</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, pp 91-92

# Chapter Four – The register of births and birth certificates

4.1 In this chapter the Committee explores the differing views of inquiry participants on whether or not donor details should be included on the births register and/or appear on birth certificates, in addition to outlining proposals for noting donor details by annotating birth certificates or issuing an addendum with the certificate. The Committee also considers practices in other jurisdictions.

#### INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

4.2 As outlined in Chapter Two, the original purpose of birth registration was to record a birth and its particulars. Mr Greg Curry, Registrar, Registry of Births, Deaths and Marriages gave the Committee an overview of the birth registration process:

The birth registration process essentially begins when a child is born to a mother and the mother, the parents, are given a form called a Birth Registration Statement, which is provided by the hospital or the midwife, and the parents are required by the Act to Complete the form and forward it to the Registry of Births, Deaths and Marriages within 60 days. When the registry receives that form we check that form against the notification provided separately by the hospital or the midwife and where those details are correct those details are entered on the register. <sup>96</sup>

- 4.3 A birth certificate is a certified extract of the information held on the Register of Births; the Register of Births holds more information than that which appears on a birth certificate, for instance, a child's birth weight, and whether or not the birth was a multiple birth.<sup>97</sup>
- 4.4 The Committee heard that donor details could be included on the register of births without appearing on birth certificates. The Registrar, Mr Greg Curry, commented on the practicalities of including donor details on the register but not on birth certificates:

Donor details could be recorded on the births register. The question as to whether it would appear on a birth certificate is at the discretion of the Registrar at the moment. I can require anything that is held on the register in relation to a birth to be included on the birth certificate. Whether donors would become parents or the equivalent of parents would of course be a matter for Parliament. 98

4.5 The Committee heard from Ms Gabrielle Carney of the Department of Attorney General and Justice that there are no legal barriers to including donor details on the register of births but not on birth certificates:

There do not appear to be any legal barriers to information being included on the birth register but not on a birth certificate. A birth certificate certifies some of the

<sup>&</sup>lt;sup>96</sup> Mr Greg Curry, Registrar, Registry of Births, Deaths and Marriages, Transcript of evidence, 1 March 2012, p 7

<sup>&</sup>lt;sup>97</sup> Births, Deaths and Marriages Act 1995 s 17 and Births, Deaths and Marriages Registration Regulation 2011 r 5

<sup>&</sup>lt;sup>98</sup> Mr Curry, Transcript of evidence, 1 March 2012, p 9

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information that is contained on the register; however, it does not contain all information that is contained on the register. For example, the weight of the child at birth, the place of birth of the child's parents and the existence of half siblings are some details that may be contained on the birth register but will not be included on a birth certificate. <sup>99</sup>

4.6 Some inquiry participants suggested that donor details could be included on the births register but not appear on birth certificates. Professor Jenni Millbank submitted that the inclusion of donor details on the register of births should be symbolic only and not entail any legal parentage consequences for the donor:

I submit that the best approach is to create a flexible, consent based system to allow for the voluntary recording of donor identity on the birth register.

This would operate:

- 1. in addition to but not instead of the Central Register;
- 2. only with the consent of both legal parents and the donor, not as a mandatory or general system;
- 3. to allow for a symbolic recognition of the donor as a genetic parent with no consequences for the state or federal rules on legal parentage.  $^{100}$
- 4.7 The Law Society of New South Wales supported the inclusion of donor details on the register of births, with only the legal parents being included on a birth certificate:

The [Elder Law and Succession] Committee's view is 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 Committee'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. <sup>101</sup>

- 4.8 The Information and Privacy Commission submitted that if donor details were included on the births register, it should be possible to omit these personal details from birth certificates. 102
- 4.9 The Commission for Children and Young People submitted that donor details should not be included on the register of births, arguing that this information should continue to be managed separately to prevent confusion regarding legal parentage:

There are a number of reasons for not including donor details arising from ART in the register of births and for managing this information separately. Most importantly the register of births records details of a child's legal parents, and these are the names listed on the child's birth certificate. ...  $^{103}$ 

<sup>&</sup>lt;sup>99</sup> Ms Gabrielle Carney, Assistant Director, Legislation Policy and Criminal Law Review Division, Department of Attorney-General and Justice, Transcript of evidence, 1 March 2012, p 4

<sup>&</sup>lt;sup>100</sup> Submission 17, Professor Jenni Millbank, p 4

<sup>&</sup>lt;sup>101</sup> Submission 22, Law Society of New South Wales, p 1

<sup>&</sup>lt;sup>102</sup> Submission 29, Information and Privacy Commission, pp 2-3

<sup>&</sup>lt;sup>103</sup> Submission 16, NSW Commission for Children and Young People, p 2

### Inclusion of donor details for private arrangements

relevant stakeholders:

4.10 The inclusion of donor details on the register of births could enable the recording of donor details for those people conceived through private arrangements. Donor conceptions through private arrangements are not currently recorded in the ART Central Register held by the Ministry of Health, or on the register of births. The Committee discusses private arrangements in detail in Chapter Four.

# INCLUSION OF DONOR DETAILS ON BIRTH CERTIFICATES Purpose of birth certificates

4.11 Birth certificates issued by the Registry of Births, Deaths and Marriages are an official certified copy of the registration data held by the Registry. The primary function of birth certificates is to provide evidence of a person's identity, age, place of birth and parentage for a range of practical and legal purposes. The format of birth certificates in New South Wales has remained unchanged for approximately 50 years. The Committee heard from the Registrar of Births, Deaths and Marriages, Mr Greg Curry, that the Registry was planning a review of the current format of birth certificates and would undertake consultation with

... The review that we are planning, to give the Committee some background and perhaps refer to an earlier question as well, where there is some dispute over the contents of the register those matters can sometimes be heard by the Administrative Decisions Tribunal. In a matter approximately one year ago a member of the tribunal made some observations regarding the format of the birth certificate to the effect that the format had been unchanged for some years, and although that was a side comment in the matter at hand we looked at that comment and when we examined the issue we found that we had not changed the format of the birth certificate for approximately 50 years. The only change we could identify was that in the early 1990s where we had previously recorded details of previous children of that marriage we changed the word "marriage" to "relationship", and that prompted us to consider that it was appropriate that the format be reviewed.

The consultation that we are proposing to undertake would include parents groups, medical organisations, providers of assisted reproductive technology services, organisations providing counselling, other departments such as Centrelink, Immigration and Citizenship, Human Services, law enforcement agencies, the Australian Bureau of Statistics, the Ombudsman, the Anti-Discrimination Board, the Law Society, the Bar Association, community legal centres, maternity hospitals, the Department of Health, midwives and doctors, demographers, medical ethics committees. <sup>105</sup>

4.12 The Committee heard that although the form of birth certificates and particulars included on them have remained virtually unchanged for 50 years, the function of birth certificates has changed with time. As the Deputy Information Commissioner Mr John McAteer remarked, birth certificates have become increasingly important in terms of proof of identity:

 $<sup>^{104}</sup>$  Victorian Law Reform Commission , *Assisted Reproductive Technology and Adoption: Final Report*, February 2007, p 143

<sup>&</sup>lt;sup>105</sup> Mr Curry, Transcript of evidence, 1 March 2012, p 8, see also <a href="http://www.bdm.nsw.gov.au/feedback-birth-certificate.htm">http://www.bdm.nsw.gov.au/feedback-birth-certificate.htm</a> accessed 3 July 2012

... historically, and at an increasing rate, the birth certificate has become a form of identification verification rather than in practice the document that the Births Deaths and Marriages Act refers to: Being a recording of particulars relating to births and other particulars as prescribed by the regulations for individuals born in New South Wales. To illustrate this point—and it is referred to in my submission—I am sure the Committee would be aware of the 100 point identification check that organisations, companies and government requires to prove identity when opening a bank account, applying for a passport, et cetera. There are three documents listed which provide 70 points out of the 100 points: a birth certificate, issued by a State or Territory, a citizenship certificate or a passport.

- 4.13 A number of submissions<sup>107</sup> pointed out that many people are under the misapprehension that birth certificates record a person's biological parentage, when in fact birth certificates record legal parentage. In many instances a person's biological parents are also their legal parents, but in cases such as adoption or donor conception one or both of the legal parents may not be a biological parent.
- 4.14 In this regard, the NSW Government submission noted that:

A birth certificate helps to provide proof of identity for the individual listed on the certificate, and is used to secure other Australian identification documents such as a passport, driver's license and Medicare Card. The birth certificate also establishes the identity of the individual's legal parents (in cases involving adoption, surrogacy or donor conceived births, this may differ from the biological parents). Legal parents have rights and responsibilities in relation to the child that others (such as a sperm donor, or biological father) do not. 108

4.15 The Registrar, Mr Greg Curry, observed that birth certificates are a record of the birth of a child, not a record of the means of conception of a child:

I guess the comment I would make on that would be that the birth certificate to date has not been a "conception certificate". It is a record of the birth of a child. It is silent as to how that child was conceived. Again, referring to the question of adopted persons where in the normal course of events an adoptive person, if you like, their origins, the fact that they are adopted does not appear on their birth certificate and there is a regime in place where they can obtain an original birth certificate. <sup>109</sup>

### Arguments for the inclusion of donor details on birth certificates

- 4.16 The Committee heard differing views on whether or not donor details should appear on birth certificates ranging from having donor details on birth certificates, having some form of annotation on a birth certificate, having donor details on a separate form such as an addendum or not including the details at all.
- 4.17 Submissions from donor conceived individuals expressed the view that they did not share the same right as other people to have a complete picture of their

<sup>&</sup>lt;sup>106</sup> Mr John McAteer, Deputy Privacy Commissioner, Information and Privacy Commission NSW, Transcript of evidence, 1 March 2012, p 21

<sup>&</sup>lt;sup>107</sup> Submission 3, Name suppressed, and Submission 10, Mr Brian FitzGerald

<sup>&</sup>lt;sup>108</sup> Submission 31, NSW Government, p 3

<sup>109</sup> Mr Curry, Transcript of evidence, 1 March 2012, p 11

identity and origins. They submitted that their birth certificates should reflect the true nature of their conception, provide a complete picture of their identity and give them information about their donor. Mr Damien Adams, a donor conceived individual, stated:

I personally despise my birth certificate as it is an erroneous document. I love my parents very much and what they did in raising me, but it does not change biological fact. My birth certificate does not accurately describe who I am, as components of our identity are a result of our heritage. 111

4.18 Miss Narelle Grech stated in her submission that the right of donor conceived people to possess birth certificates that reflect their biological parentage is an extension of a person's rights under the United Nations Convention on the Rights of the Child, article 8:

The right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference should be paramount. 112

4.19 The following case study gives the perspective of one donor conceived individual, Mrs Myfanwy Cummerford, on the inclusion of donor details on birth certificates: 113

I discovered at age 20 that was conceived via the use of anonymous donated sperm at the Royal Women's Hospital in Melbourne 30 years ago. I was miraculously able to meet and establish a relationship with my biological father in 2001. I know that I have at least three half siblings (one of whom may reside in NSW) who were also conceived using his donated sperm. Meeting my biological father and his three daughters (my other three half siblings) has been an overwhelmingly positive experience. Whilst discovering that I was donor conceived at age 20 was incredibly traumatic, I am nonetheless grateful that I was able to ascertain the truth and consider myself fortunate to have been able to form a whole picture of my own identity and family.

The situation that donor conceived people find themselves in is untenable. It is mind boggling that in 2011 there exists a group of Australian citizens who are lied to by the very document that should tell them the truth. Their birth certificate. Their primary document of identity.

That donor conceived people have no way of independently discovering the truth of their genetic parentage is an inexcusable deception, worse it is facilitated by the state.

The Victorian government initiative of allowing an addendum to indicate donor conceived status on the register of birth is commendable, however it is not enough and does not protect the interests of all donor conceived people.

I recommend that a donor conceived person's birth certificate **must** list their genetic parents as well as the legal parent(s) (if the genetic parents are not also the legal parents).

<sup>&</sup>lt;sup>110</sup> Submissions 1, 18, 19

 $<sup>^{111}</sup>$  Submission 1, Mr Damien Adams, p 5

<sup>&</sup>lt;sup>112</sup> Submission 18, Miss Narelle Grech, p 3

<sup>&</sup>lt;sup>113</sup> Submission 19, Mrs Myfanwy Cummerford, p 1

The birth certificate belongs to the donor conceived person. It is theirs for life and the information contained within is important for their descendants also. If the birth certificate lists the genetic parents then it will be virtually impossible for a person to be deceived as to the mode of their conception.

4.20 Ms Narelle Grech stated in her submission that the inclusion of donor details on the register of births and birth certificates would give donor conceived individuals important access to their medical history – access that she herself has been denied with grave consequences: 114

Earlier this year I was diagnosed with stage 4 bowel cancer, at the age of 28. I have been advised by numerous doctors that it is likely a connection to genetic factors. My mother has no family history of bowel cancer in her family and so it is likely that I have inherited this disease from my biological father (sperm donor). Had I been aware of this information at an earlier time I could have been screened and perhaps have a better chance at the cancer being cured. As it stands, I have been told that my illness is incurable and that I have approximately 5 years to live. I have recently been advised that I will need to undergo indefinate chemotherapy, after having just completed 12 rounds, following life saving emergency surgery to remove my primary tumour. This diagnoses has obviously had an enormous impact on my life and I am very concerned that my 8 half siblings, who were conceived via the same sperm donor, may be at risk of this terminal illness as well. I have no way of contacting them to warn them and they have no way of knowing they are donor conceived and more importantly at risk of bowel cancer. I have been advised that my half siblings should be screened for bowel cancer every 5 years from the age of 25. I am saddened to think that they have no way of ever knowing to be aware of this fact. The implications of falsifying birth certificates not only effects the DC person, but their entire family and generations of people yet to come.

4.21 The Committee heard that inclusion of donor details on a birth certificate would encourage parents to disclose to their children the nature of their conception. Ms Caroline Lorbach of the Donor Conception Support Group said that:

Some people, in particular donor-conceived people, and people involved in adoption, told us they believe that birth certificates should always display the names of a child's genetic parents, to reflect the biological truth about his or her parentage, and to guard against the secrecy that has historically accompanied donor conception and adoption. 115

4.22 In their submission, the Life, Marriage and Family Centre, Catholic Archdiocese of Sydney, said that birth certificates should be a record of all aspects of a person's identity:

A child's birth certificate is a crucial expression of the child's identity and as such should contain all known information about his or her parentage. The birth certificate is intended to be a service rendered by the state primarily for the *child*, and not for the parent. <sup>116</sup>

<sup>&</sup>lt;sup>114</sup> Submission 18, Miss Narelle Grech, p 3

 $<sup>^{\</sup>rm 115}$  Submission 7, Donor Conception Support Group of Australia Inc, p 6

<sup>&</sup>lt;sup>116</sup> Submission 6, Life, Marriage and Family Centre, p 1

4.23 Mr John Lindsay Mayger, a donor, stated that the birth certificate is the ideal and proper place to record a person's genetic and legal relationships and that recording genetic heritage on a birth certificate would guard against consanguinity and facilitate contact between genetically related siblings:

I am in favour of accurate genetic records being kept. This would enable a) the prevention of consanguinity, inbreeding, to the first and subsequent generations, b) tracking of any subsequently discovered genetic problems and reporting of those problems to all offspring of the donor and c) facilitating sibling solidarity if they are an only child in the family. I believe that the Birth Certificate is the ideal and proper place to record this important genetic and legal information. <sup>117</sup>

4.24 The NSW Gay and Lesbian Rights Lobby submitted that some families would like the option of listing a donor on the birth certificate. In consultations that informed their 2003 report *And then....the bride changed nappies*, they found that:

Several women indicated they felt unhappy leaving the male donor off the birth certificate, as they wanted the child to know his or her heritage and felt that the birth certificate had enormous symbolic and emotional importance to a child's sense of identity. The parents who expressed these views did not want legal consequences to follow from the naming of the male donor on the certificate, but equally they felt that a certificate of birth which excluded the male donor (through stating that he was "unknown") was a lie. 118

4.25 The NSW Gay and Lesbian Rights Lobby recommended that known egg, sperm and embryo donors could be named on the birth certificate as another important person, although the inclusion of the information should be voluntary and symbolic only:

At present we understand there is a space for the 'informer' (usually the doctor or another person present at the birth) – this space could be made generic and sperm, egg and embryo donors could be listed there without any legal effect. Such a change requires amendment to the BDM Regulation. <sup>119</sup>

4.26 The submission continued:

We consider this to be an important step in providing for the recognition of biological heritage and are of the view that it is likely to be of great symbolic and emotional importance for the child as well as for the adults involved.

Male donors who have children as a known donor to a lesbian couple may have no relationship with the child; a loose friendly relationship with the child with occasional contact; a close relationship with regular contact; or may indeed be an equal parent with the mothers, sharing residence and parental responsibility. Similarly, there are a range of relationships arising from surrogacy arrangements. There is no one-size-fits-all and we are opposed to the imposition of one through the automatic ascription of legal status to all known donors — many of whom never planned to be, or were intended to be, legal or social parents. As a result, we

<sup>&</sup>lt;sup>117</sup> Submission 5, Mr John Lindsay Mayger, p 2

<sup>&</sup>lt;sup>118</sup> Submission 23, NSW Gay and Lesbian Rights Lobby, p 5

<sup>&</sup>lt;sup>119</sup> Submission 23, NSW Gay and Lesbian Rights Lobby, pp 4-5

strongly recommend that the inclusion of a donors name on the birth certificate as an important person should not be automatic, rather it should require the consent of the legal parents and the donor.  $^{120}$ 

4.27 The Hawkesbury Nepean Community Legal Centre submitted that having the option to list a donor's name on their birth certificate may help donor conceived people to better understand their family structure and develop a fuller sense of self-identity. However they added that it should be made clear on the certificate that the person named is a donor and no legal presumptions of parentage are raised for the donor or the legal parents.<sup>121</sup>

## Arguments against the inclusion of donor details on birth certificates

- 4.28 The Committee heard from a number of submission makers and witnesses who believe that while donor conceived individuals have a right to information about their genetic origins, such information should not appear on birth certificates.
- 4.29 The Committee heard from Dr Sonia Allan that there is an important distinction to be made between a donor conceived person's desire for information and a donor conceived person's desire to have a relationship with their donor, and that the inclusion of donor details on a birth certificate could cause confusion about the relationship between donors and donor conceived people:

I am a very strong advocate, having worked or discussed with donor conceived individuals their needs for a long time now, for them having information. But one thing we have come across over the years is some confusion about a donor conceived individual's desire to have information about their genetic parentage and their desire to have a relationship with their donor. Some people think it is because they are not happy with their own parents, and that is not necessarily the case.

Some donor conceived individuals want information but they are not looking for another parent. They do not see the donor as a parent. They have their parents that have brought them up and, you know, that situation is their family. It then becomes everybody having their own opinion of what should be placed on the birth records, but I do think that it can cause confusion. I think the issues of legal parentage and release of information need to be kept quite separate for some of those reasons. 122

4.30 The Committee heard that the inclusion of donor details on birth certificates could cause confusion with respect to legal parentage and legal rights and responsibilities. The mother of a donor conceived child submitted that:

If donor details are going to be included on birth certificates it raises an issue as to what status donors may have. A donor is not considered a parent, yet inclusion of their details on a birth certificate may raise any issue as to whether they are something more than just a donor of a single cell. ... As no legal rights attach to the donor, it is questionable as to what the purpose of the details being included in the register of births would be. The donor has no claim on the child, and the child (or its

<sup>&</sup>lt;sup>120</sup> Submission 23, NSW Gay and Lesbian Rights Lobby, pp 4-5

 $<sup>^{121}</sup>$  Submission 8, Hawkesbury Nepean Community Legal Centre, p 8

<sup>&</sup>lt;sup>122</sup> Dr Sonia Allan, Transcript of evidence, 5 March 2012, p 3

parents) cannot claim any parental responsibility from the donor (including child support). 123

4.31 Ms Elizabeth Hurrell of the Fertility Society of Australia told the Committee that the current practice of recording legal parents on birth certificates supports the clear distinction between legal parentage and genetic heritage and expressed concern that the inclusion of donor details on a birth certificate could lead to uncertainty about donor's legal status:

In patients coming through clinics there is a very clear delineation that the parents are going to be the recipients of the donation, and the donor is playing the role of a donor which comes with no legal responsibility. That delineation is very clear. We are quite concerned about what the legal implications might be if the donor's name appears on the birth certificate, and the sort of confusion that that might create for families who are using donor conception. We think it is really important to have very clear legal boundaries about that.<sup>124</sup>

4.32 Dr Sonia Allan told the Committee that birth certificates currently reflect the legal relationship between a child and the parents who are caring for it. She stated that the addition of donor details to a birth certificate could create confusion about donors' legal rights and responsibilities:

Then we have an issue of the birth certificate creating conflict with what is clearly laid out in statute concerning the donor, and that relates to the donor having no rights or responsibilities. As that currently stands, they are not listed on the birth certificate for many reasons but listing them might also lead to fears that in some way they are seen as a father, if we are talking about sperm donors or otherwise if we are talking about egg or embryo donors. I think that this can be confusing because it can lead to questions about legal obligations. Again I think that the birth certificate or the idea of legal parenting should be kept quite separately to the idea of giving children and donor conceived individuals information about who their donor is. <sup>125</sup>

4.33 The submission from the Western Australian Department of Health highlighted the social and ethical implications of placing a donor's name on the birth certificate where traditionally only the legal parents' names were recorded, including:

Expectations of 'parental responsibilities' when a donor has not entered into any agreement in relation to parenting;

...The need to avoid terminology that might vest donors with any kind of 'parental' status.  $^{\rm 126}$ 

4.34 The Committee heard that as birth certificates have become a primary document for identity verification; they need to be produced to enrol at school, obtain a drivers' licence or open a bank account. Inquiry participants argued that the inclusion of donor details on birth certificates could be an invasion of privacy, as a

<sup>&</sup>lt;sup>123</sup> Submission 20, Name suppressed, p 3

<sup>&</sup>lt;sup>124</sup> Ms Elizabeth Hurrell, Board member, Fertility Society of Australia, Transcript of evidence, 1 March 2012, p 31

<sup>&</sup>lt;sup>125</sup> Dr Allan, Transcript of evidence, 5 March 2012, p 3

<sup>126</sup> Submission 30, Department of Health, Government of Western Australia, p 5

person's means of conception would be divulged every time the birth certificate was produced. Ms Elizabeth Hurrell of the Fertility Society of Australia told the Committee that:

By putting a donor's name on a birth certificate, we have concerns about the privacy of these families and the stigmatisation that could come about if a donor's name is on a child's birth certificate. That is not the sort of information that needs to be disclosed when you are taking the birth certificate along to register your child for the local soccer team or something. It is very private and personal information and in that sense we are concerned whether it is appropriate to put it on a birth certificate. 127

4.35 The Information and Privacy Commission submitted that the inclusion of donor details on birth certificates raised privacy concerns for donor conceived people:

The inclusion of donor information on a Birth Certificate would mean that an individual who was born as a result of donor conception would not be in position to prevent that information being viewed .

