

CHAPTER 7

Committee view and recommendations

7.1 This inquiry presented the committee with an opportunity to examine a number of key issues relating to past and present practices of donor conception in Australia, which have otherwise received little attention.

7.2 Evidence presented to the committee by donor conceived people, their parents and those with expertise in the area indicated, among other things, that:

- there is a need to improve consistency in donor conception legislation and regulation throughout Australia;
- there are inconsistencies between jurisdictions in relation to the regulation of donor conception on issues such as counselling requirements and limits on the number of donations;
- there are inconsistencies in relation to access to information about donors by donor conceived people, and many donor conceived people consider it to be inequitable that the amount of identifying information that donor conceived people can access varies depending on when or where they were conceived or born;
- it is important to donor conceived people to be able to access information about their donor's identity and medical history, in order to complete their sense of self-identity and to appropriately manage their health;
- there is a need for the creation of a national register as a central repository of information about donors' identities, to undertake a regulatory role and to facilitate contact between donors, donor conceived people and their siblings;
- there are difficulties in enforcing regulatory requirements on clinics, because requirements vary between jurisdictions and because there is no single overarching body to enforce the requirements, nor any organised system for sharing information; and
- a limit should be imposed on the number of donations a donor can make, to mitigate the risk of consanguinity and to minimise the number of siblings a donor conceived person might potentially have.

Regulation of donor conception practices

7.3 The committee shares concerns raised during the inquiry about the level of inconsistency that exists between jurisdictions in relation to the regulation of donor conception. While some states, such as Victoria, have highly developed legislation, the committee is particularly concerned that there are some jurisdictions in which there is no relevant legislation in place. In those jurisdictions, issues such as the prohibition of donor anonymity and access by donor conceived people to information about their donor are governed by the unenforceable NHMRC Guidelines.

7.4 Despite agreement at the Council of Australian Governments and consideration by the Standing Committee of Attorneys-General in the past nine years, the states and territories have done very little to create nationally consistent legislation. From the personal accounts provided to the committee, it is apparent 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 cross-checking occurring;
- 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.

Commonwealth's role in regulation of donor conception

7.5 At the outset, the committee notes its disappointment with the Attorney-General's Department's reluctance to provide advice to the committee in relation to the capacity of the Commonwealth to legislate in the area of donor conception. The Attorney-General's Department's failure to assist and to make its expertise available to the committee – despite specific requests to do so – has limited the committee's ability to comprehensively explore this issue.

7.6 Having said that, the committee notes that there does not appear to be a single stand-alone power under the Australian Constitution which would enable the Commonwealth to pass legislation in relation to donor conception. On the basis of evidence provided to it during the course of the inquiry, the committee is unable to make a conclusive assessment on whether the Commonwealth has the power to legislate for a national register. However, it would appear that the Commonwealth is probably unable to create a national register and legislate in this area without a specific referral of power from the states and territories. Further, it is the states and territories that have the power to regulate medical practices, the retention of medical records, registers of births, deaths and marriages, and birth certificates.

7.7 In this context, the committee notes that section 60H of the *Family Law Act 1975* (Cth) (Family Law Act) appears to have been the result of a specific referral of power by the states, to the extent that it is not supported by the marriage power under the Australian Constitution. Section 60H creates a presumption that the woman who bears a child is the child's mother and that her partner is also the child's parent for the purposes of the Family Law Act. This creates a social parentage relationship, as opposed to a biological relationship, and section 60H does not appear to be broad enough to support, for example, the creation of a register, or general parentage testing procedures.

7.8 The *Prohibition of Human Cloning for Reproduction Act 2002* (Cth) and the *Research Involving Human Embryos Act 2002* (Cth) can also be distinguished, as they rely on the corporations power, the trade and commerce power and the external affairs power.¹ In addition, the states passed mirror legislation to cover the field. The Senate Community Affairs Legislation Committee report into the bills for those Acts referred to advice from the Australian Government Solicitor (provided to the NHMRC in relation to the bills) which stated:

[u]nder the Constitution, the Commonwealth Parliament has reasonably extensive powers in this area. However these powers would not support comprehensive legislation to regulate human cloning [or] assisted reproductive technology...²

7.9 It is also unclear, on the basis of evidence presented to the committee, whether it would be possible for the Commonwealth to enact legislation under the external affairs power to give effect to international obligations under the Convention on the Rights of the Child.

