

CHAPTER 6

Rights of donor conceived individuals

6.1 This chapter discusses what rights should be accorded to donor conceived people, and in particular, considers:

- access to information about donors, including anonymity of donors and non-disclosure to donor conceived children that they were donor conceived;
- current concerns for donors, including issues relating to self-identity, access to medical records and the importance of disclosure;
- the analogy with adoption;
- the annotation of birth certificates for donor conceived people; and
- whether a 'rights' based approach is appropriate in this context.

Access to information about donors

6.2 Many of the issues of concern to donor conceived people arise as a consequence of historical practices around donor conception. The two main issues are the anonymity of donors, and the fact that many parents were often told not to disclose to their children that they were donor conceived (and often did not do so until their children were adults).¹

Anonymity of donors

6.3 Even in situations where records may exist about a donor, many donor conceived people are unable to access these records as a result of past commitments made to donors to maintain their anonymity.² Miss Narelle Grech, a donor conceived person, explained the personal impact this has had on her:

I cannot begin to describe how dehumanising and powerless I am to know that the name and details about my biological father and my entire paternal family sit somewhere in a filing cabinet...with no means to access it. Information about my own family, my roots, my identity, I am told I have no right to know.³

6.4 In those states that have enacted legislation governing donor conception, (Victoria, Western Australia, South Australia and NSW), requirements for providing

1 See, for example, *Submission 42 (name withheld)*; *Submission 78 (name withheld)*, pp [1-2]; DCSG, *Submission 122*, p. 60.

2 See, for example, Andrew, *Submission 10*; *Submission 22 (name withheld)*, p. 1.

3 *Submission 107*, p. 2.

identifying information about donors to donor conceived people are not retrospective, meaning that only people who are donor conceived after the enactment of the relevant legislation can have access to donor information under the terms of that legislation. There are also differences in the state legislative schemes, as discussed earlier in this report and as set out in Appendix 1.

6.5 Further, by legislation not having a retrospective operation, this has, in effect, provided donors with rights to anonymity if, when they donated, they did so on the understanding that their donation was anonymous. In NSW, for example, under the *Assisted Reproductive Technology Act 2007* (NSW), the NSW register can only be accessed by donor conceived people conceived after 1 January 2010. People conceived before 1 January 2010 are only able to access information if the person to whom it relates has consented.⁴

6.6 In Victoria, under the *Assisted Reproductive Treatment Act 2008* (Vic), if a donation was given before 1998, no information is available for the donor conceived person unless the donor has lodged their information on the Voluntary Register (Vic). As the Victorian Law Reform Committee observed during its inquiry, 'some gametes donated prior to 1988 are still being used in donor conception procedures', and people conceived now and into the future with these gametes cannot access any information because donors were guaranteed anonymity at the time of making the donation.⁵

6.7 In her submission, Dr Sonia Allan pointed to the inequity for donor conceived individuals arising from the inconsistent approaches to access to information about donor conception.⁶ She also submitted:

[i]t is difficult to justify a situation in which some people born as a result of the use of ART have a right to access to information about their biological parentage because they were conceived in a particular state at a particular time, but those conceived in other states or territories or prior to the introduction of legislation are not entitled and do not have access to such information.⁷

6.8 At the public hearing in Melbourne, Dr Allan stated:

...I believe, not just from a social perspective but also from a legal perspective, that, once we recognise the right of donor conceived individuals to have access to information about their genetic heritage, that recognition cannot be applied only to a small subset of donor conceived individuals or people who will be conceived via assisted reproductive

4 NSW Department of Health, http://www.health.nsw.gov.au/resources/hospitals/phc/pdf/volunteer_donor_registerart_a4.pdf, accessed 26 November 2010.

5 Victorian Parliament Law Reform Committee, *Inquiry into access by donor-conceived people to information about donors*, Interim Report, September 2010, p. xv.

6 *Submission 30*, p. 6.