If it is proposed that the BDM Act be amended to provide for the inclusion of personal information relating to donors on the Register of Births I suggest that there be consideration as to whether it may be possible to have this information withheld from Birth Certificates, particularly where the individual concerned has the capacity to make this decision themselves. 128

4.36 Dr Sonia Allan told the Committee that divulging such information on a document that has to be produced publicly could lead to discrimination for donor conceived people:

We need to produce our birth certificate in many different situations. Unfortunately, as much as we embrace new family forms and celebrate them, I do not necessarily think that having all of that information on a document that you have to produce publicly would always be favourable to the person having to produce it.

They could suffer discrimination, they could have to explain things to people that they do not want to explain, and so in that sense I think the issue really needs to be kept separate. <sup>129</sup>

4.37 The mother of a donor conceived child expressed concern that including donor details on birth certificates would result in the disclosure of private information about a child to third parties:

I consider it would be discriminatory to include these details as it immediately marks the child as different. Whilst our child will know he was conceived with the assistance of a donor, we consider that this is *his* information to share with people when he is older, not ours. By requiring these details to be disclosed by the register of births, it would immediately open the possibilities of third parties finding out he was donor conceived.

<sup>&</sup>lt;sup>127</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 29

 $<sup>^{\</sup>rm 128}$  Submission 29, Information and Privacy Commission, pp 2-3

<sup>&</sup>lt;sup>129</sup> Dr Allan, Transcript of evidence, 5 March 2012, p 3

If these details are to be included on a birth certificate then any school, doctor, bank, passport office, sporting team etc would discover our child is donor conceived when in reality it has no bearing on who he is.

... Many people do not understand donor conception. By requiring donor conceived children to have further details recorded about them, it is further stigmatising them from the moment they are born, when really they deserve to be treated like every other child. By requiring these details to be included on the register for births, any donor conceived child will lose their right to privacy as to the fact they were conceived with the assistance of a donor. Whether or not donor sperm, eggs or embryos were required to create a child has absolutely no bearing on who the child is. It does not affect their personality, their interests or any other aspect about them. <sup>130</sup>

4.38 The Victorian Law Reform Commission report, Assisted Reproductive Technology and Adoption: Final Report recommended that only the legal parents of a child should appear on a birth certificate, given the 'primary role that birth certificates play as documents with legal consequences.' The report went on to say:

... the commission believes that only those people who are recognised as the legal parents of the child should be named on the birth certificate. Given our recommendation that in all cases donors should be presumed at law not to be parents, it follows that a donor should not be recorded on the register of births or on a child's birth certificate.

Although birth certificates do have symbolic value for many people, that is not their primary purpose. To include information on the birth certificate that does not give rise to legal obligations and which does not assist in identifying a person for legal and administrative purposes would create confusion about a person's legal status in respect of the child. This could lead to problems with organisations such as government agencies, schools and health providers. It is also likely that a birth certificate listing such information would not be accepted for official purposes both within Australia and internationally. 132

# Argument for three or more parents on birth certificates and the births register

- 4.39 The Committee heard from submission makers who proposed that the inclusion of donor details in addition to legal parents on a birth certificate could be in the best interests of a child and desirable in some circumstances but not all cases of donor conception. They proposed that the addition of donor details be voluntary and only occur with the legal parents' and the donor/s consent.
- 4.40 The NSW Commission for Children and Young People argued in their submission that the inclusion of donor details on the birth certificate and/or the register of births could take place when children were:

<sup>&</sup>lt;sup>130</sup> Submission 20, Name suppressed, p 1

<sup>&</sup>lt;sup>131</sup> Victorian Law Reform Commission, *Assisted Reproductive Technology & Adoption: Final Report*, February 2007, p

<sup>&</sup>lt;sup>132</sup> Victorian Law Reform Commission, *Assisted Reproductive Technology & Adoption: Final Report*, February 2007, p 146

... conceived through informal arrangements in cases where all relevant parties agree at the time of birth that the donor is to perform a parental role for the child. This would clearly require the capacity to include three persons as parents in the register of births, and on a child's birth certificate. <sup>133</sup>

4.41 The Committee heard from Ms Elizabeth Hurrell of the Fertility Society that if donor details were to be included on the birth certificate, it should not be mandatory and all parties – legal parents and donors – should consent.

Earlier I spoke about the diversity of families we see. I guess there are some situations of which we are aware, and perhaps it applies more to lesbian couples and single women, where even though the donor has acted as a donor they might want to play a very active social role in parenting a child so that there may be situations where, if all parties are consenting, it may be in the interests of a child to have the donor's name on a birth certificate. Perhaps it is worthwhile to have a mechanism in those circumstances. We are quite clear that that is not going to apply to all the families that are using donor conception. We say that putting a donor's name on a birth certificate should not be forced on all families who have taken that legal responsibility to parent themselves. 134

- 4.42 The Law Society of New South Wales submitted that the register of births should include all the parents a child can have, including gamete donors, surrogate mothers and legal parents. 135
- 4.43 Associate Professor Nicholas Tonti-Filippini also submitted that the details of all those who perform a parenting role should be recorded by the Registrar of Births:

The obvious step to take would seem to be to legislate to require all the information about those who have parenting roles in the origin of the child, (including the genetic parents, the gestational or birth mother, and relinquishing social parents or relinquishing substitute parents), to be supplied to the Registrar. <sup>136</sup>

# Issuing annotated birth certificate or separate addendum with birth certificate

- 4.44 The Committee heard that the inclusion of donor details on a register could not help donor conceived people to obtain information about their genetic heritage unless they already knew of their donor conceived status and knew to contact the register for information. Dr Sonia Allan submitted that donor conceived individuals have a 'need and a right to know information about their genetic heritage' and that annotation or the issuing of an addendum would assist donor conceived individuals to know about the method of their conception. <sup>137</sup> Dr Allan also noted that other possible approaches included:
  - recording both the individual's genetic and social parentage on the birth certificate of a donor conceived person;

<sup>&</sup>lt;sup>133</sup> Submission 16, NSW Commission for Children and Young People, p 4

 $<sup>^{\</sup>rm 134}$  Ms Hurrell, Transcript of evidence, 1 March 2012, p 31

<sup>&</sup>lt;sup>135</sup> Submission 22, Law Society of New South Wales, pp 1-2

<sup>&</sup>lt;sup>136</sup> Submission 2, A/Prof Nicholas Tonti-Filippini, p 5

<sup>&</sup>lt;sup>137</sup> Submission 13, Dr Sonia Allan, p 25

- the issue of a separate certificate to a donor-conceived person alerting
  them to the possibility of information held on the Register of Information;
  placing a code or symbol on the birth certificate of a donor-conceived
  person; the annotation of birth certificates of all individuals to indicate the
  existence of information held on the register; or
- the issue of two certificates to all people a 'Certificate of Birth', identifying an individual's legal parentage and a 'Certificate of Genetic Heritage', indicating where an individual's genetic and legal parentage are different.
- 4.45 The NSW Government's submission to the inquiry stated that decisions about whether and how donor details should appear on birth certificates 'should be made in the framework of what is in the best interests of the child', and noted that an addendum or annotation to birth certificates may address privacy concerns:

Options for including donor information on the birth certificate would need to take into account issues of privacy, to ensure that donor-conceived children are not stigmatised by being treated differently to others' children. One such option would be to provide an endorsement (a note on the birth certificate indicating that further information is available), or a hidden addendum to the birth certificate that is then made available to the donor-conceived child when he or she turns 18. 139

### Victorian system

- 4.46 Since the enactment of the Assisted Reproductive Treatment Act 2008 (Vic) on 1 January 2010, the birth registration statement has contained a field asking whether the child was conceived by a donor treatment procedure. If the child was conceived by a donor treatment procedure, the Registrar must mark the word 'donor conceived' against the entry about the child's birth in the Register. The Committee understands that the Registry also undertakes cross-checking against records provided by ART clinics.
- 4.47 Those donor conceived adults born after 1 January 2010 who apply for a birth certificate will receive an addendum stating that further information is available from the Registry of Births, Deaths and Marriages. If the donor conceived person chooses to contact the Registry, they will be informed that their details are on the Central Register. The addendum serves as one way in which donor conceived people may find out of their donor origins if they have not already been told. The recording of 'donor conceived' status and the issuing of an addendum is governed by section 17B of the *Births, Deaths and Marriages Registration Act* 1996 (Vic):

17B Birth registration of child conceived by a treatment procedure

(1) If a birth registration statement specifies the child was conceived by a donor treatment procedure, the Registrar must mark the words "donor conceived" against the entry about the child's birth in the Register.

<sup>&</sup>lt;sup>138</sup> Submission 13, Dr Sonia Allan, pp 25-26

<sup>&</sup>lt;sup>139</sup> Submission 31, NSW Government, pp 5-6

- (2) Subject to subsection (3), when the Registrar issues a certificate certifying particulars contained in an entry about the birth of a person conceived by a donor treatment procedure, the Registrar must attach an addendum to the certificate stating that further information is available about the entry.
- (3) The Registrar must not issue the addendum referred to in subsection (2) to any person other than the person conceived by a donor treatment procedure named in the entry.
- (4) In this section *donor treatment procedure* means a donor treatment procedure within the meaning of the Assisted Reproductive Treatment Act 2008.

#### Inquiry participants' views

4.48 The Committee heard from Ms Gabrielle Carney, of the Department of Attorney General and Justice, that an addendum would be a useful way of alerting donor conceived adults that information about their donor is available and in ensuring that parents tell their children of their donor conceived status:

...if parents do not inform their child that they are donor conceived the child may never think to ask for such information from the birth register. The same issue arises under the current assisted reproductive technology (ART) register. Including reference on a birth certificate could be a way of ensuring that parents tell their children of the fact that they were donor conceived.

In Victoria a donor-conceived child's birth certificate has the same appearance as that of a naturally conceived child. However, if a child applies for their own birth certificate in their own right after they turn 18 they will be issued with a separate addendum that indicates that further information is contained on the BDM register. The child may then approach the register and be provided with the details of their donor. 140

4.49 Ms Elizabeth Hurrell, Fertility Society of Australia, told the Committee that the provision of an addendum would encourage parents to disclose to their children their donor conceived origins and give donor conceived people access to information about their genetic origins, while respecting their privacy:

The Fertility Society of Australia believes in the right of donor conceived people to know their genetic origins. There is a body of research that suggests that in the past a lot of parents have not informed their children of their donor conception. We think there would be some advantage in having something on a birth certificate that, I guess, in a way, states to parents that we have a benchmark that it is their responsibility to inform their children that they are donor conceived. If parents know that there is some sort of addendum or something like that on a birth certificate then they will have a sense of responsibility that they need to inform their children before they turn 18 years of age or whatever that they are donor conceived.

We think there is an advantage in having something like that but not the donor's details fully stated as with mother/father or mother/mother or whatever the case may be on the full body of the birth certificate. We think that having an addendum on a separate page could still be an incentive to parents to disclose the details of

 $<sup>^{\</sup>rm 140}$  Ms Carney, Transcript of evidence, 1 March 2012, p 4

donor conception to their children but it would also respect the privacy needs of families to not have to disclose this information all the time.  $^{141}$ 

4.50 The Donor Conception Support Group of Australia supported the adoption of the Victorian model as a 'a step in the right direction' in ensuring donor conceived individuals know the truth about their conception and identity. The Committee heard from Ms Caroline Lorbach of the Donor Conception Support Group that the addition of an addendum would respect the privacy of all parties:

I do not think there would be any confusion if we moved to a model like Victoria where there is an addendum to a birth certificate. Once a person applies for their birth certificate they will be told that further information is available to them if they wish to access it. It is up to that person whether they want to access that information. The name of the donor would never appear on a birth certificate. We think that would be the best result .... it has the benefit that it will respect the privacy of all parties involved: the donor conceived person, the donor and the parents. The information that the child is donor conceived is not written on that birth certificate. It is up to the donor conceived people who they want to tell. 143

4.51 The Privacy Commissioner, Mr John McAteer, told the Committee that a separate addendum would be preferable in terms of protecting the privacy of donor conceived individuals:

The Victorian example, I am not sure how it works in practice, but if there was some way where a bank teller or a registry officer in a motor registry or even a person at the passport office would not be able to glean that there was further information available that was irrelevant to proving the identity of the person, that would be preferable.

- ... Presuming there is an appropriate limitation on who can apply for a birth certificate ... to apply for it as a client or customer, my view would be that in such an example the document should have two folios in the envelope that are not affixed in any way to each other and when arriving at a banking institution or a motor registry I just bring the front folio. 144
- 4.52 Mr Ian Smith also expressed support for the Victorian system of including an addendum with birth certificates. <sup>145</sup> Vanish Inc stated that the Victorian practice of issuing an addendum provides a model that should be adopted in NSW:
  - In the case of a child being conceived with donor gametes, the Registry of Births is marked with the words "donor conceived" against the entry of the child's birth in the Register.
  - Information regarding the donor (biological parent) is recorded in the Register.
  - If and when the donor conceived person applies for a birth certificate after reaching 18 years of age the Registrar attaches an addendum to the certificate

 $<sup>^{141}</sup>$  Ms Hurrell, Transcript of evidence, 1 March 2012, pp 29-30  $\,$ 

<sup>&</sup>lt;sup>142</sup> Submission 7, Donor Conception Support Group, p 8

<sup>&</sup>lt;sup>143</sup> Ms Caroline Lorbach, National Consumer Advocate, Donor Conception Support Group of Australia Inc, Transcript of evidence, 1 March 2012, p 35

<sup>&</sup>lt;sup>144</sup> Mr McAteer, Transcript of evidence, 1 March 2012, pp 21-22

<sup>&</sup>lt;sup>145</sup> Submission 12, Mr Ian Smith, p 1

stating that further information (that is the information about the donor) is available about that birth registration.

A donor conceived person is thus, when they reach the age of 18 and if and when they apply for a birth certificate, alerted to their having been donor conceived and is able to obtain information regarding the identity of their donor/biological parent. <sup>146</sup>

4.53 However, Dr Sonia Allan told the Committee that although the Victorian system of issuing an addendum goes some way towards ensuring that donor conceived individuals actually know that there is more information for them, it only applies to individuals who apply for a birth certificate after they have turned 18. She said:

There are problems with the Victorian system. The problem with the Act, and this is really important, is the idea that this is disclosure. I do not know if you would call it a loophole but if a parent applies for the certificate prior to the child's eighteenth birthday and then the child has no reason after their eighteenth birthday to apply, the child or now adult will never know about the annotation because it is not marked on the birth certificate. The get-out of the individual knowing there is information there is to apply for the birth certificate before that person turns 18. I am not sure how you address that other than by encouraging parents to let their children know. I suppose too that at some point later down the track the donor conceived individual might themselves make an application. That is an important thing: the annotation does not necessarily mean that the donor-conceived individual will know later on. 147

#### Annotation of birth certificates

- 4.54 Some inquiry participants favoured the annotation of donor conceived individuals' birth certificates, as a way to ensure that they knew about the circumstances of their birth. The option of including a standard annotation on all birth certificates to indicate the availability of further information was also raised as an option.
- 4.55 The Registrar of Births, Mr Greg Curry, told the Committee that annotating birth certificates is a common practice for the Registry, with notations appearing on the bottom of the birth certificate's front page and continuing on to the back page where required:

... it has been our practice in the past and it is quite standard for us to provide annotations on birth certificates. Typically, for instance, if a person changes their name during their lifetime an annotation will subsequently appear on their birth certificate. It may be feasible for us to include such an annotation, where donor details were available, to the effect that further details regarding the birth were available on application. 148

4.56 Dr Sonia Allan submitted that annotation of birth certificates would ensure that donor conceived individuals know the means of their conception and that there is information on their donor available to them:

<sup>&</sup>lt;sup>146</sup> Submission 21, Vanish Inc, pp 1-2

<sup>&</sup>lt;sup>147</sup> Dr Allan, Transcript of evidence, 5 March 2012, p 4

<sup>&</sup>lt;sup>148</sup> Mr Curry, Transcript of evidence, 1 March 2012, p 9

At a minimum an annotation to the birth certificate should exist because in order to make a choice about accessing information about their donors, donor conceived individuals must know about the method of their conception in the first place. 149

4.57 Mr John Lindsay Mayger, a sperm donor, submitted that birth certificates should contain all of a person's biological and legal parentage, however a shortened, annotated form of the birth certificate should also be available:

Some adopted people and some DCP, Donor Conceived People, do not want contact with their genetic parents as they feel that this would be a violation of the relationships which they have and the love that they feel for the parents who have raised them. They not only do not want to contact their genetic relatives (donor, grandparents and siblings etc) they do not want the possibility of being contacted by them. Therefore a shortened form of Birth Certificate (annotated as such) should be available should a person wish it. But with the full information retained on a central Births Register. <sup>150</sup>

4.58 Ms Miranda Montrone proposed that after a donor conceived person reaches 18 years of age an annotated birth certificate should be made available:

However, after the donor offspring reaches the age of  $\underline{18}$  years of  $\underline{age}$ , I support a birth certificate having a notation that indicates that there is further information available about the birth of this person.  $^{151}$ 

- 4.59 The Fertility Society of Australia argued in their submission that it is the right of all donor conceived people 'to have access to identifying knowledge of their genetic origins'. However in order to make a choice about accessing information, donor conceived adults must first know their means of conception. A possible mechanism to make the relevant information available to donor conceived people without breaching their privacy would be to annotate all birth certificates:
  - Placing a standard notice on ALL birth certificates that further information may be available from the NSW Registry of Births, Deaths and Marriages at age 18.
  - Providing an addendum to the birth certificate at age 18 that provides the necessary information.

An annotation on a birth certificate only after the donor conceived person reaches maturity would give traditional parents the flexibility in inform their children of their donor origins in their childhood with the knowledge that they will need to do so by maturity. <sup>153</sup>

4.60 However, the Committee heard from the Deputy Privacy Commissioner, Mr John McAteer, that annotation of the main birth certificate would raise the issue of privacy for a donor conceived person:

<sup>&</sup>lt;sup>149</sup> Submission 13, Dr Sonia Allan, p 26

<sup>&</sup>lt;sup>150</sup> Submission 5, Mr John Lindsay Mayger, p 2

 $<sup>^{151}</sup>$  Submission 24, Ms Miranda Montrone, p 3

<sup>&</sup>lt;sup>152</sup> Submission 28, Fertility Society of Australia, p 2

<sup>&</sup>lt;sup>153</sup> Submission 28, Fertility Society of Australia, p 3

If this primary source of identification document: a birth certificate, includes by way of annexure, addendum or some marking or notation that indicates that there is further material available then that may, as an unintended consequence of the practical use of it as an identification document, indicate to the reader, the third party, that the person was essentially the result of assisted reproductive technology that they were brought into being, that they have a donor, that they may have been brought up in a certain sort of adult-child relationship—that is, two parents of the same gender, single parent with a donor through a private arrangement et cetera. Now our concern is that those are matters—before we get on to issues of genetic health, which I think the later questions address—are really the sole province from a day to-day practical point of view of the individual in whose name the certificate is issued. <sup>154</sup>

#### OTHER JURISDICTIONS

4.61 No other Australian jurisdiction includes donor details on the births register or the front face of the birth certificate, nor do these details appear on the births register or birth certificates in New Zealand or the United Kingdom.

