# Legal and Constitutional Affairs Committee Inquiry into Donor Conception in Australia

# The Past and Present Practices of Donor Conception in Australia Submitted by Helen Kane

My name is Helen Kane, and I make this submission as a private individual, with many years of experience as a social worker in the adoption, infertility, access to information field (both adoption and donor conception), and in public health and private infertility clinics. I was the Manager of the Donor Register Services located at the Infertility Treatment Authority in Melbourne, until the change in legislation in 2009 which closed these Registers, and transferred their functions to other bodies. I had previously managed Adoption Information Services in several private adoption agencies, and had been involved with implementation of the 1984 Adoption Act in Victoria, which introduced access to information for adopted people, no matter when the adoption took place. It was retrospective, and was a clear and positive success, as long as it was accompanied with good counseling and linking services, which acknowledged the needs of all the people concerned. I was also involved, as a member of the Victorian Infertility Counsellors Group, with developing a model of practice for use with people wishing to access information in relation to donor conception, as a consequence of the 1984 Infertility legislation.

# **Summary of Recommendations**

- There needs to be a universal recognition of the donor conceived person's right to know the means of their conception, and their right to know their genetic history. It must be possible for the person to know this truth and access information, no matter when they were conceived, or where that was. This requires consistent laws across all states, and the preservation of records across all states.
- ❖ Donors who give their gametes or embryos should do this without payment. It is an altruistic act, and there should be no money associated with the creation of a child. it

is illegal to "buy" a child for adoption, and the same principle applies to children created by donation. A child is not an object to be bought and sold.

- ❖ A National Donor Register should be established to preserve and protect sensitive information relating to donor conceptions, including surrogacy arrangements. It should be able to receive information from all states, and be capable of managing the information in such a way as to identify donors, children, siblings, parents, and be able to reliably establish links between the individuals and families concerned.
- A professional counseling and donor-linking service should be provided to all those accessing information from the National Donor Register, as well as those which are located in particular states.
- Counseling should be required for all parties at the time of possible donation, and use of donated gametes. Informed decision making rests on good information, provided in an environment where the issues can be identified and discussed, before it proceeds.
- Counseling and other relevant services should be available ongoingly to families of donor conceived, and to the individual donor conceived person, for them to access these as required.
- Limit the number of recipient families from the same donor to five. This may lead to as many as 10-20 half siblings, but the containment of number of families will render this easier for the individual to deal with, and reduce the possibility of consanguinity. The older practices of vast numbers of children have been very challenging to the individuals concerned.

#### (a) Donor Conception Regulation and Legislation across Federal and State Jurisdictions

There is no consistency between states around access to treatment, preservation of records, and access to information for the people concerned with donor conceptions, including the parents, the donor and the donor conceived person. Though there are now guidelines relating to consent and record keeping, there is no way of imposing good practice.

#### (b) Conduct of Clinics and Medical Services

## (i) Payment of donors

The lack of donors is often bemoaned as a problem within clinics, with the suggestion that payment for their services would increase the numbers. This reduces creation of a child to a monetary transaction, with unknown consequences for the self esteem of the person. One of the continual anxieties expressed by donor conceived people is a fear that in fact they were conceived for a \$20 fee, and hence no positive commitment to their existence by the donor.

It is an altruistic act, to donate one's gametes, and should be supported as that, as is organ donation and blood donation.

### (ii) Management of Data relating to Donor Conception

Sperm donation has been a practice for many years, and was usually carried out in private doctors rooms, until the increasing development of infertility treatment within hospital settings in the 1980's, in Victoria. This has meant that the kind of records kept varied enormously, from none at all to full hospital medical assessments of the donor, depending upon the time of the donation and treatment.

The records kept by private doctors have had no protection at all, and were commonly destroyed. This means that many people have no way of finding out about their genetic history. And the parties themselves have no way of making choices about seeking information or contact with each other.

Adoption records were protected by legislation, and had to be permanently preserved. The same standard must be applied to all records relating to donor conception. This may mean the institution where the treatment takes place is obliged to maintain the records for as long as it exists, or that they are held at a central authority with the power to protect the contents, and deal with them under law, including allowing access to information for the people directly concerned.

### (iii) Provision of Counseling and Appropriate Support Services

To create a child from donated gametes adds complexity to the workings of a family, and for the child itself, with development of identity and self esteem. It may seem a simple concept, to take the gametes of another person, but it is not so within the family system itself.

Openness and honesty is recommended, but the doing of that can present challenges at times, and parents, and donors, can need to access counseling at times.

It is imperative that all of the parties have access to good professional counseling at the time of the donation, and at necessary points over the years following this. For all the adults it is "how to tell", and "how does this feel", and "what is a parent", for the child growing, it is the "who am I", "what kind of person donates", "do I have siblings".

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

The more children born from the same donor, the more chance of them meeting without knowing that they are siblings. In the past, donors have often had a large number of children born within a short space of time, rendering those children the same cohort, within families in Melbourne, with similar aspirations (private schools, every opportunity for their children). And where the child has not known of the means of conception, there have been the anxieties of the parents who do.

A simple solution – reduce the number of families created from the same donor. And provide assistance to families in relation to how to tell their children about how they came to be a family.

#### (d) The rights of donor-conceived individuals

It is taken as a given that all people have a right to know their history and their parents. We take it for granted that we can research our family backgrounds, do our family trees, and that this is important to identity, and a sense of our place in the world, and in the generations. Why would we want to deny this basic human right to donor conceived people?

It does fall on organizations and government to protect the rights of donor conceived people in a special way, with the preservation of records, the provision of donor-linking services, and counseling services. If our society supports this way of forming a family, it has to take responsibility for attending to the needs of all concerned, in relation to this. This means making it possible for a child to be told in a loving manner, to share information, to seek information and contact with the donor, and with other children created from the same donor, and to form ongoing relationships.

The work that we did at the Donor Registers Service at the Infertility Treatment Authority affirmed the rights, and needs of all concerned, and provided a sensitive, positive service to all the parties. It was difficult and painful for the individuals at times, and was slow whilst people began to learn about each other, and to develop trust, or not. It is possible for such programs to work well for all concerned.

We do not need to fear the consequences of donor conceived individuals exercising their rights to know about themselves, but we do have to be prepared to support them, and their families and their donors in relation to this. The practices of the past have meant that no one is really prepared for this new circumstance, but the practices of the recent past, with the ITA Registers, show that it is possible to do much better in the present, if the services are provided in a positive and responsive manner.

HELEN KANE SOCIAL WORKER, 26 JULY 2010

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