Separate but uniform legislation

7.10 Many submissions and witnesses to the inquiry highlighted that donor conceived people can feel a sense of inequity and injustice that the level of accessible information about their donor can vary so considerably depending on when or where the donor conceived person was conceived or born. The committee strongly believes that this situation is unacceptable, and that each state and territory should have legislation regulating donor conception practices in that jurisdiction.

7.11 The committee considers that the creation of nationally consistent legislation is primarily a responsibility of the states and territories. In the view of the committee, the best approach to this issue would be for the state and territory governments to agree to separate but uniform legislative schemes to address the concerns of donor conceived people.

7.12 Nevertheless, the committee emphasises the critical role of the Australian Government in ensuring that the states and territories without a legislative framework enact laws to regulate donor conception practices. The Australian Government should pursue greater consistency between the legislative frameworks, with more uniform treatment of limits on donations and rights of access by donor conceived people to identifying and non-identifying information about their donor and siblings.

7.13 In particular, the committee considers that separate but uniform legislation should be established to, at a minimum:

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- 1 Senate Community Affairs Legislation Committee report, *Provisions of the Research Involving Embryos and Prohibition of Human Cloning Bill 2002*, October 2002, pp 96-97 at para 4.150.
 - 2 Senate Community Affairs Legislation Committee report, *Provisions of the Research Involving Embryos and Prohibition of Human Cloning Bill 2002*, October 2002, pp 96-97 at para 4.150.

- prohibit donor anonymity;
- set a national limit on the number of families a donor is able to assist; and
- set out the rights of access by donor conceived people to information about their donors and siblings.

7.14 Evidence before the committee highlighted that the Victorian donor conception legislation is the most comprehensive in Australia and is viewed favourably by donor conceived people, academics and practitioners. The committee considers that the Victorian legislation could be used as a model for the development of nationally consistent legislation.

7.15 While the committee acknowledges the concerns raised by some witnesses to the inquiry that further regulation could discourage sperm donors from donating, the committee considers that these concerns are outweighed by the importance of ensuring legislative protection of the rights of donor conceived people to access information about their donor.

Regulation of private arrangements

7.16 The committee received evidence suggesting that not all donor conception practices are undertaken in a clinical context and that some parties enter into private arrangements. The committee notes that private arrangements give rise to particular issues regarding the legal protection of the donors, recipients and donor conceived people, and that these issues require further examination to ensure the rights of all parties are appropriately protected. The Australian Government and state and territory governments should give further consideration as to how private donor arrangements can best be regulated.

Establishment of registers and retrospectivity

7.17 Evidence before the committee indicated a high level of dissatisfaction about the differences in legislation and regulation between the states in the management of donor conception data. Evidence also suggested that a number of clinics are failing to comply with the NHMRC Guidelines in relation to the storing of personal information of donors and donor conceived people.

A national register

7.18 The committee, therefore, considers that there would be significant benefit in having records relating to donor conception, particularly personal information about donors and donor conceived people, stored in a single national register. Noting the commitment by the Standing Committee of Attorneys-General in April 2009 to develop a discussion paper on a national model for registration of donors (in consultation with Health and Community Services Ministers), the committee considers that the Australian Government should, with the states and territories, pursue a national register of donors and donor conceived people through that process or other appropriate national forums.

7.19 The committee is mindful that the development of a national register requires careful consideration of arrangements to protect the security and confidentiality of records, as well as a clear articulation of the function of the body administering the register, to guard against 'function creep'. The committee suggests that a national register would need to be established under legislation and administered either by a statutory body or by a government department. A national register would require an appropriation, would need to employ staff, and would require legislative powers to, for example, release information and provide for DNA testing.

7.20 If the states and territories are unable to develop a national donor conception register, the committee considers that the states and territories should all establish their own centralised registers, rather than information being stored by ART clinics.