#### Western Australia

In Western Australia, the Reproductive Technology (RT) Registers that contain information on donors, recipients and participants, are maintained by the Department of Health. There is no linkage between the RT Registers and the West Australian Registry of Births, Deaths and Marriages. Under the *Human Reproductive Act 1991* (WA), the only way any person born following a treatment using donated reproductive material may know of the circumstances of their birth is through their parents. 155

#### Victoria

In Victoria, donor details do not appear on the births register or birth certificates, however, as previously outlined, the Registrar of Births notes donor conception where it is indicated on a birth registration statement and donor conceived individuals receive an addendum on a separate page alerting them that further information is available upon applying for a birth certificate when aged 18 or older.

#### New Zealand

In New Zealand, information relating to donors, donor offspring and their guardians involved in embryo, egg or sperm donation at a fertility clinic are contained within the Human Assisted Reproductive Technology (HART) Register. The HART Register is maintained by Births, Deaths and Marriages within the Department of Internal Affairs. However, donor details do not appear on the

 $<sup>^{154}</sup>$  Mr McAteer, Transcript of evidence, 1 March 2012, pp 21-22

Western Australian Reproductive Technology Council, 'Questions and answers about the donation of human reproductive material' <a href="http://www.rtc.org.au/publications/docs/Q&A.pdf">http://www.rtc.org.au/publications/docs/Q&A.pdf</a>, p 5, accessed 15 May 2012

births register or on the birth certificates of donor conceived individuals, and birth certificates are not annotated.  $^{156}$ 

The New Zealand Law Commission Report, New Issues in Legal Parenthood, recommended annotation of all birth certificates with a statement indicating that further information may be available. The Commission concluded that annotation of all birth certificates would protect the privacy of donor conceived individuals by giving them a birth certificate that was not markedly differently to all other birth certificates. The report stated:

This proposal has the benefit of signalling the fact of other information while at the same time respecting the privacy of the individuals and their families. For the vast majority of people, the additional information will be known and uncontroversial – such as their parents' addresses at their birth. However, the aim is that it would become known that Births, Deaths and Marriages holds additional information about all New Zealanders. Anyone with a sense of difference in their family will know that it is their right to ask Births, Deaths and Marriages for access to it.<sup>157</sup>

4.66 However in the response to the Law Commission's report, the New Zealand Government chose not to implement the recommendation for annotation of all birth certificates, stating:

Donor offspring (those conceived from donor eggs or sperm or in surrogacy arrangements) are reliant upon others to tell them about the circumstances of their birth before they can access information about their genetic heritage. The Law Commission's recommendations aim to alert more people to the possibility they may be donor-conceived and to encourage more parents to give this information to their children.

The Government understands the concern underlying the Commission's recommendation. However, it does not agree that a birth certificate is the appropriate place for a statement indicating that additional information may be held by Births, Deaths and Marriages. It may cause confusion for third parties relying on birth certificates as a source of information, particularly overseas organisations unfamiliar with New Zealand registry documents. The Government considers that including this information with birth certificate application forms may be a more effective way of encouraging people to enquire about their genetic origins. The Department of Internal Affairs will consider this issue further. <sup>158</sup>

#### Canada

4.67 The Committee notes the 2007 judgment in Ontario, Canada where the Court of Appeal issued a declaration that a child had three legal parents – his biological mother, biological father and the same sex partner of his biological mother. 159

New Zealand Department of Internal Affairs website, The Human Assisted Reproductive Technology (HART) Register, <a href="http://www.dia.govt.nz/diawebsite.nsf/wpg\_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register#twelve">http://www.dia.govt.nz/diawebsite.nsf/wpg\_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-(HART)-Register#twelve</a>, accessed 20 June 2012

<sup>&</sup>lt;sup>157</sup> New Zealand Law Commission, New Issues in Legal Parenthood, April 2005, p 119

<sup>&</sup>lt;sup>158</sup> New Zealand Ministry of Justice, Government Response to Law Commission Report on *New Issues in Legal Parenthood*, March 2006, <a href="http://www.justice.govt.nz/publications/global-publications/g/government-response-to-law-commission-report-on-new-issues-in-legal-parenthood-march-2006/law-commissions-recommendations-and-government-response">http://www.justice.govt.nz/publications/global-publications/g/government-response-to-law-commission-report-on-new-issues-in-legal-parenthood-march-2006/law-commissions-recommendations-and-government-response</a>, accessed 28 June 2012

<sup>&</sup>lt;sup>159</sup> AA v BB, 2007 ONCA 2, <a href="http://www.ontariocourts.on.ca/decisions/2007/january/2007ONCA0002.pdf">http://www.ontariocourts.on.ca/decisions/2007/january/2007ONCA0002.pdf</a>, accessed 21 June 2012

The judgment was widely reported as meaning that the child would receive a birth certificate with three parents, however this was inaccurate. Prior to this court judgment in Canada, the *Children's Law Reform Act* had been interpreted to mean that a child may have only two parents – one mother and one father – and that if a person sought and was successful in receiving a parentage order when there were already two parents, then one of the original parents must have their parentage extinguished.

### COMMITTEE COMMENT

- 4.68 Donor conceived individuals who participated in the Committee's inquiry were overwhelmingly in favour of donor details appearing on the births register and birth certificates. They argued that their birth certificates were false, as they did not contain the truth about their genetic parentage. Birth certificates were seen as symbolic of the impediments that adult donor conceived individuals face in trying to access information about their donors' identities.
- 4.69 Arguments against donor details being included on the births register and birth certificates focussed on the potential for creating confusion regarding legal parentage, and parental rights and responsibilities, and other unforeseen consequences in terms of family law. Privacy concerns were also raised in evidence, with participants arguing that it would be a breach of privacy to disclose a person's donor conceived status on their birth certificate, particularly in light of birth certificates being primarily used to establish proof of identity.
- 4.70 The Committee recognises that many donor conceived individuals feel strongly that their birth certificates are inaccurate and therefore perpetuate the concealment of their genetic parentage. However, the Committee notes that the purpose of the births register and birth certificates is to record a child's legal parents at the time of their birth. The births register, and birth certificates, are not intended to be a record of a child's genetic origins. Laws relating to parentage, which seek to reflect the reality of parental responsibilities in diverse modern families, mean that a child's genetic parents will not always be their legal parents.
- 4.71 The Committee is emphatic in the view that it is in the interests of donor conceived individuals to be told about their conception and to be able to access information about their donor. The Committee considers that it is unacceptable that many donor conceived adults have been denied this access.
- In the Committee's view, the key issue is to ensure that parents are supported in telling their children about their donor origins, so that children are aware that they are donor conceived and are able to access information about their donor when they reach adulthood. The Committee is not convinced that adding donor details to the births register and birth certificates is the best way to achieve this goal.
- 4.73 The Committee has concluded that donor details should not appear on the births register or birth certificates. In arriving at this conclusion the Committee has attempted to balance the right of children to information about their genetic history and identity with the potential for breach of privacy if donor conceived

status were to be clearly indicated on birth certificates. The Committee considers that honesty and openness about donor conception should be encouraged and that parents who use donor gametes should receive counselling and support to assist them with telling their children the truth about their conception. The Committee's recommendations are aimed at encouraging parental disclosure.

- 4.74 The Committee considers that requiring donors' details to appear on the births register and birth certificates is not an appropriate way to facilitate honesty about donor conception and access to identifying donor information. The Committee heard evidence regarding alternative proposals, including annotating the front face of birth certificates and issuing a separate addendum for donor conceived individuals.
- 4.75 Some participants in the inquiry proposed that all birth certificates be annotated to indicate that further information is available, while others suggested that donor conceived individuals' birth certificates could be marked in this way, to ensure that parents using gamete donors tell their children about their conception. However, many participants expressed concern that this would breach the privacy of donor conceived adults, and would stigmatise them by marking them as different. The Committee shares these concerns.
- 4.76 Many participants in the inquiry referred the Committee to recent reforms in Victoria, whereby donor conceived individuals will receive an addendum attached to their birth certificate when they apply for a birth certificate having reached the age of 18. Under this system, when parents complete a birth registration statement and indicate that their child was donor conceived, the Registrar of Births is required to note that the child was donor conceived in the relevant entry on the births register.
- 4.77 When the donor conceived individual reaches adulthood and applies for a birth certificate, the certificate is issued to them with an addendum on a separate page, which indicates that further information is available. The person is then able to seek further information and apply to obtain their donor's details from the agency that maintains the donor register, should they wish to do so.
- 4.78 Under the Victorian system, a donor's details are not recorded on the births register nor do they appear on birth certificates. However there is a notation on the births register which indicates that donor conception occurred. Donors' details are recorded on a separate register, and donor conceived individuals, recipient parents and donors can seek information that is held on this register by applying to the agency that holds it.
- 4.79 This model was supported by many inquiry participants as striking an appropriate balance between ensuring the right of donor conceived individuals to obtain information about their genetic history and identity while protecting their privacy, and at the same time encouraging parental disclosure.
- 4.80 The Committee notes that the Victorian Law Reform Committee recently considered this legislative incentive for parental disclosure and concluded that the measures adopted in Victoria were appropriate, given that recipient parents receive counselling that it is in their child's interest to know about their

conception. The Committee supports this position and considers that Victoria offers a best practice model for New South Wales.

- 4.81 On balance, the Committee favours the Victorian model of attaching an addendum to donor conceived adults' birth certificates as an appropriate way to encourage parental disclosure and to signal to parents that their child has a right to be told about the circumstances of their conception. The Committee is therefore recommending that this model be adopted in New South Wales.
- The Committee notes that stakeholders such as ART clinics will need to be advised of the changes to the birth registration statement and to birth certificates, through channels such as the Registry of Births, Deaths and Marriages and Ministry of Health websites, and relevant information brochures produced by these agencies. Clinics offering treatment involving donors will therefore be able to inform recipient parents undergoing treatment with donor gametes of the changes, as part of counselling regarding the child's entitlement to information about their conception.

#### **RECOMMENDATION 2**

That the Attorney-General introduce legislation to provide that, if a birth registration statement specifies that a child was donor conceived, the Registrar of Births, Deaths and Marriages is to note that the child was donor conceived in the entry about that child's birth on the register of births.

#### RECOMMENDATION 3

That the Registrar of Births, Deaths and Marriages is to issue an addendum on a separate page, indicating that further information is available, when a donor conceived individual aged 18 or over applies for a birth certificate.

#### **RECOMMENDATION 4**

That the Registry of Births, Deaths and Marriages and the Ministry of Health inform stakeholders of the changes to birth registration statements and birth certificates, through measures including agency websites and brochures.

#### **RECOMMENDATION 5**

That gamete donors' details continue to be held on a separate donor register (the ART Central Register), and not be included on the register of births or birth certificates.

# Chapter Five – Recording donor information

In this chapter the Committee outlines the views of inquiry participants on the recording of donor information, including where the information should be held, and how donor information can be recorded where a child is conceived through a private arrangement. The Committee examines the adequacy of current arrangements for recording donor information on the ART Central Register held by the Ministry of Health and suggestions that the register should instead be held by the Registry of Births, or another agency.

#### LOCATION OF REGISTER OF DONOR INFORMATION

- Donor information for donor conceived births has been held on the ART Central Register, maintained by the Ministry of Health since 2010. Donors who donated before this date, and individuals who were conceived with donor gametes before this date, can voluntarily register their details with the Ministry. The current NSW framework for recording donor details is outlined in detail in Chapter Two.
- The Committee heard differing views on whether the register of donor information should be kept in its current location with the Ministry of Health, or transferred to the Registry of Births, Deaths and Marriages. Inquiry participants' proposals for change included: moving responsibility for the ART Central Register and Voluntary Register to the Registry of Births, Deaths and Marriages; retaining the Registers with the Ministry of Health and giving a role to the Registry in annotating the birth register and/or birth certificates; and establishing a separate body to manage the Registers and provide counselling, support and public education on ART. The Committee examines these proposals for change in detail below.

### Inquiry participants' views on the Ministry of Health

- The Committee heard evidence about the operation of the ART Central Register in its current location, and the views of inquiry participants who considered that the Ministry should continue to manage the register.
- In terms of the cost of maintaining the current ART Central Register, the Ministry advised that the total staff cost is \$33,832, with a recent public awareness campaign costing \$33,600. The total cost of maintaining the register, including the awareness campaign is \$67,432. The Register is managed by staff of the Ministry's Private Health Care Unit, with staff costs and other costs such as IT and web support being drawn from the Unit's budget; there is no additional, discrete funding allocated for maintenance of the Register. <sup>160</sup>
- 5.6 Ms Leanne O'Shannessy from the Ministry of Health told the Committee that donor information should be held in a sole repository, however, she did not express a view on where the repository should be located. In terms of the

 $<sup>^{160}</sup>$  Ministry of Health, Answers to questions taken on notice at public hearing on 1 March 2012, p 1

suggestion that both agencies could play a part in handling donor information, Mr Greg McAllan from the Ministry made the following comment:

... Disadvantages would be double handling of data, just in terms of administrative efficiency; it is not particularly efficient to have it in two places. Another disadvantage is that it adds to confusion for the clients about where to go. Logically, you go for birth information to Births, Deaths and Marriages. On the other hand, we have already got this up and running. In that sense, I am not sure what other resources we would require to make an arrangement with Births, Deaths and Marriages if it was decided to put it on their register as well. <sup>161</sup>

- 5.7 The Fertility Society of Australia did not take a position on which agency should manage the donor register, noting that although both agencies have record management experience they require additional resources to cater to the needs of all parties who may be seeking information on ART. 162
- The Committee heard from participants in donor conception who supported the existing Ministry of Health register. A sperm donor submitted that the Registry of Births should have a role in including donors on birth certificates, but there should nonetheless continue to be a register of donor details held by Ministry of Health.<sup>163</sup>
- 5.9 Submission makers argued that the register contains genetic information and that the Ministry is an appropriate location for records of this nature. A recipient parent expressed support for retention of the current Health managed register, with no registration of details at the Registry of Births, on the basis that the Health register 'should be sufficient to enable any children to discover basic details about their donor and genetic history'. 164
- The Inner City Legal Centre expressed support for the Central Register 'as an appropriate mechanism to store information for donor-conceived people'. They argued that the Registry of Births, Deaths and Marriages is a repository of family information, and is therefore not an appropriate place to store information about a person's biological or genetic history:

... we do not think it is necessary for the Central Registry to be managed by the NSW Registry of Births, Deaths and Marriages. If people would like to explore their *family's* history then the NSW Registry of Births, Deaths and Marriages will be able to provide that information not the Central Registry.

The Central Registry is repository of information connected to the donor-conceived person's biology, not the donor-conceived person's family. As noted above, we acknowledge that it is important for medical information to be kept for the emotional and physical well being of the donor-conceived person, however we strongly advocate that this information is not familial information. We consider the distinction between parents and donors to be of great importance. In gay or lesbian families one parent will not have a biological connection to the child. In law, this

<sup>&</sup>lt;sup>161</sup> Mr Greg McAllan, Associate Director, Legal and Regulatory Services, Ministry of Health, Transcript of evidence, 1 March 2012, p 16

<sup>&</sup>lt;sup>162</sup> Submission 28, Fertility Society of Australia, p 5

<sup>&</sup>lt;sup>163</sup> Submission 3, Name suppressed, p 3

<sup>&</sup>lt;sup>164</sup> Submission 20, Name suppressed, pp 1-2

# INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS RECORDING DONOR INFORMATION

does not mean that they are not the child's parent. If the gay or lesbian couple have used a donor it is appropriate that particular information is available, if needed for the child's physical or emotional well-being, in our submission this is a health issue and unrelated to the child's identity as a member of that family. <sup>165</sup>

5.11 Professor Jenni Millbank also reflected on the respective roles of the Ministry and Registry of Births and their suitability for maintaining the donor register. She stated that while both agencies lacked certain support functions, in her view it would be unnecessary to move the ART Central Register:

The Central Register is managed by the Department of Health and is intended as a record of genetic information, including years of birth and sex of genetic half siblings. At present it lacks any facilitative or counselling functions to assist parties when they seek information under the register. This is a major omission, but will not become a pressing issue until the register has been in place for 18 years, although problems are likely to arise under the voluntary register sooner.

The Register of Births is managed by Births, Deaths and Marriages (BDM) and records legal parentage of children. BDM does not match parties or provide a range of information about broader genetic relatives beyond the family of birth. In my view it would be a dramatic shift in role for BDM to record genetic information and/or to manage dual registers of legal and genetic parentage on a general basis. There is no evidence to suggest that this is desirable or necessary. <sup>166</sup>

- Professor Millbank supported retention of the register with the Ministry, stating that 'it is premature to consider amending it as yet. A considered process exploring the range of perspectives of recipient parents, adult and mature donor offspring, donors and clinics is necessary and should be undertaken as part of the 5 year review required under s 74 of the Act. 167
- 5.13 The NSW Gay and Lesbian Rights Lobby echoed Professor Millbank's comments in favour of keeping the register in its current location, and basing any future changes on a statutory review of the register's operation. 168
- Dr Sonia Allan submitted that the existing Central Register should continue to be managed by the Ministry of Health, with a role for the Registry of Births, Deaths Marriages in facilitating individuals' knowledge about their conception: 'fundamental to access to information is the need for donor-conceived individuals to have knowledge of their conception and this is where the role of the RBDM is crucial.' Dr Allan submitted that the Registry's role should be to annotate birth certificates, so that donor conceived individuals are aware that further information is held on the Central Register.<sup>169</sup>

<sup>&</sup>lt;sup>165</sup> Submission 25, Inner City Legal Centre, p 2

<sup>&</sup>lt;sup>166</sup> Submission 17, Professor Jenni Millbank, p 5

<sup>&</sup>lt;sup>167</sup> Submission 17, Professor Jenni Millbank, p 5

<sup>&</sup>lt;sup>168</sup> Submission 23, NSW Gay and Lesbian Rights Lobby, p 7

<sup>&</sup>lt;sup>169</sup> Submission 13, Dr Sonia Allan, pp 28-9

#### Additional services

- 5.15 Dr Allan also recommended that support services be provided for donor conceived people, recipient parents and donors in relation to the collection and release of such information. <sup>170</sup>
- 5.16 Other inquiry participants also emphasised the need for adequate support services. In terms of the Ministry's management of the Register, the Donor Conception Support Group argued that its staff lacked relevant experience and training to manage the donor register, and are unable to provide necessary counselling: 'The NSW Register has no counsellors available which is something that is absolutely necessary when dealing with birth origin information.' 171
- 5.17 The Committee notes Mr Greg McAllan's evidence that it was not envisaged that the Central Register would provide a publicly funded counselling service, and therefore its staff are not trained to provide this service. Mr McAllan outlined the counselling provided by donor registries in other states of Australia:

... It depends how Rolls Royce you want the service to get. In Victoria they will give you a list of counsellors, but it is private; you pay. It is privately paid for. We do not give a list. On our website we refer people to ANZICA, the infertility counsellor association and it can nominate someone for you. But we do not think it is proper for us to be nominating approved counsellors. In Western Australia you get one counselling session and then after that you pay. So the service is not Rolls Royce in any jurisdiction, as far as I am aware. I think also in terms even of adoptions here, it is user pays for counselling sessions. ... 1772

## Inquiry participants' views on the Registry of Births, Deaths and Marriages

The NSW Government's submission to the inquiry observed that registering donor information on the Register of Births 'would represent a significant change from the current mechanism for recording such information, namely the ART Central Register'. The NSW Government emphasised the importance of considering the interests of donor conceived individuals, and stated that a single repository of donor records could have potential benefits both for donor conceived individuals and donors:

A client-centred approach and, in particular, the best interests of the child must be central in determining where donor information should be held, in order to provide a simple, easy to use and effective register for people to access their information and the information of those relevant to them. Maintaining disparate or overlapping repositories of information around donor conceived births would not provide a positive outcome in terms of the administrative costs for government nor in terms of the ease of use for individuals.