7 *Submission 30*, p. 9. See also DCSG, *Submission 122*, p. 16.

technologies in the future. Once we make that recognition, we need to apply that recognition to all donor conceived individuals...⁸

6.9 Other submissions, such as that of the Rainbow Families Council, highlighted how some siblings within the same family, who were conceived under different regulatory approaches, have different rights to access information about their donor.⁹

6.10 Ms Marianne Tome of the Victorian Infertility Counsellors Group argued that other people affected by donor conception more broadly should also have access to information about donors, not just those who are donor conceived:

[w]e recognise the right of all donor conceived individuals in Australia to have access to information about their biological parents and genetic siblings. We also recognise the rights of recipients and donors to also have access to such information.¹⁰

Non-disclosure to children

6.11 The committee learned that in the 1970s and 1980s, particularly, parents were often encouraged by doctors and clinics not to tell their children that they were donor conceived. For example, the parents of donor conceived children were told in 1982 that donor conception 'was a closed book that we were to tell no one, including the child, of the roller coaster experience'.¹¹ Another mother of a donor conceived child who was born in 1979, still has not told him that he is donor conceived:

[he] is now 30 years of age. He does not know the truth of his conception...

As time went by I began to have deep reservations about this secret which we were keeping from him.

I felt that he had the right to know but I also knew that the legislation would not allow me to get his records to pass on to my son.

I also felt that because my husband and I had divorced, I did not want to tell him without my ex husband consenting. I did not want this to be a trigger which may have caused damage to their relationship. I did approach his father about this, but he did not want his son to know.

So a few more years went by.

Every few years the issue arises for me again and keeps rearing its ugly head. There is a nagging feeling there that he has the right to know. But then when I realise that he can't get access to his records, I meet another stumbling block again, and the issue goes underground again for me.

...

8 *Committee Hansard*, 3 November 2010, p. 21.

9 *Submission 73*, p. 2. See, also, Monash IVF, *Submission 120*, p. 2.

10 *Committee Hansard*, 3 November 2010, p. 72.

11 *Submission 42 (name withheld)*.

And still I have not told him.¹²

6.12 Some parents tell their children that they are donor conceived when they become an adult.¹³ Miss Lauren Burns discovered as an adult that she and her sister were donor conceived, and described finding out in the following way:

[o]ne afternoon in...2005, when I was 21 and my sister 24, my mother sat us down and said she had something to tell us. She sat on the creased leather couch, eyes downcast, hands shaking softly. In an awkward conversation she revealed the truth, that we were both donor conceived. Finding out so late was a huge shock. My identity was splintered and the social and biological aspects of parenthood carved up. I learned my biological father was a vial of frozen sperm labelled C11.

For the next three years I didn't discuss being donor conceived, but I thought about it a lot, almost every day. I mourned the human face behind that vial, somebody I had never and would never meet. I wondered about my missing kin, who they were, what they looked like and where their interests lay. I empathised with people whose relatives have gone missing. They don't know if they are alive or dead, happy or miserable, and when, if ever, they might see each other again. It is important to recognise that the impact of the status quo is not benign. It can place children in an awful limbo. I thought about carrying this burden for the rest of my life and I was afraid.¹⁴

6.13 Dr Sonia Allan noted the difficulties associated with such an approach:

[s]imilar to adopted children wanting to meet their biological parents, donor-conceived individuals feel a strong need to connect with their donor in order to obtain a fuller sense of self-identity. Of major concern then is that individuals told late in life about their adopted or donor-conceived status may experience psycho-social difficulties. For example, where it is too late to meet their biological parents, such individuals may experience a great sense of loss.¹⁵

Current concerns for donor conceived people

6.14 As examined earlier in this report, the past requirement for anonymity of donors underpins many of the current concerns held by donor conceived individuals in relation to obtaining information about their genetic heritage. Such information is important in order to reduce the risk of consanguine relationships with unknown relatives, to be able to form meaningful relationships with donors and half-siblings, to have a more complete sense of self-identity, and for medical purposes.

12 *Submission 78 (name withheld)*, pp [1-2].

