

RECOMMENDATIONS

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.