... By creating a sole repository of information regarding genetic as well as social history, a BDM-held donor register would provide a one-stop-shop for individuals to access information regarding their origins and identity. BDM records key information relating to the birth of a child. By including donor details with BDM's existing

<sup>&</sup>lt;sup>170</sup> Submission 13, Dr Sonia Allan, pp 24-5

 $<sup>^{171}</sup>$  Submission 7, Donor Conception Support Group, p 9

<sup>&</sup>lt;sup>172</sup> Mr McAllan, Transcript of evidence, 1 March 2012, pp 15, 19

records, it would provide recognition for the important role (genetic and sometimes familial) of the donor. <sup>173</sup>

- 5.19 In its submission, the NSW Government outlined possible ways that the Registry of Births could hold donor information, summarised below:
  - The Ministry of Health maintains the current ART donor registers and transfers any necessary information to the Registry of Births this could result in duplication of information and administrative work.
  - All data held on the ART donor registers is transferred to the Registry of Births, and held on either the existing births register, or a separate register managed by the Registry. The Ministry of Health continues to be responsible for other aspects of ART, including regulation of ART providers.<sup>174</sup>

### Impact of moving the register

5.20 In terms of the effect of such a change, the NSW Government stated that there would be additional costs and an ongoing impact on the Registry's operations:

... new relationships would have to be developed between BDM and the ART providers who collect information for the existing ART Central Register (although it should be noted that there are only 13 such providers), and there would potentially be the need for new regulatory instruments to reflect the change. There would also be costs associated with closing the existing registers, transferring the information, setting up a new register or providing for the additional information within the existing BDM register, as well as ongoing administrative and potentially staffing requirements. That said, there would also be cost savings from the closure of the ART Central Register. 1775

- 5.21 The NSW Government noted that the Registry operates on a cost-recovery model and observed that, if the register were to be moved to the Registry, it would be important to ensure that the cost of registration would not act as a disincentive to donors wishing to register their details on the voluntary register, particularly given that 'under the current NSW Health system, the \$50 administration fee is waived.' 1776
- 5.22 The Committee notes the Registry's advice that 'fees for searching the donor register would be based on the fee for searching for adoption information. Currently this fee is \$50. A fee would also be charged for the issue of a birth certificate (\$46.00) if that were required. 1177
- 5.23 The Committee notes the information provided by the Registrar of Births on the financial impact of requiring the registration of donor information to be undertaken by the Registry. Mr Curry told the Committee that the Registry does not receive funds from Treasury and as a result its operations are funded through

<sup>&</sup>lt;sup>173</sup> Submission 31, NSW Government, pp 4-5

<sup>&</sup>lt;sup>174</sup> Submission 31, NSW Government, pp 4-5

<sup>&</sup>lt;sup>175</sup> Submission 31, NSW Government, pp 4-5

<sup>&</sup>lt;sup>176</sup> Submission 31, NSW Government, pp 4-5

<sup>&</sup>lt;sup>177</sup> Registry of Births, Deaths and Marriages, Answers to questions taken on notice at public hearing on 1 March 2012, p 2

the provision of services. The Registrar advised that, if the Registry were given the role of maintaining donor records, additional resources would be required. The Registrar estimated that his office would be required to process 200-300 additional registrations each year, which would make up the bulk of the increase in costs for the Registry. In terms of the registration process, the time taken for processing would vary, as ART clinics would be providing the Registry with verified identity details, while in the case of private arrangements, more verification work may need to be undertaken by the Registry in order to ensure the integrity of the register. <sup>178</sup>

- The Registrar estimated, based on his office's experience with registering adoptions, that up to four extra staff would be needed, with an approximate annual cost of \$230,000. In terms of implementation costs, an additional employee (costing around \$63,000) may also be required in the first year, to 'deal with preparation and dissemination of information, amendments, disputes and search requests.' Technical changes to the Registry's computer systems to enable altered registration could amount to \$100,000. 179
- 5.25 Mr Greg McAllan from the Ministry of Health told the Committee that transferring existing data to another agency would pose few difficulties for the Ministry due to the low number of people registered on the database. He stated that the work involved would be primarily administrative in nature, while also noting that the Ministry 'would be the register for the ART providers and, obviously, that would remain our role under the Act. 180

#### Benefits of moving the register

- Inquiry participants told the Committee of the possible benefits resulting from transferring donor data to the Registry of Births, Deaths and Marriages. Ms Gabrielle Carney from the Department of Attorney-General and Justice told the Committee that 'donor conceived people are more likely to approach the Registrar of Births, Deaths and Marriages for information regarding their genetic origins, especially if they have not been informed by their parents that they were donor conceived.' 181
- 5.27 The Hawkesbury Nepean Community Legal Centre recommended that the ART Central Register be transferred to the Registry of Births, as the most appropriate agency to hold such data, and in terms of centralising the management of information about people's genetic and medical history:

We submit that it is common practice for people to approach their Registry of Births, Deaths and Marriages when they want to find out information about their family's history and cultural heritage. ...

<sup>&</sup>lt;sup>178</sup> Registry of Births, Deaths and Marriages, Answers to questions taken on notice at public hearing on 1 March 2012 n 1

<sup>&</sup>lt;sup>179</sup> Registry of Births, Deaths and Marriages, Answers to questions taken on notice at public hearing on 1 March 2012, p 1

<sup>&</sup>lt;sup>180</sup> Mr McAllan, Transcript of evidence, 1 March 2012, p 17

<sup>&</sup>lt;sup>181</sup> Ms Carney, Transcript of evidence, 1 March 2012, p 2

We submit that because the medical history of their donor is only one aspect that assists in shaping a donor conceived person's identity, the Registry is the more appropriate agency to maintain and manage the Central Register. ...

Transferring the management of the Central Register to the Registry would centralise information about parentage and treat donor conceived people who want information about their parentage in the same way as other children seeking information about their family. 182

- 5.28 The Law Society of NSW expressed support for the Registry of Births keeping a register of donors' details. Ms Pam Suttor, representing the Law Society, told the Committee that a sole repository of records would be advantageous and that, subject to the accuracy of data, the Registry would be the appropriate agency to hold such records 'as it already has most of this information it should be able to provide an accessible, reasonable-cost information service.' 183
- 5.29 Ms Christine Whipp supported moving details to Registry, commenting that 'The current system for recording donor information has not been beneficial to those who are donor conceived and I would support a move for the details of donor conception to be kept by the Registrar of Births, Deaths and Marriages. 1184
- 5.30 Ms Miranda Montrone submitted that the current system for recording donor information is inadequate. She expressed support for moving donor information held by the Ministry on the ART Central Register to the Registry of Births and including it on the register of births. Ms Montrone submitted that the Registry should also maintain a voluntary register for information relating to donor offspring born prior to January 2010. 185
- 5.31 Miss Narelle Grech supported a system of registration whereby donor conceived status is 'noted with the Register of Births by the clinic who arranges for the treatment of donor conception to occur.' Ms Myfanwy Cummerford also submitted in favour of a requirement for clinics to report such births to the Registry of Births:

I also recommend the implementation of a system of ART clinics reporting to the registry of Births, Deaths and Marriages information regarding births where donor gametes were used to minimise the possibility of a parent falsely registering their donor conceived child as naturally conceived. 187

5.32 The Hon Greg Donnelly MLC submitted that donor information 'should be recorded and maintained by the NSW Registrar of Births, Deaths and Marriages.' 188

<sup>&</sup>lt;sup>182</sup> Submission 8, Hawkesbury Nepean Community Legal Centre, pp 5-6

<sup>&</sup>lt;sup>183</sup> Ms Pam Suttor, Councillor and Chair, Elder Law and Succession Committee, Law Society of NSW, Transcript of evidence, 5 March 2012, p 9 and Submission 22, Law Society of NSW, p 1

<sup>&</sup>lt;sup>184</sup> Submission 14, Ms Christine Whipp, p 1

<sup>&</sup>lt;sup>185</sup> Submission 24, Ms Miranda Montrone, pp 2-3

<sup>&</sup>lt;sup>186</sup> Submission 18, Ms Narelle Grech, p 2

<sup>&</sup>lt;sup>187</sup> Submission 19, Ms Myfanwy Cummerford, p 1

<sup>&</sup>lt;sup>188</sup> Submission 27, The Hon Greg Donnelly MLC, p 1

5.33 Some submission makers proposed a compromise position rather than transferring the entire register. Ms Carney from the Department of Attorney-General and Justice told the Committee that, rather than transferring responsibility for the ART register, other options would be for the Ministry to provide information on donor conceived births to the Registry or for parents themselves to provide the information voluntarily:

... if it is not possible or preferable for the ART register to be transferred to the Registry then the Ministry of Health could simply provide BDM with relevant information from the ART register as and when required. This would also ensure the veracity of the information provided to the Registry. Alternatively, legal parents could have the option of voluntarily providing such information with the donor's consent. 189

### Difficulties with moving the register

Inquiry participants' comments on possible difficulties raised by moving the register focussed on privacy and data protection, as well as the limitations on the services provided by the Registry. The Deputy Privacy Commissioner, Mr John McAteer, told the Committee that a statutory change to the current system for recording donor information would have to specifically enable the transfer of relevant data, as privacy laws prevent government agencies from transferring health or personal data to another agency, unless certain criteria are met. He also observed that the information protection principles applying to agencies mean that, if two databases were kept, a second agency may need to put measures in place in terms of the security, accuracy and currency of the data held. Having two databases also raises security issues: 'if the information was somehow compromised then there are two places or two opportunities for the information to be compromised.' 190

5.35 The Deputy Privacy Commissioner also raised the issue of possible duplication of information, should donor related data be held in two databases. However, he expressed the view that such duplication is likely to arise given the nature of donor information:

... I think the real issue though is that the medical information would probably need to be retained by the Ministry of Health or its subsidiary, and the demographic and statistical and identification information would be retained by the Registrar of Births, Deaths and Marriages. So there probably would still need to be the two holdings.

5.36 Ms Gabrielle Carney from the Department of Attorney-General and Justice observed that there are limitations on who may access data that is on the register of births when compared with the current accessibility of medical data on the ART Central Register:

The ART register maintains medical information relating to donors. In the case of a medical emergency or life-threatening situation parents can apply to the Director-General of Health for identifying donor information. Alternatively, donor conceived

<sup>&</sup>lt;sup>189</sup> Ms Carney, Transcript of evidence, 1 March 2012, p 2

<sup>&</sup>lt;sup>190</sup> Mr McAteer, Transcript of evidence, 1 March 2012, pp 24-25

<sup>&</sup>lt;sup>191</sup> Mr McAteer, Transcript of evidence, 1 March 2012, pp 24-25

people may access such information when they become adults. In contrast, ... the BDM does not retain medical information. In certain circumstances the ART register may be accessed by donors, donor conceived people, siblings of donor conceived people and legal parents of donor offspring. In contrast, access to the New South Wales birth register is generally restricted to the person in respect of whom the entry is made, subject to limited exceptions such as parents applying for their child's birth certificate and in relation to births that occurred more than 100 years ago. 192

5.37 Western Australia's Department of Health – which manages that state's donor register – echoed Mr John McAteer's comments in regard to privacy and protection of sensitive information, noting that:

... There is increasing public concern about identifying information being held on central registers and links to different databases, which can increase the vulnerability of inadvertent release of highly sensitive information. 193

- 5.38 Mr Michael Sobb emphasised the importance of accuracy in recording relevant data, and expressed concern about the potential for errors by the Registry of Births. 194
- 5.39 Ms Carney raised potential difficulties with shifting management of the existing ART Central Register in terms of the roles currently performed by both agencies. She noted that moving the register would mean significant changes to the Registry's operations, and that the Ministry of Health would need to retain some of its statutory functions, such as regulation of ART providers. In addition, the Registry of Births may not be equipped to provide any counselling services:

The potential disadvantages of this approach are that there are some health related aspects of the ART register that may be better managed by the Ministry of Health. For example, under the Assisted Reproductive Technology Act the Ministry of Health currently regulates services provided by registered ART providers. If the ART register were transferred other aspects of ART such as the regulation of ART providers would need to remain with New South Wales Health. Similarly, if counselling is to be provided to donor conceived people when they are first informed that they are donor conceived the BDM may not be well placed to facilitate this. 195

5.40 The Commission for Children and Young People also drew the Committee's attention to the other services currently provided by the Ministry of Health. The Commission submitted that, although it did not have a view on which agency should manage donor information, there were several functions associated with donor information that may need to be provided by the Registry if the registers were to be moved:

... it is noted that NSW Health performs a number of other functions in regard to donor information, including operating a voluntary register for people who were donor-conceived before 1 January 2010 and for donors who donated before this date. NSW Health has also developed internal procedures for the exchange of

 $<sup>^{\</sup>rm 192}$  Ms Carney, Transcript of evidence, 1 March 2012, p 2

 $<sup>^{193}</sup>$  Submission 30, WA Department of Health, p 4

<sup>&</sup>lt;sup>194</sup> Submission 4, Michael Sobb, p 3

<sup>&</sup>lt;sup>195</sup> Ms Carney, Transcript of evidence, 1 March 2012, p 2

voluntary information to assist donors and donor offspring seeking information about each other, and liaises with ART providers in this regard.

In addition, NSW Health assists parents of a donor-conceived child to contact the donor in exceptional circumstances such as a medical emergency. If responsibility for this information were to transfer to the Registrar, responsibility for these additional functions would also need to be transferred. The suitability of the Registrar to perform these functions, and any additional functions performed by NSW Health under the above Act, and its capacity to do so, would need to be explored. <sup>196</sup>

The Registrar of Births, Deaths and Marriages, Mr Greg Curry, stated that the Registry was not equipped to provide counselling and support services. However he noted that in the case of adoptions, the Registry works with the Department of Human Services to provide support to people who apply for a copy of their original birth certificate:

There are functions that the registry is not equipped to carry out; in particular I refer to things such as health or genetic counselling and family counselling. We have a good working relationship with, for instance, the Department of Human Services in relation to adoptions, and in the case of adoptions where a person who was adopted seeks a copy of their original birth certificate supply authority is provided by the head of the Department of Human Services, which arranges support for that person. That is something that we are not equipped to do but the division of labour, as it were, works quite effectively. ... In terms of the central ART register operated by Health, I believe there are functions operated by the health department or affiliated with the health system which we are not in a position to operate. I am thinking of the type of counselling and genetic support that one would expect to be provided to someone who was seeking details of their donor. <sup>197</sup>

5.42 The Committee discusses the provision of counselling and support services in detail in Chapter Six.

## Establishing a separate body to manage the register and perform additional functions

5.43 Some inquiry participants suggested that an independent body should be established to manage the donor register and perform other functions associated with donor conception. Dr Sonia Allan told the Committee that broader consideration should be given to the future role of the register and whether the agency managing the register should be performing additional functions. She argued that there are further support functions that go beyond the administrative nature of the current register, which should be performed by the body that manages the register:

I would say I suppose to me it is not so much an issue of where the information is held but primarily it is dependent upon how the register operates. So I believe at the moment the central register, because it is only new, is simply a repository for information, so I imagine that if the same were to be so of the Births, Deaths and Marriages Register then there is not really much difference. But I think what needs to be looked at is whether or not in the future the role of the Central Register, or

<sup>&</sup>lt;sup>196</sup> Submission 16, NSW Commission for Children and Young People, p 1

 $<sup>^{197}</sup>$  Mr Curry, Transcript of evidence, 1 March 2012, p 8

wherever the information is held, goes beyond simply being a repository for information and functions in a way that is able to deal with some of the complexities surrounding donor conception.

So, to me, wherever the information is held, it needs to be either at a place that does not only hold information but can assist with information exchange, guiding applicants to information, the process of receiving information and how to handle the information that they have received. The information in relation to donor conception I would view as not the same as somebody simply going and applying for a birth certificate and getting information about their legal parents or their birth parents. There are things that go beyond that like providing assistance to people—if that is required or wished for—if there are issues about the fact that donor conceived people could be genetically related to siblings in a number of families. So it is much more complex than simply having information held on the register. <sup>198</sup>

5.44 Professor Jenni Millbank also proposed reforming the current system to better address the needs of people affected by donor conception, through the provision of additional support services. She told the Committee that 'it is very worthwhile considering making a separate quasi or semi-independent entity to deal with these functions and to fund it accordingly':

... The central register held by Health does not provide this kind of counselling and assistance function. Clinics themselves usually provide those functions but some people have gone through clinics that have closed down or that have changed hands and have different personnel, so people are not always able to go back and access those services. ... Our system is set up so that young adults can access information about their donors and limited information about genetic half-siblings. We do not have a system that takes into account the wide range of people's curiosity about non-identifying information or the ability or interest that some people have in making contact when they are still children. ...

We really have not thought about how to deal with those kinds of lateral relationships. Some clinics are facilitating that contact on a voluntary basis. Community groups are setting up their own websites and making those links on a completely unregulated and kind of rogue basis. It is clear we need to have some way of responding to those needs and interests to accommodate that broader range of interests and to do so in a way that involves oversight and the provision of counselling services so that people can consider their decisions. ... <sup>199</sup>

5.45 Ms Caroline Lorbach from the Donor Conception Support Group argued that a separate agency should be established to assist people by providing necessary information and recommendations for counselling:

... So people are left high and dry as to where they go for help and they are coming to our group—we are not trained counsellors either, we can suggest to people that they perhaps look to places like Relationships Australia, but at the moment there are no organisations that will help people who are struggling with this information except for us. We need something that is either a separate authority or resides in a

<sup>&</sup>lt;sup>198</sup> Dr Allan, Transcript of evidence, 5 March 2012, p 1

<sup>&</sup>lt;sup>199</sup> Professor Jenni Millbank, Transcript of evidence, 5 March 2012, pp 21, 24

place that may have experience with this sort of information, like the Post Adoption Resource Centre.  $^{200}$ 

- 5.46 Ms Lorbach also noted that a standalone body would have its own website, which would mean that information is easier to find. This would result in improved public awareness about the donor register, and provide encouragement for people to register on the voluntary register.<sup>201</sup>
- 5.47 The Fertility Society of Australia also submitted in favour of the establishment of a separate agency to perform broader educational and co-ordinating functions associated with ART and the donor registers, as is the case in Victoria:

... in New South Wales at the moment the needs of donors and donor-conceived people, the register is kind of being managed administratively but there is an absence of any resources linked to that. It would be useful to have a tribunal or advisory body that has people experienced in working in assisted reproductive technology to manage the complex and sensitive requests that come up with donor conception. The models that exist in Australia already exist in Victoria and Western Australia too, as we have talked about, but I guess we advocate VARTA as the model that works well. We see the potential functions of a tribunal as being things like community education re donor conception, education for parents about telling a child, better coordination of information about donor-conceived adults.

### Where donor information is held in other jurisdictions

- As noted in Chapter Three, not all Australian jurisdictions maintain donor registers. Western Australia's Reproductive Technology Register and Voluntary Register are maintained and managed by the Department of Health. South Australia has passed legislation enabling a donor conception register to be kept by the Minister for Health, although no register has been established to date.
- 5.49 Some submission makers who expressed support for transferring responsibility for donor registers to the NSW Registry of Births cited Victoria's transfer of its donor registers from VARTA to the Registry of Births, Deaths and Marriages in 2010, and argued that NSW should also adopt this approach. However, a Victorian Parliamentary Committee inquiry has since recommended that responsibility for managing the donor registers be returned to VARTA.
- The amendments to Victoria's donor conception system in 2010 meant that the Infertility Treatment Authority (VARTA's predecessor) was no longer responsible for managing the donor registers and for providing associated counselling. These services shifted to the Registry of Births, Deaths and Marriages and the Department of Human Services respectively. VARTA 's role changed to focus on public education and community consultation.

<sup>&</sup>lt;sup>200</sup> Ms Caroline Lorbach, National Consumer Advocate, Donor Conception Support Group of Australia Inc, Transcript of evidence, 1 March 2012, pp 38-39

 $<sup>^{201}</sup>$  Ms Lorbach, Transcript of evidence, 1 March 2012, pp 40-41

<sup>&</sup>lt;sup>202</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 32

<sup>&</sup>lt;sup>203</sup> Submission 8, Hawkesbury Nepean Community Legal Centre, pp 5-6; Submission 11, Ms Jennie Burrows, pp 2-3; Submission 24, Ms Miranda Montrone, pp 2-3

- 5.51 The Victorian Committee noted that the rationale for shifting management of the registers had been to normalise donor conception, and that the Registry of Births was considered to be the appropriate agency to manage the records. The Victorian Committee examined the Registry's management of the registers and detailed the criticisms it had heard regarding the altered service arrangements. The Committee's comments on the current system focussed on the shortcoming and limitations of counselling and support for stakeholders. It also noted that the division of responsibilities between the agencies involved in donor conception, and the limits on exchange of information between them, meant that the system was 'disjointed and difficult for donor-conception stakeholders to navigate.' 204
- The Victorian Committee concluded that the purpose of moving the donor registers to the Registry of Births had not been realised and that the change had resulted in a reduction in services to stakeholders. It recommended that a single agency should perform all services related to donor conception in order to improve the standard of service, and its accessibility and efficiency. The Committee concluded that 'VARTA is the agency best placed to provide all services related to donor-conception' and that counselling and support services should be modelled on the services that had previously been provided by VARTA (previously known as the ITA).