13 See, for example, Miss Lauren Burns, *Submission 40*, pp 3-4; Ms Kimberley Springfield, *Submission 52*, p. [1].

14 Miss Lauren Burns, *Submission 40*, pp 3-4.

15 *Submission 30*, p. 11.

Self-identity of the donor conceived

6.15 The difficulties that donor conceived individuals may experience in relation to accessing information about their donors mean that many do not know the identity of their biological father, mother, or parents, and they may also be deprived of non-identifying information such as the cultural extraction of their forebears. The DCSG submitted that donor conceived people have a need for this information in order for them to complete their own sense of identity:

[i]t is a basic human right to know of one's origins. Every person should have a right of access to information and to contact...those who make up their biological and social heritage, enabling them to complete a picture of themselves and their identity.¹⁶

6.16 The DCSG placed this issue in a human rights context, arguing that the Convention on the Rights of the Child supports the right of every child to know their biological identity.¹⁷ The DCSG particularly pointed to article 7.1 of Convention which provides that:

[t]he child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.¹⁸

6.17 In her submission, Dr Sonia Allan suggested:

[a]cademic literature has increasingly emphasised that relations based on blood are less important in shaping a child's development than previously thought. However, it is also the case that societies such as Australia place great weight on 'blood relations [as]... the basis of kinship'. Despite a child's development being shaped by social as much as biological factors, **knowledge of one's immediate genetic heritage is thus considered integral to the self-identity of most people.**¹⁹

6.18 Mrs Caroline Lorbach from the DCSG agreed:

[t]he 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 their date of birth has produced a minority group afforded fewer rights than their younger counterparts. The federal government has a responsibility to store and

16 *Submission 122*, p. 23. See also Mr Michael Linden, *Submission 9*, pp 3 and 5.

17 *Submission 122*, pp 126-128. See also Rainbow Families Council, *Submission 73*, p. 1.

18 In addition, Article 8.1 of the Convention states that signatories undertake to preserve a child's 'identity, including nationality, name, and family relations'. Article 8.2 states that where a child is illegally deprived of their identity, signatories shall work with a view to re-establishing that identity (Office of the United Nation High Commissioner for Human Rights website, 'Convention on the rights of the child', <http://www2.ohchr.org/english/law/crc.htm>, accessed 30 June 2010).

19 *Submission 30*, p. 11, emphasis in original.

protect the existing records before they are lost or destroyed forever and to ensure that donor conceived people have the same rights that everyone else in the population has, regardless of when they were born and what state they were conceived in.²⁰

6.19 Ms Susan Hurst, the mother of a donor conceived child, suggested that donor conceived people not only need information about the donor, but also need to be able to form relationships with other biological relatives:

[t]o be human is to be part of a long line of biological history - 2 sides. ...[Donor conceived] children will most likely have a wonderful life [but] there is family that this person deserves to have the opportunity to know. Biological [g]randparents (who may not have wanted their grandchildren donated away), half brothers, half sisters, uncles, aunties and cousins. People that would/could make our cherished donor conceived children 'whole' - and who also deserve consideration. Donor conceived children need transparency. They need to know who they are.²¹

6.20 However, not all donor conceived people want to meet their donor. Miss Claire Armitage explained that meeting the donor who enabled her conception was not the issue for her:

I do not care to know the man who helped to biologically produce me. I do, however, care to know where I am from, in the world, where my cultural roots lie, as well as my ancestors. At this time in my life, I want to know where I am from, so I might finally navigate where I am going.²²

6.21 Another submitter also does not necessarily want to meet his biological father. He stated that he calls his social father 'dad':

...because that is what he is to me[. H]e has partly raised me and always treated me as his son.

...[T]here would be some information about my biological father I would like to know but I don't think I would [want] to meet him and I definitely wouldn't want anything from him. I already have a father and he will always be my father.²³

20 *Committee Hansard*, 2 November 2010, p. 3.

21 *Submission 2*, p. 2.

22 *Submission 13*.

23 *Submission 158 (name withheld)*, pp 1 and 9.

