Submission to Australian Parliament

Senate Legal and Constitutional Affairs Committee

Inquiry into Donor Conception in Australia

On 23 June 2010 the Senate referred the following matter to the Legal and Constitutional Affairs Committee for inquiry and report.

The past and present practices of donor conception in Australia, with particular reference to:
(a) donor conception regulation and legislation across federal and state jurisdictions.
(b) the conduct of clinics and medical services, including:

  (i) payments for donors,
  (ii) management of data relating to donor conception, and
  (iii) provision of appropriate counselling and support services;

(c) the number of offspring born from each donor with reference to the risk of consanguine relationships; and
(d) the rights of donor conceived individuals.

As an approved infertility counsellor having worked in the field of Assisted Reproductive Technology since 1993 I welcome the opportunity to address the terms of reference of this Australian Parliament Senate Inquiry.

(a) donor conception regulation and legislation across federal and state jurisdictions

Consistency and harmonisation of regulation and legislation across federal and state jurisdictions is pivotal in reducing the burden on those creating their families using donor conception. With the increased mobility of Australian population due to employment and family reasons having uniform laws and regulation would reduce much stress for the already challenging times faced by those seeking donor conception. Furthermore it is inequitable that in the same country some people are disadvantaged in having access to treatment afforded to others merely by residing in other parts of the same country. We have created citizens with different rights by merely being born or residing in different jurisdictions within the same country. A national register including all those involved in donor conception would be an example of creating consistency across the jurisdictions.

(b) the conduct of clinics and medical services, including:

(i) payments for donors
(ii) management of data relating to donor conception, and
(iii) provision of appropriate counselling and support services

Compliance by fertility clinics and medical services offering donor conception with, at the minimum, the RTAC COP must continue in the interests of all parties involved in assisted donor conception. In some states, such as Western Australia, fertility clinics are also required to comply with the state legislation *the Human Reproductive Technology Act 1991.* Regulated fertility clinics give participants reassurance and confidence to undertake assisted conception. Single women and lesbian couples choose to access quarantined sperm from regulated clinics to create their families rather than take health risks by finding their own donors. Even where they do select to use a known donor they choose to have the donor sperm quarantined through a fertility clinic.

(i) payments for donors

Having provided implications counselling to sperm donors since 1994 and egg/embryo donors since 2001, the current altruistic philosophy which guides the donation of human reproductive material is just and consistent with Australian cultural values concerning donation of human body parts. Donors' motivation is a response to the plight of other human beings who require assistance to have a family. Becoming a donor provides them with the opportunity to be able to provide a 'gift' in a very meaningful way and the motivation for the majority is not payment. I would support the current arrangement of reimbursement for reasonable expenses associated with their donation.

(ii) management of data relating to donor conception

The management of data relating to donor conception is critical in ensuring that donor conceived persons have access to information about their genetic heritage and relevant medical history. Until the donor conceived persons are adults there should also be accessibility to a flow or exchange of information between donors and recipients concerning matters of significance for all parties such as health information. The WA legislation addresses this by maintaining donor registers of all parties involved in donor conception since 1991. The WA government also established the Voluntary Register in 2002 to enable those families created using donor conception prior to the 1991 legislation to exchange information and establish contact with all parties involved their donor conception on a voluntary basis.

(iii) provision of appropriate counselling and support services

Appropriate counselling and support services must be made available at all levels of engagement with donor conception. These services must be available from the outset through to support with issues that arise as a result of donor conception including telling the children and managing future contact and information exchange with the donor and other genetically related families. Implications counselling must be a routine step in preparing participants for donor conception and accessed at the outset by those proposing donor conception. This is essential in assisting participants fully understand the implications of this path and the unique consequences for themselves and any children to be born. Important components to be covered at this stage include legislative constraints, access to identifying information, consanguinity, number of other families that donor conceived persons may be related to, telling issues for themselves, the child and larger family. At the decision making stage participants benefit from peer support by meeting and talking with those who have already created their families using donor conception. This assists to allay concerns and fears about embarking on this path of family creation. Support counselling is especially important during treatment especially if the participants are not falling pregnant and may require support to deal with associated grief and loss. However support counselling may also be necessary at the decision making stage particularly if the non genetic parent or couple are still grieving their inability to have a child that is genetically related to them both. Support with discussing donor conception with their child is another stage that participants require access to counselling and support services. It is important for parents to understand the gravity of the consequences for the child and for their family of not disclosing this information to their donor conceived offspring. The impact of secrecy and non-disclosure can be a "troublesome burden" as reported by parents (Daniels et al. 2009.)

According to Scheib and Hastings, “The secrecy, risk of inadvertent disclosure, and perceived deception by one’s parents is highly likely to damage family relationships and the psychological and medical well-being of the donor-conceived person (reviews in McGee et al. 2001; McWhinnie 2001; Ethics Committee ASRM 2004; Daniels/Meadows 2006).

Accessible counselling and support services for donor conceived persons especially for those who have been impacted negatively by discovering the nature of their conception is essential. There is currently a lack of affordable and accessible services for this group of donor conceived persons who are often in the early stages of adulthood.

(c) the number of offspring born from each donor with reference to the risk of consanguine relationships

In WA the decision was made to limit the number of offspring born from each donor to five (5). The reasons involved the risk of consanguinity as well as reducing the ‘psychological bewilderment’ for the donor conceived person when they choose to establish contact with genetic siblings. The WA decision was heavily influenced by the input of a donor conceived adult from overseas who shared their distress at discovering that they were potentially related to 200 other donor conceived persons from one donor.

(d) the rights of donor conceived individuals

Donor conceived people’s rights to access information about their genetic heritage and medical histories that most of us take for granted should be safeguarded. They must also be able to make contact with other donor conceived persons born from the same donor. In the interests of psychological well being appropriate counselling and support must be accessible for donor conceived persons in preparing for information exchange and possible contact with their donor and/or genetic siblings.

Summary

Levelling the playing field for donor conceived persons by ensuring they can access information about their genetic and medical history and have contact with the donor and genetic siblings uniformly across jurisdictions is a basic human right. As a society we must take responsibility for the consequences of assisted reproductive technology and ensure that we do not create second rate citizens, who may feel disenfranchised or shamed by the nature of their conception. It is surely in all of our interests to ensure that donor conceived persons and their families emerge psychologically intact following this path of family creation.

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References

Daniels, Ken/Gillett, Wayne/Grace, Victoria (2009) “Parental information sharing with donor insemination conceived offspring: A follow-up study.” Human Reproduction 24/5, S. 1099-1105.

Lesbian mothers and their donor-conceived children: Family processes, child development and long-term outcomes Joanna E. Scheib 1, 2 & Paul D. Hastings1
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