#### Committee comment

- As part of its consideration of whether donor details should be included on the register of births, the Committee has examined the operation of the existing system for recording donor details, through a register held by the Ministry of Health (the ART Central Register). The Committee heard evidence about the current register, including arguments in both favour and against retaining it with the Ministry of Health. Inquiry participants noted that moving the register to the Registry of Births, Deaths and Marriages would provide a more streamlined and centralised service to people seeking family and genetic information. Participants also pointed to the Registry's expertise in records management.
- Other participants argued that the register should continue to be held by the Ministry of Health. It was noted that some health-related functions relevant to assisted reproductive treatment are performed by the Ministry and that these functions, including the registration of ART providers, would continue to be performed by NSW Health. The Deputy Privacy Commissioner observed that some medical data in relation to ART may still need to be retained by the Ministry. The Committee also heard evidence that it is premature to assess the adequacy of the existing register, or consider moving it, as it has only been operating since January 2010.
- 5.55 The Committee notes that the Victorian Parliament's Law Reform Committee has recommended that responsibility for Victoria's donor registers be moved from the Registry of Births to VARTA, the agency that previously managed the Victorian registers (under the Health portfolio). South Australia has introduced

<sup>&</sup>lt;sup>204</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors* – Final report, March 2012, pp 137-44, 146-47

<sup>&</sup>lt;sup>205</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors* – Final report, March 2012, pp 147-52

legislation providing for the establishment of a donor register by the Minister of Health, and Western Australia manages its donor register through the Department of Health. The Committee considers that consistency with other jurisdictions is desirable. In this regard, the Committee will monitor future developments in Victoria, including the government's response to the Law Reform Committee's recommendation. Victoria's system is considered to represent best practice in terms of access to donor conception information and associated support services.

- 5.56 The Committee is not persuaded that the ART Central Register should be moved from its current location with the Ministry of Health to the Registry of Births. Stakeholders' criticisms of the Ministry's management of the register centred on the lack of support services and the Committee is not convinced that moving the register would result in improved services to donor conceived individuals and their families. The Committee notes that the Victorian Law Reform Committee concluded that moving that state's donor registers to the Registry of Births had resulted in a reduction in services to donor conceived individuals.
- 5.57 The Committee is of the view that management of the donor register should be more than a purely administrative, record-keeping role, and that the location of the register should therefore be considered in the context of what support services should be made available in relation to donor conception and ART, and how these services should be provided. The Committee considers that it would be premature to recommend changes to the management of the register until these wider issues are assessed.
- 5.58 The Committee intends to examine the proposal to set up a standalone body, and other suggestions for improving support services, as part of a future inquiry. In the interim, the Committee is recommending that the donor register continue to be managed by the Ministry of Health.

#### FINDING 1

There was insufficient evidence for the Committee to recommend changes to the management of the ART Central Register. The management of the Register should be examined in the context of the support services that may be required by donor conceived individuals, donors and their families. The Committee will give further consideration to these issues as part of a future inquiry.

In the interim the ART Central Register should continue to be managed by the Ministry of Health.

### RECORDING DONOR INFORMATION FOR PRIVATE ARRANGEMENTS

5.59 The Committee heard evidence regarding the registration of donor conceived births that occur outside a regulated clinical setting, through private arrangements between donors and recipients. The ART Act, which established the current system for recording donor information, only applies to children conceived through ART providers and does not cover private arrangements. This means that, as the NSW Government submission notes, 'Conceptions using so-called non-medical donations or private arrangements are not covered by this definition, and, as such, information on private donors and their offspring are not

recorded by the ART Central Register'. The system therefore does not provide for such donors to be 'formally recognised as the donor of the child, or for children born as a result of private donor arrangements to formally get access to information about their donor parent. <sup>206</sup>

5.60 The Committee heard from stakeholders who argued that it should be possible for participants in private arrangements to register their information on the donor register. Ms Caroline Lorbach told the Committee that the Donor Conception Support Group had received inquiries from participants in private arrangements who wished to include their details on the donor register:

... we have people coming to our group who have used private arrangements or are planning to and now that a few more people are aware of the registers we are getting asked the question can they put their names on the register, and we tell them no, but I am also giving them the phone number of the register and saying speak to them as well. So we are getting people coming thinking even though they have gone through a private arrangement where they know that person they would like the safeguard of having information on a government register in case at some stage they lose track of that person, so there is somewhere if anything happens to them or their own private records that their children can go to find the information as well. <sup>207</sup>

The NSW Government submitted that, while making it a requirement for such information to be recorded would be impractical, enabling the voluntary registration of private arrangements would give all donor conceived children equal access to information, regardless of whether they were conceived though an ART provider:

The existing voluntary register could be expanded to provide for information relating to private arrangements. This would allow for the collection and disclosure of information relating to all donors and their offspring to be consistently managed under existing mechanisms contained in the voluntary register. While the provision of such information on a voluntary basis entails some risk of misinformation, this risk is considered minimal. <sup>208</sup>

- Registering information about births resulting from private arrangements on the births register as part of the normal birth registration process was also identified as a possible means of recording information about such births. The NSW Government stated that the information provided could be verified through a formal notice to the Registry of Births by the parents and donor, and subject to the obligations outlined under the *Births, Deaths, and Marriages Registration Act* 1995. 209
- 5.63 There are some issues raised by such a proposal, and the Registrar of Births pointed to the question of whether people should be compelled to record donor information in private arrangements, and also noted the identity verification steps that could be taken to ensure the integrity of the births register:

<sup>&</sup>lt;sup>206</sup> Submission 31, NSW Government, p 3

<sup>&</sup>lt;sup>207</sup> Ms Lorbach, 1 March 2012, p 39

<sup>&</sup>lt;sup>208</sup> Submission 31, NSW Government, p 4

<sup>&</sup>lt;sup>209</sup> Submission 31, NSW Government, p 4. It is an offence to make a false representation in a notice to the Registry under section 57 of the *Births, Deaths, and Marriages Registration Act 1995*.

... The question that arises immediately is that were such an informal arrangement made between three or four people, what level of compulsion should exist and rest with the donor or the parents to require the recording of that information. I point out also that the registry holds records in perpetuity. We have an obligation to ensure the integrity of the register. We would therefore take some steps, perhaps by statutory declaration, to obtain some level of confidence about the identity of the donors. <sup>210</sup>

- 5.64 Mr Greg McAllan from the Ministry of Health expressed reservations about registering private arrangements on the current voluntary register, citing the verification of information and ensuring consent by all parties as potential difficulties. However, Mr McAllan also noted that surrogate births are included on the ART Central Register based on information provided by the intended parents, and that this information is tested in the Supreme Court when parenting orders are made.<sup>211</sup>
- 5.65 Ms Elizabeth Hurrell, representing the Fertility Society of Australia, stated that 'given that we know this is happening, then it is important to put these opportunities for registration in place if possible'. However, she commented on the potential difficulties of regulating private arrangements:

... It is going to be very difficult to mandate something like this in a totally unregulated area. I am not quite sure how you could do it. We do not see any harm if both parties consented and were fully informed of the implications of having their names on a register. I do not see that it is a problem if the donor and recipient are both consenting to that. But I do not know how you would manage it. You would need to put lots of safeguards in place. <sup>212</sup>

- 5.66 The Inner City Legal Centre expressed support for the recording of donor details for private conception arrangements. <sup>213</sup>
- 5.67 The Committee received a submission from a sperm donor with experience in making donations through private arrangement. Mr John Lindsay Mayger outlined the ways in which single women and couples can source donors privately, and expressed concern that donors' records can be lost in some privately organised conceptions:

I am currently a 'free lance' sperm donor to single and partnered lesbians and to single straight women commonly referred to as SMCs, Single Mothers by Choice as well as married women whose husbands are infertile. I have 13 little children (7 girls and 6 boys) aged from 7 3/4yo to 6months old. I have several current pregnancies. However, there are women who have used my sperm who have not reported either a successful conception/birth or a failure to conceive so these numbers are only a verifiable minimum. I am currently trying to help several women become mothers and I am still offering my services on international web groups and by referral.

There are many informal international web groups like Pride Angel, Co-parents.com, Coparentmatch.net and Free Sperm Donors Register to name the most popular sites.

 $<sup>^{\</sup>rm 210}$  Mr Curry, Transcript of evidence, 1 March 2012, pp 9-10

 $<sup>^{211}</sup>$  Mr McAllan, Transcript of evidence, 1 March 2012, p 18

<sup>&</sup>lt;sup>212</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 32

<sup>&</sup>lt;sup>213</sup> Mr Stubbs, Transcript of evidence, 5 March 2012, p 17

On these international sites, which operate in Australia, both donors and recipients advertise themselves and their situation. Some lesbian women and donors on these sites advertise that they want no contact between the child and the donor or the child can contact the donor when the child turns 18. Additionally some married women and their husbands want to conceal the participation of a gamete (sperm or egg) donor in the conception. Therefor genetic records can become Lost and a child is left wondering and fearful about inbreeding issues.<sup>214</sup>

5.68 Dr Sonia Allan also observed that for children conceived through private arrangements 'access to information is completely reliant on the parties to that arrangement maintaining and giving information themselves'. She expressed support for a system that would enable the voluntary recording of details of participants in private donor conception arrangements.

... I would definitely advocate the recording of details of private donations. I suppose that we have to face the reality that because they are private arrangements we have to rely on people coming forward to place details on the register and that this would therefore necessitate some kind of voluntary register continuing because a person in a private arrangement is not reported through the clinic system. I think that it really would be great if they had the opportunity to place their information on a register as in other donor conception situations.

In an ideal world, for the donor conceived, it would be nice that they have requirements that they have to do something. But it would be very hard, or you may not be able to police these private arrangements, ... The centre of the issue should be the wellbeing of the person who is ultimately being conceived. So, if we advocate anything for these people, we should be advocating that information regarding private arrangements should be made available to them. <sup>215</sup>

5.69 Professor Jenni Millbank expressed support for a voluntary system for recording private arrangements, with access to counselling and support services. However, she told the Committee that such a system should not impose a legal obligation on participants:

... At present those obligations apply to licensed ART practitioners rather than to the participants themselves and I do not think there should be an extension of that obligation to participants themselves. It should be something that is there for people to access if they think it is a useful thing to do. <sup>216</sup>

5.70 In arguing against extending mandatory registration to private arrangements, Professor Millbank stated that she did not believe 'the formal regime should include people who are acting in their private lives ... rather than within a regulated system of assisted conception'. <sup>217</sup> She also observed that people acting outside the regulated clinic system are usually using known donors:

People who have unknown donors are largely within the clinical system and people who have known donors are largely outside of it. That is true of sperm anyway.

<sup>&</sup>lt;sup>214</sup> Submission 5, Mr John Lindsay Mayger, p 1

 $<sup>^{\</sup>rm 215}$  Dr Allan, Transcript of evidence, 5 March 2012, p 6

<sup>&</sup>lt;sup>216</sup> Professor Millbank, Transcript of evidence, 5 March 2012, p 21

<sup>&</sup>lt;sup>217</sup> Professor Millbank, Transcript of evidence, 5 March 2012, p 23

People who have egg donors usually have to go through the clinic system to use IVF. People with egg donors are much more likely to know who their donor is rather than use an unknown donor. With sperm you have a much more clear division between unknown donors within the clinic system and known individuals outside of the clinic system. I do not see the need for official records of that when people actually know each other to start with. <sup>218</sup>

- 5.71 Ms Pam Suttor, representing the Law Society of NSW, also told the Committee that a mandatory requirement to register private arrangements would be impractical, pointing to difficulties with defining and verifying private donor relationships. <sup>219</sup>
- 5.72 The Commission for Children and Young People submitted that there should be provision for donors participating in private arrangements to be recorded on birth certificates, where all parties have agreed that the donor will perform a parental role:

The Commission believes that allowing the donor's name to be included in the register of births in this circumstance is likely to be in the best interests of the child. ... Formal recognition of key relationships in a child's life where there is shared parental responsibility could serve to validate and strengthen these relationships. <sup>220</sup>

5.73 However, Dr Sonia Allan stated that entering known donors on birth certificates would not be an effective way to record donor information in relation to private arrangements, as the information could subsequently be removed on the basis that a donor is not a legal parent:

... even where a known donor was originally recorded on the birth certificate this information might be removed. Of course, this simply equates to the situation where he was never put on there in the first place—recognising that only two legal parents may be recorded on the birth documents.<sup>221</sup>

#### Senate Committee's recommendation

- 5.74 The Committee notes that the recent Senate Committee inquiry into donor conception practices considered the issue of private arrangements. The Committee stated that issues raised by private arrangements required further consideration to ensure that the legal rights of all parties participating were protected, and that Australian governments should consider how best to regulate private arrangements.
- 5.75 In terms of donor registers, the Senate Committee recommended that 'donors in private arrangements be encouraged to have their information recorded and disclosed to any individuals conceived as a result of their donation on a national

 $<sup>^{218}</sup>$  Professor Millbank, Transcript of evidence, 5 March 2012, p 23

<sup>&</sup>lt;sup>219</sup> Ms Suttor, Transcript of evidence, 5 March 2012, p 12

<sup>&</sup>lt;sup>220</sup> Submission 16, NSW Commission for Children and Young People, p 3

<sup>&</sup>lt;sup>221</sup> Submission 13, Dr Sonia Allan, pp 12-13

voluntary register or separate register, if such registers are established in each state and territory.'222

### Other jurisdictions

5.76 Donor registers operating in Western Australia, Victoria and New Zealand only record information relating to gamete donation and treatments occurring at ART clinics. However in Victoria, a woman who gives birth to a child following self-insemination through a private arrangement must register the birth with the Registry of Births and must also provide the donor's details in writing to the Registrar:

In addition to the Birth Registration Statement, the mother, her partner (if any) and the donor must also submit a letter addressed to the Registrar, which gives the following details for the donor:

- full name
- date of birth
- place of birth
- postal address
- daytime phone number
- email address.

The donor must sign the letter and supply one proof of identity document. The proof of identity documents are listed in the Birth Registration Statement. The donor's details will not appear on the child's birth record or certificate. <sup>223</sup>

### Committee comment

- 5.77 The Committee heard evidence about the complexities of recording donor information in relation to private donor conception arrangements occurring outside ART clinics. There are myriad variations of individual situations which may involve donor conception and it is difficult to determine one approach that would be suitable for all of them.
- 5.78 A common concern among submission makers was that donor conceived children not be discriminated against in any way, which may happen if privately donor conceived children are unable to access information about themselves in the same way as children conceived within a formal clinic setting.
- 5.79 There is currently no means for participants in these arrangements to voluntarily register their details, and the Committee heard that there is a very real danger that such information could be lost over time. A proposal to reduce this risk, which received broad support from contributors to the Inquiry, was to enable participants in such arrangements to register their details on the existing voluntary register held by the Ministry of Health.

<sup>&</sup>lt;sup>222</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, pp 94, 105

<sup>&</sup>lt;sup>223</sup> Births, Deaths, Marriages Victoria, 'Self-insemination', <a href="http://online.justice.vic.gov.au/CA2574F700805DE7/page/Births-Self-insemination?OpenDocument&1=10-Births~&2=54-Self-insemination~&3 accessed 27 April 2012</a>

## COMMITTEE ON LAW AND SAFETY RECORDING DONOR INFORMATION

- 5.80 While the donor is often known to the recipients, this is not always the case, and registering the donors' details will provide some level of security for the donor conceived person and their family. The Committee expects that the recommended changes to the birth registration process (recommendation 2) will be applied broadly to people conceived though private arrangements as well as clinics.
- The Committee notes that in Victoria it is mandatory to submit donors' details when registering a birth resulting from self-insemination, however, the Committee feels that it is impractical and difficult to apply a mandatory requirement for these types of conceptions.
- 5.82 Enabling voluntary registration of information on privately arranged donor conceived births would necessitate some way of verifying donor and birth details and would rely on the goodwill and intent of the parties involved. Parallels between the recording of details for a voluntary register, however, can be drawn with the current process for recording parentage in surrogacy births, and the risks could be mitigated through the use of instruments such as statutory declarations.
- The Committee is recommending that the current system for recording donor information be expanded to cover private arrangements. It is important that families who have used privately arranged donors, or are considering doing so, are made aware of the change to ensure that it is effectively implemented. The Committee is therefore recommending that information regarding the voluntary registration of donor details for private arrangements be publicised on the Ministry of Health website and other relevant material such as brochures.

#### **RECOMMENDATION 6**

#### That the Minister of Health:

- a) Implement processes to enable participants in private donor conception arrangements to voluntarily register their details on the voluntary register;
- b) Publicise information on voluntary registration of details of participants in private arrangements on the Ministry of Health website and through public awareness material such as information brochures.

### Chapter Six – Accessing donor information

In this chapter the Committee will outline evidence it received on how access to donor information should be managed. This includes the age at which information can be accessed, discussion around enabling retrospective access to identifying donor details, the importance of counselling and other support services, and whether there is a need to establish a specialised body to deal with these issues.

# AGE AT WHICH DONOR CONCEIVED INDIVIDUALS CAN ACCESS DONOR INFORMATION

### State and territory legislation

- Each state and territory is governed by legislation, or the National Health and Medical Research Council (NHMRC) Guidelines if there is no legislation, which dictates the age at which donor information can be accessed. The relevant regulations are outlined below and a full discussion of this legislation can be found in Chapter Three.
- In New South Wales those donor conceived individuals conceived after 1 January 2010 are able to access information from the Ministry of Health Register from age 18. Those conceived prior to this need to contact the clinic where they were conceived in order to see if non-identifying information is available.
- In Western Australia people may request information from the compulsory register (for those conceived after 2004) once they turn 16. Those individuals conceived before 2004 can request non-identifying information from the register or seek information from the clinic where they were conceived.
- Victorian legislation provides for the release of identifying information from the Central Register to donor conceived individuals once they are aged 18, or to a child with their parent's consent, and is subject to counselling requirements. Information can be released to an individual under 18 years of age if they have written notification from a counsellor that they have received counselling and understand the implications of their request. There is also a voluntary register that allows those people who are not governed by the legislation to both register their details and access information.
- South Australia does not have a central register and all donor information is held at individual clinics. Identifying information may be accessed, however, if all parties consent and the information is available. Donor conceived individuals may access non-identifying information from age 16.
- 6.7 Queensland, Tasmania, the Northern Territory and the Australian Capital
  Territory do not have any legislation governing access to donor information. They
  operate within the framework provided by the NHMRC guidelines on the use of

<sup>&</sup>lt;sup>224</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 44

Assisted Reproductive Technology (ART) in clinical practice and research and the Fertility Society of Australia's Reproductive Technology Accreditation Committee (RTAC) Code of Practice. Current procedures in these states allow donor conceived individuals to contact their clinic to see what records are held.

6.8 In terms of what age people should be given access to information about their donor, the NHMRC Guidelines specify that:

People conceived using donated gametes are entitled to know their genetic parents. On request, clinics must arrange for either a medical practitioner, or an appropriately qualified health professional, to provide at least the following information, to a person conceived through ART procedures, provided that he or she has either reached the age of 18 years or acquired sufficient maturity to appreciate the significance of the request (including any implications for his or her younger siblings):

- all medical and family history information ...;
- identifying information about the gamete donor ...; and
- the number and sex of persons conceived using the gametes provided by the same gamete donor, the number of families involved, and any identifying information that these siblings have consented to being released
- 6.9 While 18 is the most commonly seen age across Australia and this is mirrored in overseas jurisdictions, the Committee received some evidence in favour of lowering this age and this is discussed below.

### Suggested age limits

- 6.10 A common theme among the submissions received by the Committee is the necessity of having full and identifying donor information available in order to allow an individual a complete understanding of their medical and genetic history. Several submissions voiced the opinion that the earlier a child is aware of their conceptual history, the better their outcomes in later life. <sup>226</sup>
- 6.11 The NSW Commission for Children and Young People noted that while parents can access this information on behalf of their child, there may:

... be occasions where a young person 14 years or older wishes to seek medical assistance independently of their parents, and that they should be able to access medical information about the donor of relevance to their health for this purpose (s 49 of the *Minors (Property and Contracts) Act 1970* recognises the right of a minor ages 14 years or above to consent to medical and dental treatment). The Commission is also of the view that donor conceived young people should be able to access information about their donor such as their ethnicity and physical characteristics, independently of their parents". 227

NHMRC, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research, <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="http://www.nhmrc.gov.au/">http://www.nhmrc.gov.au/</a> files <a href="http://www.nhmrc.gov.au/">nhmrc/publications/attachments/e78.pdf</a> accessed 3 April 2012

<sup>&</sup>lt;sup>226</sup> See Submission 1, Damien Adams, for a discussion of research into this issue.