7.21 The committee considers further that, in establishing either a single national register or a central register in each state and territory, the Australian Government and the state and territory governments should adopt a consistent approach to accessing information held on the register. A consistent approach to accessing information should focus on the rights of donor conceived people and their families to access both non-identifying and identifying information about their donor and any donor conceived siblings they may have. Donors should also be able to access non-identifying information about children created with their donations.

Age at which people can access information

7.22 The committee heard evidence that donor conceived individuals should be at least 18 years of age to be able to access identifying information about their donor. This is consistent with the approach taken in legislation in Victoria, NSW and South Australia. However, some evidence suggested that an age of 16 is more appropriate. The committee notes that donor conceived individuals in Western Australia can access identifying information about their donor from the age of 16.

7.23 On balance, the committee is of the view that donor conceived individuals should be able to access non-identifying information about their donor from 16 years of age, or at an earlier age with the support and agreement of their parents. Consistent with most donor conception legislation, the committee considers that donor conceived individuals should be able to access identifying information about their donor, once the donor conceived person reaches 18 years of age.

Retrospectivity

7.24 The committee is mindful of the fact that it is a difficult exercise to weigh the rights of donors to anonymity with the rights of donor conceived people to access information about their donors. The committee appreciates the view of donor conceived individuals that they were not privy to any agreement between their parent/s and the donor. The committee also respects that most donors made donations on the basis that they would remain anonymous. While some donors have been willing to identify themselves and form relationships with children born as a result of their

gamete donation, it appears that the majority have not. The committee could, for example, recommend that legislation be retrospective to a specific time period. However, the provisions of the Victorian legislation, for example, provide donor conceived individuals with different rights of access to information in circumstances where they had no control over the circumstances of their conception, and the committee does not consider that such an arbitrary 'line in the sand' is a satisfactory outcome.

7.25 The committee observes that none of the states with registers have made their registers retrospective, and the committee would be concerned about any overriding of prior commitments to maintain donor anonymity.³ Further, unlike the abolition of anonymity in adoptions, in which the states or territories were generally involved through public hospitals or state-run institutions, the committee understands that donating gametes often involved a contract between the donor and a private clinic or medical practitioner.⁴ While little evidence was presented to the committee on this issue specifically, the committee is concerned about any contractual or other legal obligations that exist between donors and clinics which, if breached, may potentially leave the states and territories or ART clinics open to claims for compensation.

7.26 In the absence of authoritative evidence about the legal and ethical implications of retrospectively removing donor anonymity, the committee chooses not to make any specific recommendation about retrospectivity. However, the committee supports, in principle, the rights of donors to retain the anonymity that they were guaranteed when they agreed to donate. In principle, the committee is also supportive of donor conceived individuals having a right to information about their biological heritage. The committee urges the states and territories to further consider the issue of retrospectivity in the creation of any national register (including seeking and obtaining legal advice, as considered appropriate).

Voluntary register

7.27 If, after further consideration by the states and territories of the issue of retrospectivity, registers do not have a retrospective operation, the committee supports the establishment of a national voluntary register, or voluntary registers in each state and territory. This would enable donors who have previously donated anonymously to voluntarily have their information recorded and disclosed to any individuals conceived as a result of their donation.

7.28 The committee is also concerned to ensure that, where possible, donor conceived people and donors should be able to access information, even in

3 In this context, the committee notes that the Victorian Parliament's Law Reform Committee's Interim Report in relation to its *Inquiry into access by donor-conceived people to information about donors* stated that further consideration would be given to whether access to records in Victoria should be made retrospective, at p. xiii.

4 Donor Conception Support Group website, 'National inquiry into donor conception practice', <http://www.dcsbg.org.au/legislation/inquiry.html>, accessed 30 June 2010.

circumstances where their records may have been destroyed. Where records have been destroyed, the committee strongly believes that voluntary registers should incorporate a DNA databank to allow parties to donor conception to place their DNA on record in order to trace donors and half siblings.

Publicity for the register

7.29 The committee heard evidence that publicity campaigns for the establishment of registers in Victoria were successful in raising public awareness of the register. The committee also considers that the establishment of any new registers, particularly DNA registers, should be publicised widely, to ensure as many people as possible are made aware of their existence.