Medical information

6.22 The committee received evidence suggesting that the absence of family medical histories and genetic information could have serious implications for the health of the donor conceived in terms of diagnosis and the treatment of illness.²⁴

6.23 Dr Sonia Allan submitted that the importance of access to medical information is 'undeniable' and that donor conceived individuals who are denied access to such information are placed at risk as a result of not being informed about their genetic heritage.²⁵

6.24 One submitter who was only able to obtain very limited non-identifying information in relation to his biological father expressed his personal concerns:

[o]ne of the biggest problems I have is the worry of hereditary diseases as I have no medical history on the donor.²⁶

6.25 Conversely, some donor conceived people, prior to being told of their donor conceived status, have worried needlessly about the risk of inherited health problems from their 'social' fathers.²⁷

Importance of disclosure

6.26 Over the past 30 years, the importance of disclosing to donor conceived children their biological origins has become more widely accepted. Parents are now being encouraged to tell their children that they are donor conceived. Most states and territories, including the ACT, Victoria, South Australia and Western Australia, produce booklets to assist parents to discuss this issue with their children.²⁸

6.27 Dr Martyn Stafford-Bell of the Canberra Fertility Centre advised the committee that this is not a new development:

It is not an emerging practice at all; it has been standard for years. I have been telling patients that they need to tell their children since we opened the sperm bank here in 1978.

24 See, for example, *Submission 4 (name withheld)*; *Submission 5 (name withheld)*; *Submission 11 (name withheld)*, pp 1-2; DCSG, *Submission 122*, pp 32-38.

25 *Submission 30*, p. 12.

26 Mr Callum Lorbach, *Submission 3*, p. 1.

27 Ms Louise Jamieson and the International Donor Offspring Alliance, *Submission 115*, p. 2.

28 See, for example, Parenting SA, *Donor Conception – telling your child*, Parent Easy Guide 80, <http://www.parenting.sa.gov.au/pegs/peg80.pdf>, accessed 24 November 2010; ParentLink (ACT), *Donor Conception – telling your child*, http://www.parentlink.act.gov.au/_data/assets/pdf_file/0005/33584/Donor_conception-telling_your_child.pdf, accessed 24 November 2010; Reproductive Technology Council (WA), *Talking to Children about Donor Conception*, http://www.rtc.org.au/publications/docs/Talking_to_Children.pdf, accessed 24 November 2010.

...But it is ultimately up to the parents to decide, because they may feel that it is not in the best interests of the child to know. You could think of several reasons why you should not tell a 15-year-old that they are donor conceived—or an eight-year-old.²⁹

Analogy with adoption

6.28 Adoption is a legal process where the rights and responsibilities for the care and welfare of a child are transferred from the child's birth parents to their adoptive parents, and the legal relationship between the biological parents and the child is severed.³⁰ All states and territories have legislation in relation to adoption,³¹ and Appendix 2 to this report sets out the legislation governing adoption in Australia.

6.29 This legislation provides adopted people with the right to identifying information about their biological parents, including their original birth certificate. However, legislation is not consistent between states and territories and, additionally, not all adoption legislation in Australia is retrospective. For example, in South Australia and Queensland, birth parents and adopted people may veto the release of identifying information and any contact, if the adoption was finalised prior to the commencement of the relevant legislation in those states.³²

6.30 There are contact vetoes that may be put in place in some states, and adopted people are only able to access identifying information at age 18, except in the ACT, where the age limit is 17 years and 6 months.³³ In many states and territories, adopted people may access identifying information earlier with the agreement of their adoptive parents, and in some cases, their birth parent's agreement.³⁴

6.31 Several submissions drew a parallel to retrospective changes to the law which allow the release of identifying information about the biological parents of adopted children, and proposals to retrospectively provide for identifying information about their donors to be provided to donor conceived children.

29 *Committee Hansard*, 29 October 2010, pp 12-13.

30 Australian Institute of Health and Welfare, *Adoptions Australia 2008-09*, Child Welfare Series No. 48, February 2010, p. 1.