<sup>&</sup>lt;sup>227</sup> Submission 16, NSW Commission for Children and Young People, p 2

Dr Sonia Allan was of the opinion that most 16 year olds are capable of processing and dealing with this type of information provided they have the right support and counselling around them. She suggested that access to such information from an even younger age may also be possible with the support of an appropriate adult. Dr Allan told the Committee that:

It is early in terms of its research but the indications are that the children are much better positioned not only in knowing the truth and their parents having an open and honest relationship with them, which, obviously, is very important, but also being able to deal later on and make decisions about what information they want and how they want to then proceed. <sup>228</sup>

6.13 Mr Damien Adams discussed the body of research examining identity formation and how this can be affected if a child's biological links are removed. Such effects can include 'genetic bewilderment' and psychological harm. <sup>229</sup> Mr Adams also stated that the age at which information can be accessed should be substantially lowered from the current 18 years in order to avoid this potential for psychological problems:

Late discovery of their mode of conception which frequently occurs for many varied reasons changes a person's perceptions of identity and family, thereby introducing distrust, confusion, and possibly anger between themselves and those that deceived them (McWhinnie 2000, Turner and Cole 2000). If these factors are to be considered, then the current practice of only allowing donor offspring access to identifying information once they reach the age of 18 may cause irreparable damage as the vital identity construct window has passed. And as such it would be prudent to recommend that the age at which an offspring is able to access such information should be substantially lowered, which can be assisted through truthful birth certificates. This early disclosure is supported by reports that less damage occurs when a child is told of their conception at an early age (Hewitt 2002, Jadva et al 2009) and that it is certainly more beneficial to occur before the identity construct window of adolescence occurs (Kirkman 2003).

6.14 Ms Jennie Burrows noted that the United Nations Convention on the Rights of the Child states that children have the right to know their parents and does not set an age limit.

It also gives them the right to seek and receive information at any age (article 13.1). If an age must be set, the age of 12 is one where children are experiencing issues about identity, and are expected to make important legal decisions (eg consent to their own adoption).  $^{231}$ 

6.15 However other submission makers supported the current age limit. VANISH discusses the Victorian model where a donor conceived person can apply for their birth certificate from age 18 and receive an addendum alerting them to the

<sup>&</sup>lt;sup>228</sup> Dr Allan, Transcript of evidence, 5 March 2012, p 4

<sup>&</sup>lt;sup>229</sup> Submission 1, Mr Damien Adams, p 5

<sup>&</sup>lt;sup>230</sup> Submission 1, Mr Damien Adams, p 5

<sup>&</sup>lt;sup>231</sup> Submission 11, Ms Jennie Burrows, p 2

- availability of further information. VANISH were of the opinion that this is an effective practice and could also be established in NSW.<sup>232</sup>
- 6.16 Several other submissions also expressed general support for maintaining the age of 18 as being appropriate for a donor conceived person to access their conception details.<sup>233</sup>
- 6.17 The Australian Christian Lobby also recommended that donor conceived persons have the right to non-identifying information about their donor whenever they are required for medical purposes.<sup>234</sup>
- The recent Senate Legal and Constitutional Affairs References Committee Inquiry into Donor Conception Practices in Australia recommended that identifying information about donors be available to donor conceived individuals at age 18, or younger if agreed to by the states and territories; and that non-identifying information be made available to the donor conceived person at age 16, or younger if agreed to by the states and territories.<sup>235</sup>

#### Committee comment

- 6.19 The Committee recognises the importance of access to identifying donor information by donor conceived individuals. This is currently regulated at age 18 in most Australian states but the Committee acknowledges that there are some circumstances in which it may be appropriate for such information to be released to a person younger than 18. In Victoria, identifying donor information can be released to an individual under 18, provided they have been counselled and can provide a written statement from a counsellor that they are sufficiently mature to understand the consequences of the disclosure of such information. The Committee notes that the recent Victorian Law Reform Committee Inquiry did not recommend any changes to this provision.
- The Committee received evidence that access to donor information should be available to people under the age of 18 and that this could have significant psychological benefits. When a person knows their true genetic history from a young age it forms an integral part of their identity. The Committee also notes that international frameworks such as the UN Convention on the Rights of the Child do not place an age limit on a child knowing their parentage.
- 6.21 Section 38 of the Assisted Reproductive Technology Act 2007 (NSW) enables information to be accessed before the child turns 18. It allows the disclosure of information to the parent, or an appropriate person if the parent of the child is unable or unwilling to seek information on the child's behalf, and the information cannot be reasonably obtained by the appropriate person in any other way.

<sup>&</sup>lt;sup>232</sup> Submission 21, VANISH Inc, p 2

<sup>&</sup>lt;sup>233</sup> Submission 24, Ms Miranda Montrone, p 3; Submission 26, Australian Christian Lobby, p 5; Submission 28, The Fertility Society of Australia, p 4

<sup>&</sup>lt;sup>234</sup>Submission 26, Australian Christian Lobby, p 3

<sup>&</sup>lt;sup>235</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, para 7.73

- 6.22 The Committee considers that the current legislation enabling access by donor conceived persons to donor information when they reach adulthood is sufficient, and did not receive compelling evidence to show that the age should be lowered. The Committee also believes that early disclosure by a child's parents is ideal and current legislative provisions enable this by allowing parents to access information on their child's behalf. It is important that both the donor and the donor conceived person are well placed to deal with the consequences of obtaining information when they choose to do so, and that as there is no retrospective access currently permitted, the existing access provisions are adequate.
- 6.23 In the Committee's view, the current provisions in the Assisted Reproductive Technology Act 2007 for disclosure of information to adult offspring born as a result of treatment using donor gametes and in the case of children, to parents or an appropriate adult, are adequate and should be retained.

#### FINDING 2

The provisions in the Assisted Reproductive Technology Act 2007 for disclosure of information to adult offspring born as a result of treatment using donor gametes and in the case of children, to parents or an appropriate adult, are adequate and should be retained.

#### ACCESS AND PARENTAL DISCLOSURE

- 6.24 The preceding discussion details at what age the donor conceived child is capable of understanding and dealing with their genetic history. It assumes that they know they are donor conceived and are seeking further details.
- 6.25 But the Committee notes that irrespective of age, any request to access such information is dependent upon the information about a child's donor conception having already been disclosed by their parents. Dr Allan noted that:

Donor-conceived individuals cannot make a decision about whether or not they wish to access information about themselves unless they know they are donor conceived. It is my submission therefore that the RBDMs should annotate the birth certificate of a donor conceived individual to alert them to the fact that further information that they may wish to obtain is held on the Central Register. Knowing such notation will be given to the donor-conceived individual may encourage parents to disclose. As such, it is also my submission that NSW works towards ensuring that adequate counselling and support services are made available to recipient parents, donors and donor-conceived individuals in the move towards openness and sharing of information.<sup>236</sup>

6.26 This highlights another common theme among submissions which discussed the importance of having appropriate counselling and support services in place to encourage disclosure by parents. This will be discussed later in this chapter.

<sup>&</sup>lt;sup>236</sup> Submission 13, Dr Sonia Allan, p 29

- 6.27 It is unknown what proportion of donor conceived people are aware of the circumstances of their conception, however some studies suggest that a majority do not know that they are donor conceived. 237
- There has been a significant shift in attitudes to disclosure over the past several years. The recent Victorian Law Reform Committee *Inquiry into Access by Donor-Conceived People to Information About Donors* observed that:

A culture of secrecy was pervasive in the early days of donor-conception, despite contemporaneous changes to adoption laws to eliminate secrecy...Donor-conception practices in Victoria have evolved significantly over time to encourage far greater openness. Legislation regulating donor conception has incrementally introduced provisions allowing donor-conceived people to access information about their donors...<sup>238</sup>

- 6.29 The issue of parental disclosure is a complicated one and Dr Allan commented that 'I am not sure how you address that other than by encouraging parents to let their children know'. 239
- 6.30 Some individuals believe that one means of ensuring disclosure is to issue an addendum with birth certificates as a means of alerting donor conceived individuals that further information is available about their birth entry, and encouraging parents to tell their donor conceived child the truth. This is the current practice in Victoria. The Committee discusses birth certificates more fully in Chapter Four.
- 6.31 It is relevant to note the Victorian Law Reform Committee's finding that a person's parents should be primarily responsible for informing them of their donor conceived status. In this regard the Committee commented that:

...it can be very distressing for a person to discover as an older child or as an adult that he or she is donor-conceived. This discovery can have a significantly adverse effect on the donor-conceived person's relationship with his or her parents, and the extended family. The Committee also notes evidence from studies of adoption that indicate this trauma can be exacerbated where the revelation is made by third parties, such as, presumably, the state government.

The Committee holds the view that where a person is aware that he or she is donor-conceived, and wishes to contact his or her donor, it is in that person's interests that the state provide identifying information to assist his or her desire for knowledge. The Committee also holds the view that in the majority of cases, it is in the interests of a donor-conceived person to be told by his or her parents of the manner of his or her conception. 240

<sup>&</sup>lt;sup>237</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 5

<sup>&</sup>lt;sup>238</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p xix

 $<sup>^{239}</sup>$  Dr Allan, Transcript of evidence, 5 March 2012, p 4. The 'Time to Tell' campaign is discussed in more detail in para 6.88 of this chapter.

<sup>&</sup>lt;sup>240</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 64

In considering the Victorian mechanism for disclosure by the state (that is, the addendum to birth certificates) the Committee concluded that although disclosure by the state could undermine parent-child relationships, the existing provisions should be maintained as an incentive for parental disclosure:

The Committee cannot be certain ... that it is in the best interests of a donor-conceived person for the state (or any third party) to circumvent that person's parents, and reveal that he or she is donor-conceived. If the state were to do so, the Committee would be concerned that the state's actions would undermine the parental relationship that the donor-conceived person would ideally rely upon when considering his or her place in the world. ... However, the Committee does not believe it is appropriate to repeal existing mechanisms by which the state may inform a donor-conceived person of his or her status. <sup>241</sup>

6.33 The Victorian Committee recommended that the legislative provisions be retained 'so that incentives for parents to tell their children about the circumstances of their conception remain in place'. 242

#### Committee comment

- 6.34 The Committee heard various viewpoints from stakeholders concerned with the issue of how donor conceived children find out about the circumstances of their conception. While some were in favour of annotating a child's birth certificate, or otherwise marking it, to indicate donor conception, others expressed the view that it is up to the parents of the child to decide how and when they talk to their children, and this should not be dictated by government policy.
- Shifts in social mores mean it is more commonly accepted now to discuss and be aware of issues surrounding donor conception, but evidence presented to the Committee demonstrated that many parents who used donor gametes to conceive their child have not informed them. While some have suggested annotating the front of birth certificates, the Committee is concerned that an annotation could impinge on an individual's right to privacy, and needs to be balanced carefully against the incentive it will provide to parents to disclose information to their children. The Committee has instead recommended that NSW adopt the Victorian system of issuing an addendum with birth certificates to donor conceived adults, in order to encourage parental disclosure.
- 6.36 The Committee believes that parents should be encouraged and supported in disclosing to their children that they are donor conceived. The Committee recognises the vital role that counselling plays in this process, both at the time of treatment and later on to encourage parents to tell their children about their conception. The Committee is hopeful that changing attitudes and improved support for families will result in greater disclosure rates.

<sup>&</sup>lt;sup>241</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 64

<sup>&</sup>lt;sup>242</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, pp 64-65

#### RETROSPECTIVITY

- 6.37 The Terms of Reference for this Inquiry did not include consideration of retrospectivity, but it is apparent from the responses received by the Committee that the issue of people accessing information about donors and donor conceived children for conceptions prior to January 2010 is of vital importance to any discussion around general access provisions.
- 6.38 The Committee heard differing viewpoints from submission makers, from those who advocate retrospective access and those who oppose it, to those who can see a role for a policy which allows partial access.
- 6.39 The Senate Legal and Constitutional Affairs References Committee Inquiry into Donor Conception Practices in Australia observed the absence of any authoritative evidence in the matter and decided not to make any specific recommendations in relation to retrospectivity.<sup>243</sup>
- 6.40 The Committee did, however, make the following recommendation:

The committee recommends that, if after further consideration by the states and territories of the issue of retrospectivity, registers will not be retrospective, a national voluntary register or separate register in each state and territory should be established to allow donors who previously donated anonymously to agree to have their information recorded and disclosed to any individuals conceived as a result of their donation. <sup>244</sup>

6.41 The Victorian Law Reform Committee's *Access by Donor-Conceived People to Information about Donors* recommended that retrospective access to donor information be introduced, subject to contact vetos and improved counselling and support:

Recommendation 1: That the Victorian Government introduce legislation to allow all donor-conceived people to obtain identifying information about their donors.

Recommendation 2: That, with the introduction of the legislation described in Recommendation 1, the Victorian Government introduce provisions for contact vetoes that may be lodged by a donor or a donor-conceived person following counselling, with the following features:

- That contact vetoes only be available to people conceived from gametes donated prior to 1998, and the donors of these gametes;
- That donors may only lodge a contact veto after they have been informed that a donor conceived person has lodged an application for identifying information about them;
- That a veto prohibits contact between the donor and the donor conceived person;

<sup>&</sup>lt;sup>243</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, para 7.26

<sup>&</sup>lt;sup>244</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, para 7.74

- That suitable penalties be established for breach of a veto;
- That a veto lapses within five years if not renewed by the person who lodged it; and
- That the person who lodged a veto may withdraw it at any time.

### Inquiry participants' views

- Participants in this inquiry drew parallels between donor conception and the adoption process and the changes in legislation that granted retrospective access to information about birth parents for adoptees.
- 6.43 Mr Adams made the point that similar policies should be implemented for donor conceived children as occurred with adoption:

...there are several similarities between adoption and donor conception and the effects it can have on the child and as such the practices of donor conception should implement the same policies that entitles the adopted child to knowledge of their biological parents.  $^{246}$ 

- The Donor Conception Support Group outlined the experience that NSW had in reforming its legislation to allow all adoptees to access their birth parent information no matter when they were born. They noted that it is a basic human right to know one's origins and that 'the denial of such right of access to one group, i.e. donor offspring, within the broader community can have severe adverse effects on their perception of themselves and their position in the world.'<sup>247</sup>
- 6.45 The Donor Conception Support Group also drew parallels with the release of adoption records and argued that fears of breaches of privacy were not borne out:

Fears around retrospectivity in the donor conception experience have been expressed similarly to those of adoption history. Yet in the adoption model research has shown that the fears initially expressed have either not been realised in the large majority of cases, or not to the depth or extent to which they were initially expressed. Why would donor conception be any different?<sup>248</sup>

- 6.46 Associate Professor Tonti-Filippini noted that 'bringing parity to the interests of donor conceived people compared to people who were adopted is an important step'. 249
- 6.47 Several submission makers<sup>250</sup> cited the United Nations Convention on the Rights of the Child as providing a general basis for the knowledge of genetic heritage, as

<sup>&</sup>lt;sup>245</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p xxv

<sup>&</sup>lt;sup>246</sup> Submission 1, Mr Damien Adams, p 6

<sup>&</sup>lt;sup>247</sup> Submission 7, Donor Conception Support Group of Australia, p 12

<sup>&</sup>lt;sup>248</sup> Submission 7, Donor Conception Support Group of Australia, p 16

<sup>&</sup>lt;sup>249</sup> Submission 2, Associate Professor Nicholas Tonti-Filippini, p 6

it specifies the right to know one's parents as far as possible as a basic human right and defines these as both genetic parents and birth parents.<sup>251</sup>

#### 6.48 Ms Narelle Grech explained that:

It is the responsibility of the Australian policy makers to set a good and right example. In the case of donor conception I believe that medical professionals and law makers in each state need to be held accountable for ensuring donor conceived people never have to question their family history or identity as I and many others have had to. It is disempowering, hurtful and frustrating to be denied such vital information.

Agreements made by consenting adults in the past failed to recognise the donor conceived person's inherent right to a true identity, as is now enshrined in the UN Convention on the Rights of the Child (UNROC). Australia is a signatory to this, yet it has failed to ensure these same rights are upheld for all donor conceived people. <sup>252</sup>

- 6.49 Dr Allan submitted an article for the Committee's information, which outlines the main arguments in favour of the retrospective release of donor information to donor conceived individuals as being:
  - as the number of individuals who are affected increases, so too will the demand for information;
  - the identified issues of genealogical bewilderment and identity confusion may be mitigated by the release of information;
  - access to correct medical information is important;
  - donor conceived people can allay their fears and risk of forming consanguineous relationships;
  - there is an inconsistency in providing information to some but not all donor conceived individuals;
  - there is an analogy with adoption; and
  - international human rights frameworks are consistent with the release of such information.<sup>253</sup>
- Associate Professor Tonti-Filippini noted the important role that legislation would play if retrospectivity were to be introduced. By requiring a government agency to take responsibility for the storing of and access to the information, it would remove any liability from those clinics who originally undertook not to release the information.<sup>254</sup>

<sup>&</sup>lt;sup>250</sup> See submissions by D Adams (1), N Tonti-Filippini (2), the Life, Marriage and Family Centre (6), Hawkesbury Nepean Community Legal Centre (8), J Burrows (11), S Allan (13), N Grech (18), Australian Christian Lobby (26), G Donnelly MLC (27), Donor Conception Support Group (7).

<sup>&</sup>lt;sup>251</sup> Allan, S, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', in *Journal of Law and Medicine*, 19, 2011, p 364 <sup>252</sup> Submission 18, Ms Narelle Grech, p 1

<sup>&</sup>lt;sup>253</sup> Allan, S, 'Psycho-social, ethical and legal arguments for and against the retrospective release of information about donors to donor-conceived individuals in Australia', in *Journal of Law and Medicine*, 19, 2011

<sup>&</sup>lt;sup>254</sup> Submission 2, Associate Professor Nicholas Tonti-Filippini, p 4

- 6.51 Those supporting retrospectivity referred to the NHMRC guidelines around donor conception which state that 'the welfare of people who may be born as a result of the use of ART is paramount'.<sup>255</sup>
- 6.52 The Donor Conception Support Group argued that:

The denial of such rights of access to one group can have severe adverse effects on their perception of themselves and their position in the world. We are concerned that denial of rights purely on the basis of date of birth has produced a minority group afforded less rights than those of their younger counterparts.<sup>256</sup>

- Advocates of retrospective legislation maintain that it would not only follow best practice as set out in the NHMRC guidelines and international human rights frameworks, but will also bring medical, psychological and social benefits to those affected by it. They also argue that concerns about donors' consent and right to privacy are outweighed by the rights of donor conceived individuals to information.
- 6.54 Associate Professor Tonti-Filippini noted that to 'maintain the anonymity now for those who were given undertakings would continue the injustice to those who were donor conceived.<sup>1257</sup>
- 6.55 Ms Amy McGowan from the Inner City Legal Centre expressed the view that:

I can understand that here would be concerns, especially- I guess it is almost contract law — whether the donor had consented or whether they would have given their donation had they known that they would be on a central register. However, all of our views are informed by the best interests of the child, and having access to that information is very important and likely trumps those other concerns. <sup>258</sup>

6.56 In an article provided by Dr Allan, Mr Richard Chisholm argued that:

...there is a formidable argument to the effect that knowledge of one's genetic origins is, at least for many people, a matter of fundamental importance to their sense of identity and self-worth; and that ignorance, as well as undermining this sense, could lead to risks of a medical kind, and a risk of inadvertently partnering a half sibling. <sup>259</sup>

6.57 He goes on to state that 'the argument against retrospective legislation based on expectations of anonymity at the time of adoption has been overwhelmed by arguments for openness and information rights.' 260

<sup>&</sup>lt;sup>255</sup> NHMRC, Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research, <a href="http://www.nhmrc.gov.au/files-nhmrc/publications/attachments/e78.pdf">http://www.nhmrc.gov.au/files-nhmrc/publications/attachments/e78.pdf</a>, accessed 3 April 2012, p 9

<sup>&</sup>lt;sup>256</sup> Ms Lorbach, Transcript of evidence, 1 March 2012, p 34

<sup>&</sup>lt;sup>257</sup> Submission 2, Associate Professor Nicholas Tonti-Filippini, p 5

<sup>&</sup>lt;sup>258</sup> Ms Amy McGowan, Solicitor, Inner City Legal Centre, Transcript of evidence, 5 March 2012, p 17

<sup>&</sup>lt;sup>259</sup> Chisholm, R, 'Information Rights and Donor Conception: Lessons from Adoption?', in S Allan (ed), 19(4), *Special Edition of the Journal of Law and Medicine*, June 2012, p 734

<sup>&</sup>lt;sup>260</sup> Chisholm, R, 'Information Rights and Donor Conception: Lessons from Adoption?', in S Allan (ed), 19(4), *Special Edition of the Journal of Law and Medicine*, June 2012, p 739

- 6.58 There are ethical aspects for both sides in the balancing of concerns around privacy and access to information. One way of dealing with such issues, as suggested by both the Donor Conception Support Group and Dr Allan, would be to enable the donor to put a contact veto in place which enables them to retain some control even if retrospective access were granted.<sup>261</sup>
- 6.59 The Committee recognises, however, that there are distinctions between adoption and donor conception, particularly with regard to confidentiality. The NSW Law Reform Commission observed that confidentiality in relation to genetic parentage was maintained for different reasons for ART and adoption. With adoption the confidentiality was driven by government policy, while the secrecy around donor conception has been based on decisions by parents and the medical profession. 262
- It is equally important to note another distinction between adoption, which is a legal process that is primarily guided by the best interests of a living child and ensuring they have a safe and stable family, and assisted reproductive treatment, which is primarily concerned with the interests of prospective parents and providing them with the opportunity to have a child. 263
- The Hawkesbury Nepean Community Legal Centre Inc<sup>264</sup> and the Fertility Society of Australia<sup>265</sup> expressed the view that it would be unfair to those donors who donated on the condition of anonymity to release their information retrospectively, and advocated for no changes in respect of this provision. Ms Hurrell told the Committee that:

The Fertility Society is really emphatic that we do not support retrospectivity. How can I put it? The whole use of donor conception, I guess, nowadays we do not have anonymous donation anymore. It is a thing of the past and we support openness and voluntary registers and so on, but we cannot change that past practice. It would be very wrong to force people who donated in the past anonymously to disclose this information. It would have negative effects for them and their families as well as the donor-conceived families who consented to anonymous donation in the past. I want to be really emphatic about that.