Oversight of clinics

7.30 The committee is very concerned about the current regulation of ART clinics under the NHMRC Guidelines in states and territories that do not have legislation, and through the clinic accreditation processes undertaken by the Reproductive Technology Accreditation Committee of the Fertility Society of Australia. It appears, from evidence presented to the committee during the course of the inquiry, that some clinics are being accredited, even when they are not following the NHMRC Guidelines, particularly in relation to retaining information about donors and requests for donors to come forward.

Regulation of clinics

7.31 Despite having heard evidence about how the accreditation process operates, the committee is concerned that the accreditation process appears to lack transparency. The committee is of the view that this system of industry regulation has failed donor conceived people. The committee therefore considers that there is significant capacity to improve the oversight of clinics performing ART procedures in relation to their responsiveness to donor conceived people and their families.

7.32 Accordingly, the committee is of the view that the Australian Government, in conjunction with the Fertility Society and the NHMRC, should review the current regulatory processes for ensuring compliance with the NHMRC Guidelines. The committee considers that this review should be undertaken by the Australian Government in the next two years.

7.33 Further, the committee recommends that if, after the review has been undertaken, it is considered that the current regulatory processes are not sufficient, the Australian Government should explore options for developing a comprehensive regulatory framework. As it is unclear on the basis of evidence presented to the committee whether it would be possible for the Australian Government to enact legislation to regulate donor conception practices, the committee is of the view that the Australian Government should work with the states and territories to develop such a regulatory framework.

7.34 The committee heard evidence that one way to address the apparent lack of transparency about clinic accreditation, and complaints about the way in which clinics are complying with the NHMRC Guidelines, would be to create a position of ombudsman for assisted reproductive treatments. The committee holds the view that donor conceived people should have the ability to engage in a process that resolves complaints about clinics who, for example, fail to contact donors to encourage them to come forward, or use sperm or oocytes from donors who are unwilling to be identified. The Australian Government should play a proactive role, in conjunction with the Fertility Society, in creating a review mechanism which can be accessed by donor conceived people, their parents and donors to investigate and address complaints about the performance of clinics in relation to their obligations under the NHMRC Guidelines.

Importation of gametes and embryos from overseas

7.35 The committee heard evidence that the NHMRC Guidelines do not cover the importation of sperm and, in particular, the rights of individuals conceived using imported donor gametes and embryos to access information about their donor. The committee strongly urges the National Health and Medical Research Council to review the NHMRC Guidelines in relation to the importation of gametes and embryos from overseas.

7.36 There was only one compelling reason provided to the committee in evidence as to why importation of gametes and embryos should continue. This relates to circumstances where the parties have a particular ethnic background and are otherwise unable to obtain gametes or embryos from a person with the same ethnic background in Australia. However, other than in these specific circumstances (or other similar circumstances), the committee's preference is to ban the importation of gametes and embryos from overseas donors.

7.37 The committee is of the strong view that banning the importation of gametes and embryos from overseas, except in the circumstances set out above, will assist to enhance access by donor conceived individuals to information about their donor, and where possible, to enable donor conceived people to establish relationships with any genetic siblings and the donor.

Protection of records

7.38 The committee notes that records relating to donor conception treatment contain information that is vitally important for donors and donor conceived people, as well as their descendants. Such records must be kept indefinitely and by a body which can maintain appropriate protections for the security and confidentiality of the records. The committee strongly suggests that a moratorium be placed on destruction of these records to ensure their availability if information is to be retrospectively released either now or in the future.

7.39 The committee agrees with the view expressed by many submitters and witnesses that it is not reasonable to expect clinics to have an ongoing responsibility

for maintaining contact details for donors, donor recipients and donor conceived people, or for arranging contact between donor conceived people and their donors or siblings. Equally, it is not reasonable to expect donor conceived people to bear the responsibility for personally seeking out clinics or practitioners to try to locate information about their genetic identity. Instead, these details should be maintained in a national register or centralised state and territory registers, as noted above.

7.40 The Australian Government, the states and the territories should work together, including through the Council of Australian Governments, to develop a nationally consistent way to manage records relating to donor conception and to ensure that these records are appropriately preserved.