31 *Adoption Act 1994* (WA), *Adoption Act 1984* (Vic), *Adoption Act 2000* (NSW), *Adoption Act 1988* (SA), *Adoption Act 1988* (Tas), *Adoption of Children Act 1964* (QLD), *Adoption of Children Act 1994* (NT) and *Adoption Act 1993* (ACT).

32 Australian Institute of Health and Welfare, *Adoptions Australia 2008-09*, Child Welfare Series No. 48, February 2010, pp 66-67 and 68.

33 For example, in Tasmania, Northern Territory and Queensland (where they are called 'objections').

34 Australian Institute of Health and Welfare, *Adoptions Australia 2008-09*, Child Welfare Series No. 48, February 2010, p. 32. As at 30 June 2009, there are 8,633 contact and identifying information vetoes in place across Australia. Of all vetoes in place as at 30 June 2009, 55 per cent were lodged by adopted people, and 41 per cent were lodged by birth parents. However, in 2008-09 there were 3,607 applications for both identifying and non-identifying information.

6.32 For example, Ms Louise Jamieson and the International Donor Offspring Alliance submitted:

[p]arents wishing to adopt nowadays are required to accept their child's own history and heritage. No longer is a child or baby considered a "clean slate". There is a thorough vetting and preparation process, whereby would-be adoptive parents must work through their own motivations, acknowledge the separate identity of the child/ren they wish to adopt, and recognise the grief and loss already experienced by the child/ren.

How much more should this be the case in donor conception, where the situation is arguably even more complex (owing to the innate imbalance between the mother/father genetic/adoptive relationships).³⁵

6.33 Similarly, Ms Elizabeth Marquardt from the Centre for Marriage and Families, Institute for American Values observed:

[d]onor conception in my country [the United States of America]—and I believe also in yours—functions much more like a market. Rather than being an institution or centred on the best interests of the child, donor conception operates more as a market oriented around the desires and rights of parents to acquire children. There is a very different set of ethics and practices involved. Sometimes people say to me, 'Aren't donor conception and adoption the same thing?' I say, 'No, they're not, and if you think that they are, then fine, let's treat donor conception like we treat adoption. Let's have studies, screenings and inquiries about whether people are a fit parent, and let's have the state say, "No, I'm sorry, you cannot do this", as they say to adoptive parents sometimes.' People are horrified by that.³⁶

Birth certificates

6.34 There were some suggestions that, in order to ensure that a person's true genetic links are recorded and accessible to that person, birth certificates of donor conceived people should be annotated.³⁷

'True' birth certificates

6.35 Dr Sonia Allan noted that options to recognise a person's genetic links on their birth certificate include:

- annotating the birth certificate of a donor-conceived person with their donor conceived status;
- recording both the individual's genetic and social parentage;
- issuing a separate certificate to a donor-conceived child alerting them to the possibility of information held on the register; or

35 *Submission 115*, p. [1]. See, also, DCSG, *Submission 122*, pp 22-31.

36 *Committee Hansard*, 2 November 2010, p. 22.

37 See, for example, Dr Sonia Allan, *Submission 30*; Miss Narelle Grech, *Submission 107*, p. 6.

- issuing a certificate of birth, identifying legal parentage, and a certificate of genetic heritage, indicating where an individual's genetic and legal parentage are different.³⁸

6.36 The committee was advised that Victoria will be making a notation on birth certificates in the future so that 'when a person applies for a birth certificate they will be told that further information is available and asked if they want to access that information'.³⁹

6.37 At the Melbourne public hearing, Mr Damian Adams spoke of his concerns about inaccurate birth certificates:

I despise the document that contains my birth details. While my parents never hid the truth from me and I have always known of my conception, to me it represents state sanctioned fraud and deception. I have since investigated through the courts about having my dad's name removed from this and left as blank, but as they have never dealt with a case like this they were unable to provide any advice. As it will also cost considerable money to do, it will have to wait, but it is still something that I will do. I feel ashamed that I have passed on an untruthful surname to my children. Looking back, I should have given them my wife's maiden name, because at least that has concrete familial heritage. Birth certificates must be the accurate and truthful records of paternity that they are always meant to be.⁴⁰