- 6.62 Professor Jenni Millbank expressed her opposition to the idea of retrospectivity, but drew a distinction between the release of identifying and non-identifying information, as the latter would be less intrusive for the donor. 267
- 6.63 Ms Carney from the Department of Attorney General and Justice, in giving evidence before the Committee, noted the competing principles and interests

 $<sup>^{\</sup>rm 261}$  Dr Allan, Transcript of evidence, 5 March 2012 p 7

<sup>&</sup>lt;sup>262</sup> NSW Law Reform Commission, *Names: Registration and certification of births and death*, report 61 (1988), 199, para. 4.101-4.103

<sup>&</sup>lt;sup>263</sup> Tobin, J, 'Donor Conceived Individuals and Access to Information About their Genetic Origins: The Relevance and Role of Rights', in S Allan (ed), 19(4) *Special Edition of the Journal of Law and Medicine*, June 2012, p 755

<sup>&</sup>lt;sup>264</sup> Submission 8, Hawkesbury Nepean Community Legal Centre, p 6

<sup>&</sup>lt;sup>265</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 32

<sup>&</sup>lt;sup>266</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 32

<sup>&</sup>lt;sup>267</sup> Professor Millbank, Transcript of evidence, 5 March 2012, p 22

raised by retrospectivity and suggested that access to non-identifying details may be a compromise position:

The department does not have a formal position on whether identifiable donor information should be provided on a mandatory basis for births before 2010; however, we suggest that the issue be approached with great care. As a general principle retrospective legislation that derogates from existing rights reduces legal certainty and undermines the rule of law. Strong justification is required in order to retrospectively impose an obligation or adverse effect on rights and liberties since fairness requires that the legal rights and obligations governing certain conduct be known at the time the conduct occurs. Many donors would have donated on the condition of anonymity. To reverse this position through legislation is likely to cause concern from those who donated anonymously, many such people may have donated on an altruistic basis and could feel legitimately aggrieved by such a prospect.

...if it is accepted that there is an interest in donor conceived people being made aware of the identity of their donors, it must be accepted that this interest remains regardless of whether a child was conceived before or after 2010. It may be that an acceptable compromise would be for non-identifying details of pre-2010 donors being made available to donor conceived people. 268

6.64 Ms Carney noted also that effective enforcement of any requirement to provide retrospective information would rely on ART clinics, as there was no government ART register for donor details prior to 2010. Thus the provision of retrospective records would depend on the ART provider remaining open and maintaining records of donations and resulting births. <sup>269</sup>

#### Committee comment

- 6.65 The Committee considers that retrospective access to donor information is a vital issue for all those affected by donor conception practices. The current situation in NSW for donor conceived people born prior to 2010 means that they rely on a voluntary register to access information about their donor, and there is no guarantee that such information will be available. Evidence was presented to the Committee which demonstrated there is considerable benefit to donor conceived individuals in knowing their genetic history, for a range of reasons including psychological and health benefits as well as social benefits.
- The Committee also received evidence from those who argued that the current system should be maintained. It was argued that anonymity should be preserved for those donors who were promised that they would remain anonymous, and that the medical profession must uphold its promises.
- 6.67 The Committee notes that the Senate Committee report did not make a recommendation about retrospectivity, while the Victorian report recommended retrospective access to donors' identifying details be granted. The Victorian Government has not yet responded to this recommendation.

 $<sup>^{\</sup>rm 268}$  Ms Carney, Transcript of evidence, 1 March 2012, p 4

<sup>&</sup>lt;sup>269</sup> Ms Carney, Transcript of evidence, 1 March 2012, p 4

- In considering retrospectivity there are several interrelated issues which also need to be taken into account. These include issues such as what support would be provided to donor conceived persons, their families, and donors, if such information was disclosed and how the considerable administration of such a change would be managed.
- The Committee feels that all parties have genuine and valid opinions which need to be considered on their merit and in significant detail before any decisions can be made regarding the current information access provisions. As retrospectivity was not included in the Terms of Reference for this Inquiry, comprehensive evidence specific to this issue was not received. As such, the Committee is unable to recommend changes to the current provisions regarding retrospective access. The Committee intends, however, to undertake a further inquiry into issues, such as retrospectivity, that were raised during this Inquiry but were not encompassed by the Terms of Reference.

#### FINDING 3

The issue of granting donor conceived individuals retrospective access to information about their donor was not covered by the Terms of Reference for the Inquiry. The Committee is therefore unable to make any recommendation for change.

The Committee will undertake a future inquiry into matters raised during this Inquiry that were not encompassed by the Terms of Reference, including retrospective access to information.

#### COUNSELLING AND RELATED SERVICES

- 6.70 Several participants in the Committee's inquiry made the observation that when examining issues of access to birth origin information it is necessary to consider what support systems are in place for both donors and donor conceived people and their families.
- 6.71 The Central Register is currently managed by the NSW Ministry of Health, which has no counselling functions or ability to assist parties when they are seeking information.
- 6.72 Many submissions received by the Committee discussed the importance of having appropriate counselling mechanisms in place both at the time the ART is undergone and later on when the information is accessed. The Victorian Law Reform Committee took the view that 'at certain points during the process for access to information, counselling for the donor conceived person should be compulsory, and strongly recommended for donors'. 270
- 6.73 The Fertility Society told the Committee that ART clinics in NSW are currently required to offer counselling to individuals or couples undergoing fertility treatment under both the RTAC code of practice and the NHMRC guidelines in

<sup>&</sup>lt;sup>270</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 78

order to obtain accreditation.<sup>271</sup> Ms Hurrell outlined the nature of the counselling provided by clinics:

What this means in practice is that if you have a couple presenting who need to use a donor because one of the partners is infertile, both the donors and the recipient couple will have at least two sessions of counselling before they commence treatment. The purpose of that counselling, which we call implications counselling, is to make sure that all parties are fully informed about the implications of the decision that they are making to be either a donor or a recipient, and to ensure as far as possible that they are making informed consent in proceeding to treatment. <sup>272</sup>

- 6.74 While ART clinics operate under the RTAC code of practice and NHMRC guidelines, the level of counselling service available in each state is different. In Victoria it is compulsory under legislation to attend one counselling session prior to treatment, which is paid for by the individual.<sup>273</sup> In NSW counselling sessions are also privately paid for.<sup>274</sup>
- 6.75 In Western Australia counselling is compulsory and one free session per treatment cycle and one when deciding to end treatment are provided, and subsequent sessions are privately paid for.<sup>275</sup> Donor information is only released to applicants after they have had a professional counselling session.<sup>276</sup>
- 6.76 For donor conceived individuals in New South Wales who want to access identifying information about their donor and consider making a connection with them there are no explicit counselling supports. In the case of adopted people seeking birth information, the Registrar of the Registry of Births, Deaths and Marriages told the Committee the Department of Human Services arranges support for that person before they are issued with their pre-adoption birth certificate.<sup>277</sup>
- 6.77 However in terms of ART, the Registry is not equipped to provide certain services:

There are functions that the registry is not equipped to carry out; in particular I refer to things such as health or genetic counselling and family counselling...In terms of the central ART register operated by Health, I believe there are functions operated by the health department or affiliated with the health system which we are not in a position to operate. I am thinking of the type of counselling and genetic support that one would expect to be provided to someone who was seeking the details of their donor. <sup>278</sup>

6.78 Inquiry participants expressed the view that current counselling and support services are inadequate. Ms Lorbach told that Committee that the support

<sup>&</sup>lt;sup>271</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 28

<sup>&</sup>lt;sup>272</sup> Ms Hurrell, Transcript of evidence, 1 March 2012, p 29

<sup>&</sup>lt;sup>273</sup> Melbourne IVF, <a href="http://mivf.com.au/ivf-fees/ivf-costs">http://mivf.com.au/ivf-fees/ivf-costs</a>, accessed 4 March 2012

<sup>&</sup>lt;sup>274</sup> IVF Australia, Sperm Donation, <a href="http://ivf.com.au/sites/ivf.com.au/files/attachments/cln-au/sites/ivf.com.au/files/attachments/cln-au/sites/ivf.com.au/files/attachments/cln-au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sites/ivf.com.au/sit

<sup>026</sup> known sperm donation.pdf, accessed 4 April 2012

<sup>&</sup>lt;sup>275</sup> Reproductive Technology Council, <u>www.rtc.org.au/faqs/index.html</u>, accessed 28 March 2012

<sup>&</sup>lt;sup>276</sup>Reproductive Technology Council, <a href="http://www.rtc.org.au/faqs/index.html#anonymous\_known">http://www.rtc.org.au/faqs/index.html#anonymous\_known</a>, accessed 4 April 2012

<sup>&</sup>lt;sup>277</sup> Mr Curry, Transcript of evidence, 1 March 2012, p 9

<sup>&</sup>lt;sup>278</sup> Mr Curry, Transcript of evidence, 1 March 2012, p 9

currently provided by the Ministry of Health is not adequate as people are referred to counsellors experienced in infertility counselling, as opposed to birth origin information counselling.<sup>279</sup>

6.79 Ms Hurrell pointed out that donor conception raises long term issues that may require support:

Down the track, as a child grows and develops, there are other counselling issues that may come up for families that are donor conceived. They relate to things like parents seeking guidance about how to disclose to a child about their donor conception. Some parents have a lot of anxiety about that, and it connects emotionally with a lot of issues to do with infertility. There could be counselling about donors making decisions about whether they want to put their details on a donor register, and donors often have to think about that in the context of their family and the implications of their family. <sup>280</sup>

- 6.80 Birth origin counselling in Victoria is currently provided through the Family Information Networks and Discovery (FIND), administered by the Department of Human Services. When the BDM Register receives an application seeking identifying information it informs FIND that the applicant will contact them to arrange a counselling session. Similarly, if an applicant is seeking non-identifying information the Register will also inform FIND that the person is likely to contact them. It is important to note that the donor conception stakeholder must have a referral from the Register to contact FIND and this can only be offered at the initial stage of application. <sup>281</sup>
- 6.81 FIND provides a single counselling session with the aim of helping the applicant to manage their expectations of the process. FIND is of the opinion that one counselling session is usually enough.<sup>282</sup>
- 6.82 Melbourne IVF offers private counselling services and until recently has been the only clinic to do so for those donor conceived individuals conceived prior to 1988. Relbourne IVF provides linkage counselling and support to the donors, the offspring and the recipient parents but does not provide support for those wishing to contact donor conceived siblings or donors looking to contact their donor conceived children. Relationship to contact their donor conceived children.
- The Victorian *Inquiry into Access by Donor-Conceived People to Information about Donors* received evidence that the current counselling system in Victoria is not sufficiently meeting the needs of donor conception stakeholders. The main problems identified by the Committee are a lack of counselling and support, no donor linking services, limited services for pre-1988 stakeholders, limited

 $<sup>^{\</sup>rm 279}$  Ms Lorbach, Transcript of evidence, 1 March 2012, p 38

 $<sup>^{280}</sup>$  Ms Hurrell, Transcript of evidence, 1 March 2012, p 29

<sup>&</sup>lt;sup>281</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 134

<sup>&</sup>lt;sup>282</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 134

<sup>&</sup>lt;sup>283</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 135

<sup>&</sup>lt;sup>284</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 135

information exchange between agencies, and a system that is disjointed and difficult to navigate. <sup>285</sup>

### 6.84 The Victorian Committee recommended that:

The agency referred to in Recommendation 14 offer comprehensive and ongoing counselling and support services, in association with managing the donor registers, to all donor-conceived people, recipient parents and donors, and their relatives, and that counselling be compulsory for:

- A donor-conceived person who is seeking identifying information about his or her donor;
- A donor who is seeking identifying information about his or her donorconceived offspring; and
- A donor or donor conceived person who applies to lodge a contact veto.<sup>286</sup>
- 6.85 The Senate Legal and Constitutional Affairs References Committee Inquiry into Donor Conception Practices in Australia highlighted the critical role played by counselling both before and after donor conception procedures. The Committee concluded that:

... the level of counselling provided to donors, donor conceived people and their families should be improved, and that counselling accreditation processes should ensure that counsellors who provide counselling to donors, donor recipients or donor conceived people have knowledge or experience of the issues involved with donor conception. Wherever possible, counsellors should be independent from the clinics themselves. <sup>287</sup>

#### 6.86 Further to this, the Committee recommended that:

- counselling should be mandatory for donors and donor recipients prior to undergoing a donor conception procedure;
- donors and donor recipients should be able to elect to receive counselling on the donor conception process and its consequences from a counsellor independent of the fertility clinic in which they are undertaking treatment;
- parents of donor conceived individuals should have access to counselling following the birth of their child, to equip them to be able to tell their child about their conception and to support their child in dealing with any selfidentity issues that may arise; and
- donor conceived individuals should have access to counselling as they
  mature and, in particular, when making contact for the first time with their
  donor or half-siblings. Such counselling should be voluntary, except where

<sup>&</sup>lt;sup>285</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 137

<sup>&</sup>lt;sup>286</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information About Donors - Final report*, March 2012, p 153

<sup>&</sup>lt;sup>287</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, para 7.50

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the donor conceived person is aged under 18 and is making contact for the first time with their donor or half-siblings, in which case counselling should be mandatory. <sup>288</sup>

- 6.87 Submission makers also highlighted the importance of public education for the donor conception community as it not only promotes openness and discussion but also encourages people to register their details on the voluntary register where they have not previously done so.
- In Victoria, VARTA has previously run a successful public education campaign entitled 'Time to Tell' which advocated disclosure by parents to their donor conceived children. The 'Time to Tell' campaign was intended to publicise the legislation that allowed donor information to be released and to offer parents techniques for discussing these issues with their children. The main features of the campaign are outlined in more detail in the article 'Donor Conception, Secrecy and the Search for Information' by Dr Sonia Allan. 290
- 6.89 Dr Allan noted that one of the benefits of this type of campaign is that it can lead to donor linking. <sup>291</sup> This linking, of course, may require further counselling to be provided.
- 6.90 Professor Millbank told the Committee that in addition to donor matching and counselling, DNA testing and the provision of general information and support are services that are frequently required by individuals involved in ART.<sup>292</sup>
- 6.91 At the moment some of these needs are met by voluntary organisations referring enquiries to relevant counselling and support bodies, but evidence presented to the Committee demonstrated a need for an agency which can provide the diverse services associated with ART.
- 6.92 Professor Jenni Millbank noted that it is 'very worthwhile considering making a separate quasi or semi-quasi entity to deal with these functions and to fund it accordingly'. She observed that approximately 3% of live births in Australia are the result of some type of ART procedure (not including those occurring outside the clinic system) and 'it is right to be thinking about putting in place support systems and services for them.' The Committee discusses proposals to set up a standalone agency in greater detail in Chapter Five.

### Committee comment

6.93 As mentioned above, counselling is an important issue that must be considered as part of any discussion on the issue of granting donor conceived individuals retrospective access to donors' identifying details. While counselling is currently

<sup>&</sup>lt;sup>288</sup> Parliament of Australia, Senate Legal and Constitutional Affairs References Committee, *Donor conception practices in Australia*, February 2011, para 7.89

<sup>&</sup>lt;sup>289</sup> VARTA, <a href="http://www.varta.org.au/">http://www.varta.org.au/</a>, accessed 17 April 2012

<sup>&</sup>lt;sup>290</sup> Dr Sonia Allan, 'Donor Conception, Secrecy and the Search for Information', in *Journal of Law and Medicine*, Vol 4, No 12, June 2012, p 647

<sup>&</sup>lt;sup>291</sup> Dr Allan, Transcript of evidence, 5 March 2012, p 5

<sup>&</sup>lt;sup>292</sup> Professor Millbank, Transcript of evidence, 5 March 2012, p 19

<sup>&</sup>lt;sup>293</sup> Professor Millbank, Transcript of evidence, 5 March 2012, p 24

required for couples undergoing fertility treatment, there is no requirement for it when receiving donor conception information. In examining the issue of retrospective access, consideration would also need to be given to the need for mandatory counselling and a public education campaign, as recently recommended by the Victorian Law Reform Committee. In addition to counselling, other relevant services include letterboxing, support groups and donor linking.

- 6.94 The Committee considers that considerable consultation and deliberation is required on the best means of providing these services in New South Wales, and whether it should be based on an existing model, or whether a new model may need to be developed.
- 6.95 The experience of other jurisdictions such as Victoria and Western Australia in establishing legislation, practices, policies, and relevant bodies in relation to the ART sector has lessons and benefits that can be used by NSW in developing appropriate structures to manage the issues relevant to the sector.
- The Committee found that this inquiry raised several issues that were outside the Terms of Reference, namely issues around access to information and counselling and support services. These are complex and sensitive issues which require further consultation and consideration. The Committee has concluded that an additional inquiry would provide it with an opportunity to consult with stakeholders regarding these issues. The Committee intends to conduct such an inquiry in the near future.

#### FINDING 4

The provision of counselling and support services and public education in relation to donor conception are important issues that require further examination. These matters should be considered as part of a broader review of the current system for managing donor conception information, and access to this information. The Committee will examine these issues as part of a future inquiry.

# Appendix One – List of Submissions

1	Mr Damian Adams
2	A/Prof Nicholas Tonti-Filippini
3	Name suppressed
4	Mr Michael Sobb
5	Mr John Lindsay Mayger
6	Life, Marriage and Family Centre, Catholic Archdiocese of Sydney
7	Donor Conception Support Group of Australia Inc.
8	Hawkesbury Nepean Community Legal Centre Inc.
9	Plunkett Centre for Ethics
10	Mr Brian FitzGerald
11	Ms Jennie Burrows
12	Mr Ian Smith
13	Dr Sonia Allan
14	Ms Christine Whipp
15	Confidential
16	NSW Commission for Children and Young People
17	Professor Jenni Millbank
18	Miss Narelle Grech
19	Mrs Myfanwy Cummerford
20	Name suppressed
21	VANISH Inc
22	The Law Society of New South Wales
23	NSW Gay and Lesbian Rights Lobby
24	Ms Miranda Montrone
25	Inner City Legal Centre
26	Australian Christian Lobby
27	The Hon Greg Donnelly MLC
28	The Fertility Society of Australia
29	Information and Privacy Commission
30	Department of Health, Government of Western Australia
31	NSW Government

## INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS LIST OF SUBMISSIONS $\label{eq:list}$

32 Women's Legal Services

## Appendix Two – List of Witnesses

## 1 March 2012, Macquarie Room, Parliament House

Witness	Position and Organisation
Ms Gaby Carney	Assistant Director, Legislation Policy and Criminal Law Review Division
Mr Stephen Bray	Policy Officer, Legislation, Policy and Criminal Law Review Division
	Department of Attorney-General and Justice
Mr Greg Curry	Registrar
Ms Debbie Leyshon	Assistant Registrar, Registrations Division
Ms Lisa Karam	Manager, Amendments
	Registry of Births, Deaths and Marriages
Ms Leanne O'Shannessy	Director, Legal and Regulatory Services and General Counsel
Mr Greg McAllan	Associate Director, Private Health Care Unit, Legal and Regulatory Services
	Ministry of Health
Mr John McAteer	Deputy Privacy Commissioner
	Information and Privacy Commission
Ms Elizabeth Hurrell	Representative of Australian and New Zealand Infertility Counsellors Association
	Fertility Society of Australia
Ms Caroline Lorbach	National Consumer Advocate
	Donor Conception Support Group of Australia

## 5 March 2012, Waratah Room, Parliament House

Witness	Position and Organisation
Dr Sonia Allan	
Ms Pam Suttor	Chair, Elder Law and Succession Committee
	Law Society of NSW
Mr Dan Stubbs	Director
Ms Amy McGowan	Solicitor
	Inner City Legal Centre
Professor Jenni Millba	nk

## Appendix Three – Visit of inspection

#### Monday, 27 August 2012 Melbourne, Victoria

On 27 August 2012, a delegation of the Committee travelled to Melbourne as part of the inquiry into the inclusion of donor details on the register of births. The purpose of the visit was to meet with stakeholders who have responsibility for relevant aspects of the assisted reproductive treatment process in Victoria, including managing the donor registers and providing counselling.