Payments for donors

7.41 The committee considers that the prohibition on payments for donations of sperm, oocytes or embryos should be maintained. While noting that the level of demand for sperm donation in Australia exceeds the supply, the committee is concerned that allowing payment for donations could encourage people to donate out of financial need and without proper consideration of the full consequences of their donation.

7.42 The committee also notes the views expressed at several of the public hearings by donor conceived people that knowing their donor was paid could have a significant adverse impact on a donor conceived person, and could impede the development of future relationships between a donor conceived person and their donor.

'Reasonable expenses'

7.43 The committee supports the continuation of reimbursement of 'reasonable expenses' incurred by donors. However, the committee notes that there is a level of confusion about what constitutes 'reasonable expenses' and this gives rise to considerable variations in practice between clinics. Mindful of the differing processes undertaken by both men and women in donation, the committee is not in a position to make a determination of what expenses should be reimbursed. However, the committee considers that there should be more detailed guidance on what constitutes 'reasonable expenses' to ensure the policy is applied consistently to donors across Australia, and in any importation of gametes and embryos into Australia.

7.44 The committee emphasises the role that the Australian Government, in conjunction with the state and territory governments and the Fertility Society, should pursue in the creation of more detailed guidelines on what constitutes 'reasonable expenses' for donors.

Counselling and support services

7.45 The committee is of the view that counselling is critically important at a number of stages prior to, and following, donor conception procedures. This is to

ensure that donors and donor recipients enter into treatment with a full understanding of the consequences, and that donors, donor recipients and donor conceived people have support in dealing with issues which might arise as a result of donor conception. It is also important that parties who undertake donor conception by way of private arrangements have access to counselling.

7.46 The committee considers that, in most circumstances, parties should have a choice about whether or not they wish to undertake counselling, but that counselling should be mandatory prior to participants undertaking donor conception, and also where donor conceived people aged under 18 years are making contact for the first time with their donor or donor siblings.

7.47 The committee also holds the view that clinics have an ethical obligation to ensure that parties participating in ART procedures have given their informed consent prior to undertaking treatment. Accordingly, the committee considers that clinics should be responsible for funding the provision of counselling for donors and donor recipients prior to those parties undertaking ART.

7.48 However, it is not appropriate that clinics should be expected to have the sole responsibility of providing ongoing support to donors, donor recipient parents and donor conceived people to address issues arising from donor conception, such as issues of self-identity and commencing contact. In particular, clinics should not be required to fully fund all counselling for donors, donor recipient parents and donor conceived people. This is particularly the case given that the committee received evidence stressing the importance of counsellors being independent from the clinics themselves. Currently, most counsellors who provide this type of counselling are employed by clinics.⁵

7.49 While it would be beneficial for affected parties to have access to counselling free-of-charge, the committee considers that, in conjunction with counselling provided by the clinics, it is also a matter for state and territory governments to determine whether it is possible to fund the provision of independent counselling, within available resources. This counselling should be available to donors, donor recipient parents and donor conceived people, once a donor conceived child has been born, to assist people affected by donor conception to deal with issues that may arise in the future.

7.50 In summary, the committee considers 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

5 See, for example, VARTA, *Annual Report 2010*, Appendix 1, p. 48, accessed at <http://www.varta.org.au/annual-reports/w1/i1003573/> on 27 January 2011, and Ms Marianne Tome, Victorian Infertility Counsellors Group, *Committee Hansard*, 3 November 2010, pp 72-73.

experience of the issues involved with donor conception. Wherever possible, counsellors should be independent from the clinics themselves.

Risk of consanguinity and limits on donations

7.51 The committee acknowledges arguments that limiting the number of donations may result in the level of supply of sperm, in particular, being less than demand. However, it is of fundamental importance to the best interests of donor conceived people that limits are placed on donations. This is to reduce the risk of consanguinity, and to provide the best opportunity for donor conceived people to have future relationships with their donors and donor siblings. In particular, the chance of forming meaningful relationships between donors and their offspring may be reduced if there are too many donor children born from the one donor.

7.52 The committee is concerned that there is little reliable evidence on the numbers of donor conceived people in Australia. The committee holds the view that there is a need to improve the amount of information about the number of donor conceived people in order to better establish the risks of consanguinity.