6.38 Many submissions noted that the way birth certificates currently work makes it possible for parents to conceal the truth from a donor conceived child.⁴¹ For example, Mr Adams commented:

[t]he ability for recipient parents to conceal the truth is made easier for them due to the fact that they are allowed through the institutionalisation of donor conception practices to create fraudulent birth certificates...Replacing biological parents with non-biological parents on a birth certificate and allowing it to occur enshrines deception into the law.⁴²

6.39 Ms Romana Rossi, a parent of a donor conceived child, also suggested that truthful birth certificates would encourage parents to tell the truth to their donor conceived children about their origins.⁴³ Similarly, Ms Louise Jamieson and the International Donor Offspring Alliance suggested that truthful birth certificates are

38 *Submission 30*, p. 21.

39 Mrs Caroline Lorbach, DCSG, *Committee Hansard*, 2 November 2010, p. 10.

40 *Committee Hansard*, 3 November 2010, pp 5-6.

41 See, for example, Mr Damian Adams, *Submission 38*, p. [6]; Ms Romana Rossi, *Submission 75*, p. [3]; DCSG, *Submission 122*; p. 39.

42 *Submission 38*, p. [6].

43 *Submission 75*, p. 3.

provided in some countries for adopted children, 'protecting families' privacy, whilst ensuring that the truth of their adoption cannot be withheld from adoptees'.⁴⁴

6.40 Miss Lauren Burns also drew an analogy with adoption:

I think there is also the issue of owning the information. At the moment we are quite beholden to other people to inform us; whereas I think the paradigm should shift to recognise that it belongs to us...I think there are a number of mechanisms to do with, for example, birth certificates. With adoption a biological birth certificate is issued, and then a social or legal parentage birth certificate is then reissued, but you can always go back and find that information. There are various means of doing so, parenting orders and so forth, in which you can maintain both the social and the biological information available to the child. I think you avoid a lot of the trauma of finding out later in life.⁴⁵

6.41 Mrs Myfanwy Cumberford noted that concealing information about a person's biological heritage affects not just the donor conceived child, but also their descendants:

[t]he lack of any formal record documenting the familial link between the gamete donor and any children produced means that should the recipient parents not disclose then the donor conceived person has no way of ascertaining the truth. And any descendant researching their family history shall be (colloquially) led up the garden path.⁴⁶

6.42 One submission suggested that birth certificates should not identify anyone other than the legal and social parents of the child.⁴⁷ Another suggested that the social parent of the donor conceived person should be able to determine when, and if, information about the donor should be passed on to their donor conceived child, rather than the government having control of this process through, for example, annotating birth certificates.⁴⁸

6.43 Another submission noted that birth certificates are used for banking, kindergarten, school and many other identity uses. The submitter suggested that '[i]t is not necessary to label a donor child or humiliate them when producing their birth certificate for such purposes'.⁴⁹

44 *Submission 115*, p. [1]. At the time of adoption, a new birth certificate is issued to the child bearing the name of his or her adoptive parent/s, and the child's new name, if it changes. However, once adopted children reach a certain age, generally 18 years, they are able to access their original birth certificate with their birth parent's details on it.

45 *Committee Hansard*, 3 November 2010, p. 11.

46 *Submission 63*, p. [2].

47 Tonia, *Submission 7*, p. 6.

48 Ms Vanessa Ferguson, *Submission 55*, p. 4.

49 Tonia, *Submission 7*, p. 6.

6.44 Similarly, Dr Sonia Allan submitted that any suggestions to annotate birth certificates for donor conceived people should not be considered lightly:

[these suggestions] are [not] without shortcomings...and some are more problematic than others. It might be argued in the alternative that it would be unacceptable (or traumatic) for a person to find out that they were donor conceived by way of application for a birth certificate if their parents have not told them about their conception. Similarly having a different birth certificate or a birth certificate that is marked in some way when compared to those of non donor conceived people might result in a donor conceived individual feeling stigmatised or resenting that information about their conception may be known to others when they, for example, use their birth certificate to open a bank account, get a driver's licence or any of the many other things for which birth certificates must be shown.⁵⁰

6.45 However, in response to any suggestion that donor conceived people could be discriminated against if their birth certificates record that they were donor conceived, one submission noted that birth certificates are not actually required to be presented for many purposes, especially not in many contexts that are likely to result in discrimination.⁵¹

Is a 'rights' approach appropriate in this context?

