Australian Government
Australian Law Reform Commission

Professor Rosalind Croucher
President

Ms Julie Dennett
Committee Secretary
Senate Standing Committee on Legal and Constitutional Affairs

14 July 2010

Dear Ms Dennett,

Inquiry into the past and present practices of donor conception in Australia

The Australian Law Reform Commission (ALRC) welcomes the opportunity to contribute to the Senate Standing Committee's inquiry into donor conception practices in Australia, referring to prior work undertaken by the ALRC that may be of relevance to the inquiry.

In the inquiry on the protection of human genetic information in Australia, *Essentially Yours*, ALRC Report 96 (2003), Chapter 35 considered the matter of parentage testing This has the closest connection with the issues raised in the Committee's inquiry under paragraph (a), 'donor conception regulation and legislation across federal and state jurisdictions', as an aspect of such regulation may concern the testing in order to determine parentage of a person conceived through donor genetic material. Paragraph (b) (ii) concerning the 'management of data relating to donor conception' and (d), in relation to 'the rights of donor conceived individuals', may also provide points of relevance with ALRC Report 96.

As noted in *Essentially Yours*, there are many reasons why a person may seek parentage testing:

> A man may seek parentage testing to confirm or deny suspicions that he may not be the biological father of a child who is said to be his own offspring. A woman may seek parentage testing to confirm or deny her suspicions that her child is not the biological child of her husband or partner. A child may seek parentage testing to establish a biological link with a parent for the purposes of identity, child support, family provision or succession to property. A person may seek parentage testing to provide evidence of a family relationship in the context of an Australian visa application.[1]

Parentage testing may be outside the Committee's terms of reference as not being, strictly, an aspect of 'donor conception and regulation'. When it comes to the later paragraph, concerning the rights of donor conceived individuals, a closer connection may be found. In *Essentially Yours*, stakeholders raised a number of common themes including, for example, that children have a right to know their biological parents.[2] The ALRC commented, however, 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

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[1] *Essentially Yours*, ALRC Report 96 (2006), [35.4].

[2] Ibid, [35.23].

> 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.[3]

In relation to the issue of the rights of donor conceived individuals, I refer the Senate Standing Committee to the discussion in *Essentially Yours* Chapter 35 on access to parentage testing and the applicable regulatory framework. The inquiry considered two options for reform: the first involving regulation of the access to genetic testing; the second, preserving the right of individuals to make a direct approach to a laboratory, but seeking to regulate the laboratories themselves.

The inquiry recognised that:

> the consequences of parentage testing can be of profound significance to the individuals tested and to others whose parentage status is affected by the results of the test. Test results may lead to the destruction of long-standing social relationships between adults and children, and between partners in a relationship. … [S]ignificant financial consequences may turn on the results. It is essential in this context to ensure that parentage testing is performed to the highest standards of technical proficiency and in accordance with sound ethical principles.

As summarised in *Essential Yours*, despite the support expressed in several submissions for court supervision of parentage testing in every case, the inquiry considered that this approach would be overly prescriptive. The cost, delay and potential exposure of a court order was likely to act as a deterrent to testing, or to force interested persons ‘underground’ to unregulated parentage testing available through mail order or over the Internet.[4] In order to ensure that the highest standards are maintained the inquiry concluded that all parentage testing in Australia should be performed by laboratories accredited by the National Association of Testing Authorities, Australia (NATA) in accordance with NATA standards, provided those standards are upgraded to address the full range of scientific and ethical concerns, such as procedures for protecting the integrity of the sample, consent to testing, and the provision of information about the availability of counselling.[5]

To that end, the inquiry recommended that:

- The Commonwealth should enact legislation to provide that DNA parentage testing in Australia is conducted only by laboratories accredited by NATA, and only in accordance with NATA accreditation requirements.
- NATA should review its accreditation requirements for DNA parentage testing to ensure that they meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing information about counselling.
- The Commonwealth should review Part IIA of the *Family Law Regulations 1984* (Cth) to ensure that the requirements for parentage testing meet the highest technical and ethical standards, particularly in relation to consent to testing, protecting the integrity of genetic samples, and providing information as to counselling.

Further, to minimise uncertainty or complexity between these two regulatory frameworks, the Inquiry recommended that in reviewing Part IIA of the *Family Law Regulations 1984* (Cth), the

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[3] Ibid, [35.13].
[4] Ibid, [35.81].
[5] Ibid, [35.83].

Commonwealth should have regard to the proposed accreditation requirements for DNA parentage testing developed by NATA.[6]

Other parts of Chapter 35 considered issues concerning matters such as consent to parentage testing, particularly concerning children, and the admissibility in, for example, Family Court proceedings of parentage testing reports. Such matters appear to be outside the purview of the present Standing Committee inquiry. The material on counselling and disclosure of results, however, may be relevant, as paragraph (b)(iii) identifies the 'provision of appropriate counselling and support services' in the conduct of clinics and medical services as a relevant matter.