Limits on donations

7.53 The committee agrees that there needs to be a uniform limit on donations throughout Australia for the limit to have any meaning. This is because differing limits between jurisdictions make it possible for individuals to deliberately circumvent the limit that applies in one jurisdiction by going to another jurisdiction (which is further obstructed by the lack of a national standard of registration for donors between the states and territories). However, limits should not be expressed in such a way as to limit a donor's ability to have their own biological families.

7.54 Evidence presented to the committee suggested that there should be a limit of either one, five or ten families. The committee is of the view that, in an ideal world, there should be a limit of one family for each donor. The committee heard evidence that having a significant number of genetic siblings may: impact on the ability of donor conceived individuals to form meaningful relationships with their siblings; affect the donor conceived individual's sense of self-identity; and, further, increase the risk of consanguinity among donor conceived individuals.

7.55 Although there is very limited empirical evidence or research currently available, the committee considers that, as a starting point, each donor should only be able to assist one family in Australia, in addition to their own. However, if a donor wishes to be able to assist up to, what should in the committee's view be, a maximum of four families (in addition to their own), the clinic proposing to use a donor more than once must be required to consider evidence of the following factors:

- the number of genetic relatives that the person conceived would have as a result of the treatment;
- the consent of the donor with respect to the number of families to be created;

- whether the donor has already donated gametes at another clinic; and
- the risk of a person conceived with donor gametes inadvertently having a sexual relationship with a close genetic relative (with particular reference to the population and ethnic group in which the donation will be used).

7.56 The limit of between one and four families should be reviewed once more empirical evidence on the risk of consanguine relationships is available, to ensure that the limit takes into account the balance between the risk of consanguinity and the impact that consistent limits have on reducing the supply of gametes. However, in reviewing this limit, consideration must also be given to the importance of donor conceived people having meaningful relationships with their half-siblings, and issues of self-identity for donor conceived individuals.

Enforcing limits

7.57 The committee heard evidence that it is difficult for clinics to ensure that donors are not donating in a number of states and, therefore, breaching limits set by states. The committee believes that there needs to be national oversight or inter-jurisdictional sharing of data to ensure that the limits are followed and enforced. This could be achieved by the states and territories supporting the establishment of a national register or by the states and territories developing central registers to facilitate the sharing of information.

7.58 Until this is implemented, the committee recommends that clinics and medical services should amend their donor consent forms to allow clinics and medical services to share information across jurisdictions to ensure that donors are complying with limits.

Rights of donor conceived individuals

7.59 The committee considers that all children entering this world should have knowledge of their genetic parents and a right to their genetic history, regardless of the circumstances of their conception. In particular, the committee emphasises the importance of donor conceived people having access to their genetic, medical and social history, to help in the development of their sense of self-identity and so that they can effectively manage their health.

7.60 The committee recognises that, in order for donor conceived people to have as much information as possible about their genetic, medical and social history, records should be retained. The committee reiterates its view that a moratorium should be placed on the destruction of all records held by government agencies, doctors, clinics and ART providers, and again stresses the importance of keeping these records indefinitely, securely and confidentially.

7.61 Accordingly, the committee takes the view that jurisdictions which do not already have legislation in place should legislate to protect the rights of donor conceived people to their genetic, medical and social history.

Birth certificates

7.62 The committee heard evidence that many donor conceived people support the annotation of birth certificates of donor conceived people to ensure that they have a way to access information about their genetic heritage. The committee is sympathetic to arguments that identifying a person's biological parents in their birth certificate would help ensure donor conceived individuals do not have their identity withheld from them and could minimise the risk of consanguine relationships. However, annotated birth certificates should not be used as a way of forcing parents to tell their children about their parentage.

7.63 Instead, it is the committee's view that donor conceived children should have a notation made on their birth certificates so that, when a donor conceived person over the age of 18 applies for a birth certificate, they will be told that further information is available and asked if they want to access that information. This proposal emphasises the importance of each state and territory establishing their own registers so that this information can be provided to donor conceived people.

Acknowledgement

7.64 The committee appreciates the efforts of submitters and witnesses and, in particular, would like to thank those donor conceived individuals who gave evidence to the committee at the public hearing in Melbourne. Those submitters, in sharing their own personal stories and experiences, provided both compelling and moving evidence to the committee.