6.46 While many submissions and witnesses framed the issues surrounding donor conception in terms of the rights of donor conceived individuals or the rights of donors, some research in related areas of public policy suggests that an approach that focuses on 'rights' may not be of great assistance in this context.

6.47 The Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee's (AHEC) 2003 report into the protection of human genetic information in Australia, *Essentially Yours: The Protection of Human Genetic Information in Australia*, ALRC Report 96, considered analogous issues relevant to genetic parentage testing and cautioned that:

...this is not an area in which it is especially useful to draw on the language of 'rights'—whether that be a child's 'right' to know his or her biological parentage, or a man's 'right' to know who are his biological offspring. This is an area that requires a careful balancing of interests of mothers, fathers and children in different biological and social relationships with each other. To privilege the interest of one party by accepting a claim to an absolute right fails to give adequate regard to the interests of others involved in the equation.⁵²

50 Submission 30, p. 22.

51 Submission 127 (name withheld), p. 7.

52 ALRC, Submission 8, p. 2; ALRC and AHEC, *Essentially Yours: The Protection of Human Genetic Information in Australia*, pp 861-862.

6.48 By contrast, and in the context of the current inquiry, the Public Interest Law Clearing House (PILCH) argued that the issue of access by donor conceived individuals to donor information in Victoria raises a number of complex human rights issues:

[o]n the one hand, the denial of access to donor identifying information may be inconsistent with...[provisions of the *Charter of Human Rights and Responsibilities Act 2006* (Vic)] including the freedom of expression (including freedom to seek and receive information of all kinds), the right to recognition and equality before the law, the protection of families and children, and cultural rights. On the other hand, the right of donors to privacy and reputation may be impinged upon if access to donor identifying information is too freely available.

A balance must be struck between the rights of donors and donor conceived individuals. PILCH submits that a human rights-based approach to access to donor information provides a helpful framework for addressing and balancing these concerns in a nuanced way.⁵³

6.49 Mr Lyle Shelton of the Australian Christian Lobby focussed on the importance of the rights of the child:

[w]here the state must provide a regulatory framework—which it must around issues of new reproductive technologies—it is incumbent upon the state to ensure that kids' rights come first.⁵⁴

...

...[i]t requires us to make hard choices between the rights and often legitimate desires of adults and the human rights of children.⁵⁵

6.50 It should also be noted that the *Assisted Reproductive Treatment Act 2008* (Vic), *Assisted Reproductive Technology Act 2007* (NSW), the *Reproductive Technology (Clinical Practices) Act 1988* (SA) and the *Human Reproductive Technology Act 1991* (WA) all emphasise the importance of the welfare of donor conceived children. In NSW, the importance of a child's right to information about their donor is also recognised. In relation to the WA legislation, Dr Nyaree Jacobson of the Western Australia Department of Health stated:

[w]e are very much focused on the rights of donor conceived individuals. Our legislation is very concerned that donor conceived individuals be able to access identifying information about their genetic origins.⁵⁶

53 *Submission 125*, p. 8.

54 *Committee Hansard*, 29 October 2010, p. 42.

55 *Committee Hansard*, 29 October 2010, p. 43.

56 Dr Nyaree Jacobson, Western Australia Department of Health, *Committee Hansard*, 3 November 2010, p. 35.

6.51 However, despite the importance placed on the welfare of donor conceived people, much legislation regulating donor conception practices, such as the *Assisted Reproductive Treatment Act 2008* (Vic), is not retrospective and grants different rights of access to information to donor conceived children, depending on when they were born.⁵⁷

57 See Appendix 1.