The inquiry considered that:

> The provision of counselling before and after parentage testing is an important means of ameliorating the emotional impact of parentage testing and maintaining existing family relationships. By undergoing counselling before engaging in parentage testing, a child may gain an understanding of the reasons his or her parent is seeking the test and may discuss the possible impact of the test results on any existing relationships with that parent. Similarly, a parent may gain a better understanding of the consequences of the test for his or her relationship with the child or with the other parent.[7]

The provisions in the *Family Law Act 1975* (Cth) providing for counselling in a number of contexts, such as in proceedings relating to children, were contrasted with situations where parentage testing was conducted outside the family law framework, in which case there is no requirement that those involved obtain counselling before or after testing.[8]

The inquiry found that it was difficult to assess how many persons undergoing parentage testing have an effective opportunity to be counselled. Although it ascertained that several accredited laboratories had on-site counsellors available, and several laboratories referred clients to other counselling services, or forwarded the test report to the client's medical or legal practitioner in the expectation that they would provide counselling, if necessary, it seemed that neither accredited nor non-accredited laboratories commonly provided counselling services.[9]

The conclusion reached was that access to counselling before and after parentage testing is an important means of minimising the emotional and psychological impact of such testing on the persons involved. It was noted that although a large number of submissions supported the proposal for compulsory counselling, other submissions raised legitimate doubts about the utility of *compulsory* counselling in all cases involving parentage testing. The inquiry considered that, in the majority of cases, where parentage is confirmed, the parties may not consider counselling necessary, and even in those cases in which a parentage exclusion is reported, the parties may be able to deal with the information without the need for third party counselling. However it was also acknowledged that there will be cases in which the test results 'are shattering to those involved and may impact negatively on the social parent's relationship with the child, and potentially with the family'.[10]

In assessing the balance to be drawn between protecting individuals (especially minors) from harm, and respecting an individual's autonomy to make decisions affecting personal and family life, the

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[6] Ibid, [35.85]–[35.86], Recs 35–1 to 35–3.

[7] Ibid, [35.182].

[8] Ibid, [35.183]

[9] Ibid, [35.184].

[10] Ibid, [35.198].

inquiry concluded that counselling should be available and encouraged, but should not be universally imposed upon all individuals undergoing testing, regardless of their own wishes. The inquiry therefore recommended that NATA should develop accreditation requirements that required laboratories performing DNA parentage tests to inform all persons who provide genetic samples of the availability of counselling, both at the time the samples are submitted for testing and at the time the results are made available. This advice should explain the importance of counselling for that person's ongoing relationship with the child. In addition, laboratories should provide all parties with a list of available counsellors at the time the samples are received, and upon receipt of the results.[11]

The chapter also considered testing for kinship, other than parentage testing. This might arise in the circumstances of the Standing Committee's inquiry where a donor conceived individual seeks to establish their kinship, for example, with a sibling. As noted in *Essentially Yours*, kinship testing falls outside the *Family Law Act 1975* (Cth), the *Family Law Regulations* and the then NATA accreditation requirements—hence, both accredited and non-accredited laboratories may offer such testing.[12] The lack of regulation in this area was a matter of concern for the inquiry, but recognised that 'some of the special features of parentage testing, which justified heightened regulatory scrutiny, may be absent in the case of broader kinship testing' and that 'the test outcome may have a lesser capacity to produce emotional or psychological harm'.[13] Nonetheless, the inquiry recommended that NATA should extend its accreditation program to cover DNA kinship testing other than parentage testing.[14]

Another area considered in the inquiry, in Chapter 21, was access to family genetic information, in particular individuals' rights of access to genetic information about themselves, or their genetic relatives, held by health professionals. The conclusion reached was that the *Privacy Act 1988* (Cth) should be amended to permit a health professional to disclose genetic information about his or her patient to a genetic relative of that patient where the disclosure is necessary to lessen or prevent a serious threat to an individual's life, health or safety, even where the threat is not imminent.[15] In addition, it was recommended that individuals have a limited right to access genetic information about first-degree genetic relatives for similar purposes.[16] To give effect to such objectives the ALRC also recommended that the National Health and Medical Research Council (NHMRC), in consultation with the Office of the Federal Privacy Commissioner, should develop guidelines for health professionals dealing with disclosure of genetic information to the genetic relatives of their patients.[17] In June 2009, after extensive consultation, the NHMRC finalised the *Guidelines for National Privacy Principles about Genetic Information* under s 95AA of the *Privacy Act*. The Guidelines outline the circumstances in which genetic information may be used and disclosed for the purposes of lessening or preventing a serious threat to the life, health or safety of an individual.

The ALRC suggests that the matter of a donor child's access to genetic familial information may also be of relevance to the Senate Standing Committee's inquiry into donor conception practices. Such a question is clearly analogous to the kinds of matters referred to in Chapter 21 of *Essentially Yours* that are noted in the preceding paragraph. As health services become more dependent on an individual's genetic makeup, it may be important to ensure that children have access to information

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[11] Ibid, [35.200], Rec 35–11.
[12] Ibid, [35.202].
[13] Ibid, [35.203].
[14] Ibid, [35.207], Rec 35–12.
[15] Ibid, Rec 21–1.
[16] Ibid, Rec 21–3.
[17] Ibid, Rec 21–2.

about their genetic relatives. This was not a matter considered directly by the ALRC, but it may be an issue worth exploring by the Committee.

Yours sincerely,

Professor Rosalind Croucher