Recommendation 1

7.65 The committee recommends that jurisdictions which do not already have legislation in place, namely Queensland, Tasmania, the Northern Territory, and the Australian Capital Territory, should, as a matter of priority, establish legislation to regulate donor conception in those jurisdictions.

Recommendation 2

7.66 The committee recommends that the Australian Government pursue all available policy and political options, including through the Council of Australian Governments and the Standing Committee of Attorneys-General, to ensure that nationally consistent legislation relating to donor conception is developed as a matter of priority.

Recommendation 3

7.67 The committee recommends that any nationally consistent legislation should include, at a minimum:

- **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; and**
- **protection for the welfare and interests of donor conceived children.**

Recommendation 4

7.68 In the context of the development of nationally consistent legislation relating to donor conception, the committee recommends that the Australian Government and state and territory governments give consideration to how private donor conception arrangements can best be regulated to ensure the rights of donors, recipients, and donor conceived individuals are appropriately protected.

Recommendation 5

7.69 The committee recommends that the Australian Government, through the Standing Committee of Attorneys-General, do everything possible to ensure the establishment, as a matter of priority, of a national register of donors, and that such a national register should also include information about donor conceived individuals.

Recommendation 6

7.70 The committee recommends that a national register established by the Australian Government and state and territory governments should have a particular focus on:

- **security arrangements;**
- **privacy protections; and**
- **a clear articulation of the role of the body administering the register.**

Recommendation 7

7.71 While the committee strongly recommends the establishment of a national donor conception register, if this is not achieved, the committee recommends that each state and territory should put in place their own centralised register.

Recommendation 8

7.72 The committee recommends that, in the establishment of state and territory central registers, consistency in approach to the granting of access to information held on those registers should be a matter of priority.

Recommendation 9

7.73 The committee recommends that a central register, either in the form of a single national register or a separate register in each state and territory, should operate according to the following principles regarding access to information:

- donor conceived individuals should be able to access identifying information about their donor, once the donor conceived person reaches 18 years of age, or such younger age as agreed by all states and territories;
- 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; and
- donors, donor conceived individuals, and recipient parents, as well as 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 such younger age as agreed by all states and territories).

Recommendation 10

7.74 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.

Recommendation 11

7.75 The committee recommends 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 voluntary register or separate register if such registers are established in each state and territory.

Recommendation 12

7.76 The committee recommends that any voluntary registers incorporate a DNA databank, to enable donors and donor conceived individuals to have their details placed on the register for possible matching, in circumstances where records relating to their identities have been destroyed.

Recommendation 13

7.77 The committee recommends that the states and territories jointly fund a campaign to widely publicise the establishment of either a national voluntary register or separate voluntary registers in each state and territory.

Recommendation 14

7.78 The committee recommends that the Australian Government review, within a period of two years after this report, the current regulatory framework for overseeing compliance by clinics and medical practitioners with the National Health and Medical Research Council Guidelines on the use of assisted reproductive technology in clinical practice and research, with a focus on:

- whether the regulatory framework is adequate to ensure compliance with the guidelines;
- whether sanctions applied to clinics for failure to comply with their obligations under the guidelines are sufficient; and
- whether a more comprehensive regulatory framework is required.

Recommendation 15

7.79 If, following the review as set out in Recommendation 14, it is considered that the current regulatory framework for clinics and medical practitioners undertaking assisted reproductive technology procedures is not sufficient, the committee recommends that the Australian Government, through the Council of Australian Governments and the Standing Committee of Attorneys-General, work with the state and territory governments to develop a more comprehensive regulatory framework.

Recommendation 16

7.80 Regardless of the outcome of the review described in Recommendations 14 and 15, the committee recommends that the Australian Government, in consultation with the Fertility Society of Australia, create a review mechanism (for example, an Ombudsman-type mechanism or health complaint commission), that can be accessed by donor conceived individuals and parties undergoing assisted reproductive technology procedures, to investigate and address complaints against clinics, including when they fail to comply with their obligations under the National Health and Medical Research Council Guidelines or relevant legislation and regulation.