Three Committee members (Mr John Barilaro MP, Mr Jai Rowell MP and Mr Guy Zangari MP) and one staff member (Ms Carly Maxwell) attended the visit.

#### **Victorian Assisted Reproductive Treatment Authority**

The Committee met with the following people:

- Ms Louise Johnson, Chief Executive Officer
- Ms Kirsten Mander, Chairperson

#### Registry of Births, Deaths and Marriages

The Committee met with Ms Erin Keleher, Secretary of the Victorian Births, Deaths and Marriages Registry.

#### **Victorian Parliamentary Law Reform Committee**

The Committee met with the following people:

- Mr Clem Newton-Brown, Chair
- Ms Jane Garrett, Deputy Chair
- Mr Anthony Carbines
- Mr Russell Northe
- Mrs Donna Petrovich

#### **Department of Human Services**

The Committee met with the following people:

- Mr Keith Smith, Manager, Children Youth and Families
- Mr Matthew Reeder, A/Manager, Family Records and Intercountry Services
- Ms Angela Karavidas, Manager, Family Information Network and Discovery.

## Appendix Four – Extracts from Minutes

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 4)

4.07pm, Monday, 17 October 2011 Room 1254, Parliament House

#### Members Present

Mr Barilaro, Mr Lalich, Mr Zangari

### **Apologies**

Mr Edwards, Mr Rowell

Officers in attendance: Ms Carly Sheen, Ms Dora Oravecz, Ms Jenny Whight

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari, that the minutes of the deliberative meeting of 11 October 2011 be confirmed.

2. \*\*\*\*

# 3. Forward planning – commencement of the proposed inquiry into inclusion of donor details on the register of births

Terms of Reference

The Committee discussed the draft terms of reference for the inquiry.

Resolved, on the motion of Mr Zangari, seconded by Mr Lalich, that the Committee inquire into and report on whether there should be provision for the inclusion of donor details on the register of births maintained by the Registrar of Births, Deaths and Marriages.

Call for Submissions – advertising and writing to stakeholders

The Committee discussed how submissions should be called for and which stakeholders should be informed about the inquiry.

Resolved, on the motion of Mr Zangari, seconded by Mr Lalich, that the Committee advertise the call for submissions to the inquiry in the Sydney Morning Herald and on the Committee website, and write to relevant stakeholders with a closing date of 21 December 2011.

#### **Inquiry Timeline**

The Committee noted the indicative timeline for the conduct of the inquiry and the completion of the report.

Media Statements

The Chair advised the Committee that he would prepare a media release announcing the inquiry and circulate it to members. The media release would also be published on the Committee's website.

## 4. \*\*\*\*

The committee adjourned at 4.13pm until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 5)

3.38pm, Tuesday 14 February 2011 Waratah Room, Parliament House

#### **Members Present**

Mr Barilaro, Mr Lalich, Mr Zangari, Mr Rowell

### **Apologies**

Mr Edwards

Officers in attendance: Ms Carly Sheen, Ms Dora Oravecz, Ms Jenny Whight, Ms Clara Hawker

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Barilaro, that the minutes of the deliberative meeting of 17 October 2011 be confirmed.

## 2. Inquiry into the inclusion of donor details on the register of births

#### a. Submissions – consideration of and approval for publication

Resolved, on the motion of Mr Lalich, seconded by Mr Rowell, that all the submissions be published on the website except for numbers 3 and 20, which will be partially published, and number 15 which will remain confidential.

#### b. Public hearing arrangements – 1 March and 5 March

#### Witness selection

Resolved, on the motion of Mr Rowell, seconded by Mr Lalich, that the following witnesses be called to give evidence before the Committee:

- Attorney-General's Department
- Registry of Births, Deaths and Marriages
- Ministry of Health
- NSW Commission for Children & Young People

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- Information and Privacy Commission
- The Fertility Society of Australia
- Donor Conception Support Group of Australia Inc
- Dr Sonia Allan
- Professor Jenni Millbank
- The Law Society of NSW
- Inner City Legal Centre

#### Approval for witness travel expenses

Resolved, on the motion of Mr Rowell, seconded by Mr Lalich, that the Chair write to the Speaker seeking approval for funds to cover travel expenses for witnesses, where necessary, to enable them to attend the public hearings.

## c. Correspondence to the Victorian Registry of Births, Deaths and Marriages and the Victorian Reproductive Treatment Authority

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari, that the Committee write to the Victorian Registry of Births, Deaths and Marriages and the Victorian Reproductive Treatment Authority to seek further information on relevant matters.

# 3. Informal private briefing for members on registration of births and relevant matters

The Chair welcomed the following individuals:

Mr Greg McAllan (Associate Director, Private Health Care Unit, Legal and Regulatory Services, Ministry of Health); Ms Leanne O'Shannessy (Director, Ministry of Health); Mr Greg Curry (Registrar, Registry of Births, Deaths and Marriages); Ms Debbie Leyshon (Assistant Registrar, Registration Services, Registry of Births, Deaths and Marriages); Mr Stephen Bray (Policy Officer, Legislation, Policy and Criminal Law Review Division, Department of Attorney-General and Justice). Following their presentations the Chair and the Committee members thanked them for their attendance.

## 4. \*\*\*\*

The committee adjourned at 4.20pm until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 6)

3.34pm, Thursday 23 February 2011 Waratah Room, Parliament House

#### **Members Present**

Mr Barilaro, Mr Lalich, Mr Zangari, Mr Rowell, Mr O'Dea

### **Apologies**

Mr Edwards

Officers in attendance: Ms Carly Sheen, Ms Dora Oravecz, Ms Jenny Whight, Ms Clara Hawker

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Lalich, that the minutes of the deliberative meeting of 14 February 2012 be confirmed.

## 2. Membership of Committee

The Committee noted the receipt of correspondence from the Government Whip, dated 23 February, advising of the nomination of Mr Jonathan O'Dea to act as a substitute Committee member for Mr Garry Edwards, until Mr Edwards is able to attend Committee meetings. The Committee welcomed Mr O'Dea to the meeting.

## 3. Correspondence

The Committee noted the receipt of correspondence from the CEO of the Victorian Assisted Reproductive Treatment Authority, dated 17 November 2011.

The Committee noted that the Chair had written to the Victorian Registry of Births, Deaths and Marriages, dated 14 February 2012; and the Victorian Assisted Reproductive Treatment Authority, dated 14 February 2012.

## 4. Inquiry into the inclusion of donor details on the register of births

Public hearing arrangements

The Committee noted the final witness schedule for the public hearings on 1 March and 5 March and discussed arrangements and relevant procedures relating to the public hearings.

The committee adjourned at 3.40pm until 9.30am on Thursday 1 March 2012.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (No. 7)

9:30 am, Thursday 1 March 2012 Macquarie Room, Parliament House

#### **Members Present**

Mr Barilaro (Chair), Mr Rowell, Mr Lalich, Mr Zangari, Mr O'Dea (until 11.59am)

Staff in attendance: Carly Sheen, Dora Oravecz, Clara Hawker, Jenny Whight

# 1. Public hearing: inquiry into the inclusion of donor details on the register of births

The press and the public were admitted. The Chair opened the public hearing and, after welcoming the witnesses, gave a short opening address.

Ms Gaby Carney, Assistant Director, Legislation Policy and Criminal Law Review Division, Department of Attorney-General and Justice and Mr Stephen Bray, Policy Officer, Legislation Policy and Criminal Law Review Division, Department of Attorney-General and Justice both affirmed and examined.

Ms Carney made a brief opening statement.

The Chair commenced questioning the witnesses, followed by other members of the Committee. Evidence concluded, the Chair thanked the witnesses for their attendance. The witnesses withdrew.

Mr Greg Curry, Registrar, Registry of Births, Deaths and Marriages and Ms Debbie Leyshon, Manager, Registrations, Registry of Births, Deaths and Marriages both affirmed and examined. Ms Lisa Karam, Manager, Amendments, Registry of Births, Deaths and Marriages sworn and examined.

The Chair commenced questioning the witnesses, followed by other members of the

Evidence concluded, the Chair thanked the witnesses for their attendance. The witnesses withdrew.

The Committee took a short adjournment at 10:45am and resumed the public hearing at 11:00am.

Ms Leanne O'Shannessy, Director, Legal and Regulatory Services and General Counsel, Ministry of Health and Mr Greg McAllan, Associate Director, Private Health Care Unit, Legal and Regulatory Services, Ministry of Health both affirmed and examined.

The Chair commenced questioning the witnesses, followed by other members of the Committee.

Evidence concluded, the Chair thanked the witnesses for their attendance. The witnesses withdrew.

## INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS EXTRACTS FROM MINUTES

Mr John McAteer, Deputy Privacy Commissioner, Information and Privacy Commission affirmed and examined.

Mr McAteer made a brief opening statement.

The Chair commenced questioning the witness, followed by other members of the Committee. Evidence concluded, the Chair thanked the witness for his attendance. The witness withdrew.

The Committee took an adjournment at 12:30am and resumed the public hearing at 1:30pm.

Ms Elizabeth Hurrell, Representative of Australian and New Zealand Infertility Counsellors Association, Fertility Society of Australia affirmed and examined.

Ms Hurrell made a brief opening statement.

The Chair commenced questioning the witness, followed by other members of the Committee. Evidence concluded, the Chair thanked the witness for her attendance. The witness withdrew.

Ms Caroline Lorbach, National Consumer Advocate, Donor Conception Support Group of Australia sworn and examined.

Ms Lorbach made a brief opening statement.

The Chair commenced questioning the witness, followed by other members of the Committee. Evidence concluded, the Chair thanked the witness for her attendance. The witness withdrew.

The public hearing concluded at 2:59 pm.

## 2. Deliberative meeting (2:59pm)

#### a) Minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Rowell, that the minutes of the deliberative meeting of 23 February 2012 be confirmed.

#### b) Publication orders

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari, that the corrected transcript of evidence given today be authorised for publication and uploaded on the Committee's website.

The deliberations concluded at 3:03pm and the Committee adjourned until Monday 5 March 2012 at 9:15am.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (No. 8)

9:28 am, Monday 5 March 2012 Waratah Room, Parliament House

#### **Members Present**

Mr Barilaro (Chair), Mr Rowell, Mr Lalich, Mr Zangari, Mr O'Dea

Staff in attendance: Carly Sheen, Dora Oravecz, Jenny Whight

# 1. Public hearing: inquiry into the inclusion of donor details on the register of births

Dr Allan and Professor Millbank gave evidence via telephone, pursuant to Standing Order 295.

The press and the public were admitted. The Chair opened the public hearing and, after welcoming the witness, gave a short opening address.

Dr Sonia Allan, Senior Lecturer in Law, Deakin University School of Law affirmed and examined.

The Chair commenced questioning the witness, followed by other members of the Committee. Evidence concluded, the Chair thanked the witness for her evidence.

Ms Pam Suttor, Chair, Elder Law and Succession Committee, Law Society of NSW sworn and examined.

The Chair commenced questioning the witness, followed by other members of the Committee. Evidence concluded, the Chair thanked the witness for her attendance. The witness withdrew.

Mr Daniel Stubbs, Director, Inner City Legal Centre and Ms Amy McGowan, Solicitor, Inner City Legal Centre both affirmed and examined.

Mr Stubbs and Ms McGowan made brief opening statements.

The Chair commenced questioning the witnesses, followed by other members of the Committee.

Evidence concluded, the Chair thanked the witnesses for their attendance. The witnesses withdrew.

The Committee took an adjournment at 11:30am and resumed the public hearing at 1:00pm.

Professor Jenni Millbank, Professor, Faculty of Law, University of Technology, Sydney affirmed and examined.

The Chair commenced questioning the witness, followed by other members of the Committee. Evidence concluded, the Chair thanked the witness for her evidence.

The public hearing concluded at 1:38pm.

### 2. Deliberative meeting (1:39pm)

#### c) Minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Rowell, that the minutes of the deliberative meeting of 1 March 2012 be confirmed.

#### d) Publication orders

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the corrected transcript of evidence given today be authorised for publication and uploaded on the Committee's website.

#### e) \*\*\*\*

The Committee discussed forward planning for the inquiry.

The deliberations concluded at 1:46pm until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 9)

10.37am, Thursday 19 April 2012 Waratah Room, Parliament House

#### **Members Present**

Mr Barilaro, Mr Lalich, Mr Zangari, Mr Rowell (by telephone), Mr O'Dea

Officers in attendance: Ms Carly Maxwell, Ms Dora Oravecz, Ms Clara Hawker, Mr Ben Foxe

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Lalich, seconded by Mr Zangari, that the minutes of the deliberative meeting of 5 March 2012 be confirmed.

## 2. Inquiry into the inclusion of donor details on the register of births

a. \*\*\*\*

#### b. Publication orders

Resolved, on the motion of Mr Lalich, seconded by Mr Rowell, that the answers to questions taken on notice by the Registry of Births, Deaths and Marriages, the Ministry of Health and the Department of Attorney-General and Justice be authorised for publication and uploaded on the Committee's website.

#### c. Victorian Law Reform Committee report

The Committee noted the tabling of the Victorian Law Reform Committee's report on access to information by donor conceived people. Discussion ensued.

#### d. Forward planning

The Chair opened discussion on issues and options for reform outlined in a document prepared by Committee staff, and on forward planning for the inquiry. The Committee discussed the issues document provided by Committee staff.

The Committee agreed that Committee staff would conduct further research on some of the issues and prepare a briefing for members' information.

The Committee deliberated on what further information was required to be gathered in the preparation of a draft report on the inclusion of donor details on the register of births. The Committee agreed that Committee staff would research means for Committee members to consult additional relevant stakeholders in order to obtain further evidence.

The Committee agreed that Committee staff would prepare draft correspondence to the NSW Attorney-General seeking further information regarding the proposal to establish nationally consistent donor conception registers.

The Committee also agreed that Committee staff would research approaches taken in comparable jurisdictions.

Discussion ensued.

The Committee agreed that Committee staff would compose a briefing paper for the next meeting regarding possible contact with Victorian stakeholders in relation to the Victorian Law Reform Committee's recommendations on access to information by donor conceived people.

Discussion ensued.

The Committee agreed that staff would prepare draft correspondence to NSW ART clinics regarding their record keeping practices and the information they provide to donor conceived individuals.

The Committee adjourned at 11.22am until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 10)

9.37am, Thursday 10 May 2012 Parkes Room, Parliament House

#### Members Present

Mr Barilaro (Chair), Mr Lalich, Mr Rowell, Mr Zangari

## **Apologies**

Mr Edwards

Officers in attendance: Ms Carly Maxwell, Ms Dora Oravecz, Ms Clara Hawker, Ms Jenny Whight

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the minutes of the deliberative meeting of 19 April 2012 be confirmed.

## 2. Inquiry into the inclusion of donor details on the register of births

#### Correspondence

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the Committee write to:

- ART clinics in NSW seeking information on their record keeping practices and the information they provide to donor conceived individuals;
- the NSW Attorney-General seeking information on a national model for the harmonisation of donor conception registers.

#### Consideration of proposed visit of inspection to Victoria

The Committee noted the briefing paper regarding possible contact with Victorian stakeholders in relation to the Victorian Law Reform Committee's recommendations on access to information by donor conceived people. Discussion ensued.

Resolved, on the motion of Mr Zangari, seconded by Mr Lalich, that the Committee seek approval from the Speaker for funding for three Committee members and one staff member to visit Victoria, to consult with relevant stakeholders and obtain further information on the Victorian experience and on other issues relevant to considering the inclusion of donor details on the register of births.

#### Forward planning

The Committee discussed the forthcoming private briefing with a donor conceived adult.

The Committee adjourned at 9.45am until 24 May 2012.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 11)

1.40pm, Thursday 24 May 2012 Room 1153, Parliament House

#### **Members Present**

Mr Barilaro (Chair), Mr Edwards, Mr Lalich, Mr Rowell, Mr Zangari

Officers in attendance: Ms Carly Maxwell, Ms Dora Oravecz, Ms Clara Hawker, Ms Jenny Whight

## 1. Private briefing for members from a donor conceived individual

The Committee welcomed a donor conceived individual and their support person. The Committee was briefed by the donor conceived person about their perspective and personal experiences.

At 2.08pm the donor conceived individual and their support person withdrew.

#### 2. Confirmation of minutes

Resolved, on the motion of Mr Zangari, seconded by Mr Rowell, that the minutes of the deliberative meeting of 10 May 2012 be confirmed.

## 3. Correspondence

The Committee noted incoming correspondence from Reproductive Medicine Albury.

## 4. Forward planning

The Committee discussed arrangements for the forthcoming visit of inspection to Victoria.

#### 5. General business

The Chair welcomed Mr Edwards back to the Committee.

The Committee adjourned at 2.13pm until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 12)

3.45pm, Tuesday 19 June 2012 Waratah Room, Parliament House

### **Members Present**

Mr Barilaro (Chair), Mr Edwards, Mr Lalich, Mr Rowell, Mr Zangari

Officers in attendance: Ms Helen Minnican, Ms Carly Maxwell, Ms Dora Oravecz, Ms Clara Hawker, Ms Jenny Whight

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Edwards, seconded by Mr Rowell, that the minutes of the deliberative meeting of 24 May 2012 be confirmed.

## 2. Correspondence

The Committee noted incoming correspondence from:

- Next Generation Fertility
- Fertility East

- Royal Hospital for Women clinic
- \*\*\*\*

## 3. Forward planning

- a) The Committee discussed arrangements for the forthcoming visit of inspection to Victoria. Committee staff agreed to contact relevant stakeholders in Victoria to canvass their availability on 27 August, rather than 28 August.
- b) The Chair opened discussion on the main issues relevant to the current inquiry and preferred options for reform, as outlined in a briefing paper prepared by Committee staff.
  - The Committee agreed that Committee staff would prepare an outline of the advantages and disadvantages of some of the proposed options for reform.
- c) The Committee noted the briefing paper outlining issues that have arisen in the current inquiry that are outside its Terms of Reference. The Committee discussed the conclusion of the current inquiry and the commencement of a new inquiry into matters not covered by the current inquiry.

## 4. \*\*\*\*

The Committee adjourned at 4.07pm until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 13)

1.35pm, Wednesday 22 August 2012 Room 1153, Parliament House

#### **Members Present**

Mr Barilaro (Chair), Mr Lalich, Mr Rowell, Mr Zangari

## **Apologies**

Mr Edwards

Officers in attendance: Ms Carly Maxwell, Ms Dora Oravecz, Ms Clara Hawker, Ms Jenny Whight

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the minutes of the deliberative meeting of 19 June 2012 be confirmed.

## 2. Correspondence

The Committee noted incoming correspondence from:

- IVF Australia, dated 12 July, in response to questions sent to the clinic by the Committee regarding record keeping practices.
- The NSW Attorney-General, dated 9 August, in response to correspondence from the Committee regarding the harmonisation of donor registers.
- The author of submission no 3, dated 4 July, concerning the conduct of the inquiry.

Resolved, on the motion of Mr Zangari, that the Chair write to the author of submission no 3 regarding the conduct of the inquiry.

# 3. Inquiry into inclusion of donor details on the register of births: Options for reform

The Chair spoke to the briefing paper prepared by committee staff outlining options for reform in relation to issues that have arisen during the inquiry. Discussion ensued.

## 4. Visit of inspection

The Committee noted the final arrangements for the forthcoming visit of inspection to Victoria on Monday 27 August.

#### 5. General business

The Committee agreed to meet after the visit of inspection.

The Committee adjourned at 2.07pm until a date and time to be determined.

## Minutes of Proceedings of the Legislative Assembly Committee on Law and Safety (no. 14)

1.38pm, Thursday 20 September 2012 Room 1153, Parliament House

#### **Members Present**

Mr Barilaro (Chair), Mr Edwards, Mr Rowell, Mr Zangari

## **Apologies**

Mr Lalich

Officers in attendance: Ms Carly Maxwell, Ms Dora Oravecz, Ms Clara Hawker, Ms Jenny Whight

#### 1. Confirmation of minutes

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari, that the minutes of the deliberative meeting of 22 August 2012 be confirmed.

# 2. Inquiry into inclusion of donor details on the register of births: consideration of Chair's draft report

The Chair spoke to the draft report, previously circulated. Discussion ensued.

Resolved, on the motion of Mr Rowell, seconded by Mr Zangari, that the draft report be the report of the Committee and that it be signed by the Chair and presented to the House.

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari, that the Chair and committee staff be permitted to correct stylistic, typographical and grammatical errors.

Resolved, on the motion of Mr Edwards, seconded by Mr Zangari, that, once tabled, the Report be placed on the Committee's website.

The Committee discussed tabling arrangements.

\*\*\*

The Committee adjourned at 1.58pm until a date and time to be determined.