Recommendation 17

7.81 The committee recommends that, except in circumstances where the parties have a particular ethnic background and it is difficult to obtain gametes or embryos from a person with the same ethnic background (or in any other similar circumstances), the importation of gametes and embryos from overseas donors should be banned in Australia.

Recommendation 18

7.82 If a ban on the importation of gametes and embryos from overseas is not possible, the committee recommends that any gametes and embryos imported into Australia from overseas donors undergo the same requirements and

procedures for use in donor conception as gametes and embryos donated in Australia, including screening and counselling requirements.

Recommendation 19

7.83 The committee recommends that the Australian Government undertake a review of the National Health and Medical Research Council Guidelines to specifically address the rights of access to information of donor conceived individuals conceived with the use of gametes and embryos imported from overseas.

Recommendation 20

7.84 The committee recommends that the Australian Government and state and territory governments work together, including through the Council of Australian Governments and other appropriate national forums, to agree to a nationally consistent and permanent long-term solution to the management of records relating to donor conception, to ensure that records which identify donors, donor recipients, and donor conceived offspring, are appropriately preserved.

Recommendation 21

7.85 Until such time as Recommendation 20 is implemented, the committee recommends that a temporary moratorium be placed on the destruction of all records held by government agencies, doctors, clinics, and assisted reproductive technology providers that identify donor conception treatment procedures undertaken by donors and donor recipients.

Recommendation 22

7.86 The committee recommends that the prohibition on payments for donations of sperm, oocytes or embryos in Australia should be maintained.

Recommendation 23

7.87 The committee recommends that donors should continue to be able to be reimbursed for 'reasonable expenses' incurred in relation to their donation.

Recommendation 24

7.88 The committee recommends that the Australian Government, in consultation with state and territory governments and the Fertility Society of Australia, develop more detailed guidelines on what constitutes 'reasonable expenses' for which donors can be reimbursed.

Recommendation 25

7.89 In relation to counselling, the committee recommends 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 self-identity 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 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.

Recommendation 26

7.90 The committee recommends that state and territory governments, in consultation with the Fertility Society of Australia, should give consideration to funding the provision of counselling for donors, donor recipients and donor conceived individuals following the birth of donor conceived individuals.

Recommendation 27

7.91 The committee recommends that state and territory governments, in consultation with the Fertility Society of Australia, should develop guidelines or requirements to ensure that counsellors providing counselling to donors, donor recipients or donor conceived individuals have an appropriate understanding of the issues involved with donor conception.

Recommendation 28

7.92 The committee recommends that state and territory governments should commission research to ascertain the numbers of individuals born through donor conception in their respective jurisdictions and that, once more accurate data is obtained, further research should be conducted in relation to the risk of consanguine relationships among those people.

Recommendation 29

7.93 Noting the disparity in evidence received throughout the inquiry as to the appropriate limit for the number of families that donors should be able to assist, the committee recommends that each donor should only be able to assist up to a maximum of four families (in addition to their own) in Australia. Although the preference is that each donor only assists one family (in addition to their own), if more than one family is to be assisted, the committee recommends that the relevant clinic must consider the following factors:

- the number of genetic relatives that the persons conceived would have as a result of the treatment;
- the consent of the donor with respect to the number of families to be created;
- whether the donor has already donated gametes at another clinic; and
- the risk of a person conceived with donor gametes inadvertently having a sexual relationship with a close genetic relative (with particular reference to the population and ethnic group in which the donation will be used).

Recommendation 30

7.94 The committee recommends that the issue of limits on donations should be reviewed by the states and territories, in consultation with the Fertility Society of Australia, once further evidence becomes available about the importance of forming a strong sense of self-identity for donor conceived people and the risks of consanguine relationships.

Recommendation 31

7.95 The committee recommends that clinics and medical services should amend the consent forms which are signed by donors, to ensure that consent is given to the sharing of information with other clinics and medical services in the same jurisdiction and in other jurisdictions in Australia.

Recommendation 32

7.96 The committee recommends that, to the extent that the states and territories have not already done so, birth certificates of donor conceived children should be notated so that when they apply for a birth certificate over the age of 18 years, they can be provided with additional information about their donor conception circumstances if they choose.

Senator Guy Barnett

Chair