

That the Legal Affairs and Safety Committee

Inquiry into matters relating to donor conception information

Submission from

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Thank you for the opportunity to make a submission to your inquiry into donor conception (DC).

I have spent a large percentage of my life being involved in the issues surrounding donor conception from when my husband and I started considering using DC to create our family in the mid 1980's, a time when there was little information and no counselling (we have 3 adult children who are DC). I was a founding member of the Donor Conception Support Group of Australia (DCSG) when it formed in 1993.

In 1996 I was one of the organisers of the world's first consumer run forum looking at donor conception issues. At the Donor Issues Forum, we brought together everyone involved in donor conception: recipient parents, donor-conceived adults, egg/sperm/embryo donors, medical professionals, counsellors, and psychologists. The meeting of these parties in one room was also a world first. From this forum which was funded by the NSW Law Foundation we published the book "Let the Offspring Speak" (DCSG ISBN 0 646 32494 2) which has sold 1000 copies worldwide and which I edited.

In 2003 my book "Experiences of Donor Conception – parents, offspring and donors through the years" (Jessica Kingsley Publishers ISBN 1 84310 122 X) was published. In this book I looked at the long-term issues surrounding donor conception including such topics as: telling children about their conception, how donors feel, getting information about a child's donor. The book also includes two chapters about adults born from donor conception. Experiences of Donor Conception has also been translated into French.

Over many years I was the Consumer Advocate for the DCSG and my main task was to write submissions to state, federal and world governments regarding donor conception.

In 2010 I was one of 2 instrumental members of the DCSG who petitioned the Federal Senate and with the aid of Northern Territory Senator Trish Crossin achieved a Federal Inquiry into The Practices of Donor Conception both Past & Present. In 2011 the recommendations of this Inquiry included such things as:

- 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.

Unfortunately, none of these recommendations have flowed into any Federal legislation as it was considered that these recommendations should be the responsibility of the states.

Rights of donor-conceived persons, including to know their genetic origins;

The principles of medical ethics speak about non-maleficence and doctors are supposed to ask themselves the question: will this decision or course of action cause physical, psychological or social harm?" The problem is that doctors treat infertile people and that is their focus. But infertility treatment, especially donor conception treatment, is qualitatively different to other medical treatment. Its aim is to create another person and so medical ethics in the case of donor conception must also consider the child that is being created.

There has also been a tradition of relating primarily to the interests of the adult parties. This tradition has changed gradually over the years and in Australia all people created from Australian semen now have the opportunity to know the identity of their donor on reaching adulthood, providing they know how they were conceived.

But this does not help DC people created before these changes were put in place. It is a basic human right to know of one's own heritage, it is a right that most adults take for granted. Some may argue that many people in today's society do not know a part of their heritage for a variety of reasons, however their right to seek information is not denied to them through any legislative or regulatory framework.

Some donor conceived people will be interested in accessing their genetic information while others will have no interest. In all the years that I worked in the area of DC I have known a great many adult donor conceived people, some have wanted to access donor information while others have not but one thing they have all had in common is that they all felt that they should have the right to access information.

If you say that a donor conceived person cannot have access to information on biological parents then you are saying that they are different and will be treated differently by the very nature of their conception and birth. This is discrimination; the type of discrimination that was supposed to have been done away with decades ago with the advent of adoption legislation. I am concerned that denial of such rights purely on the basis of their date of birth has produced a minority group afforded less rights than those of their younger counterparts.

Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;

We must at this point discuss the point that makes donor conception different to adoption and that is numbers. In donor conception one person can have quite a number of offspring compared to adoption and this is probably the one area that worries some donors. This is why the Queensland Government may consider a contact veto system similar to that what has been used in adoption in some states. A contact veto system would enable those donors who

are fearful a measure of protection from unwanted contact. We would suggest that if this system were to be introduced that a contact veto should be able to be altered by each party at any time.

Access to historical clinical records and implications of retrospectivity;

All records wherever they are currently held must be given permanent protection; in donor conception these records are the equivalent of true birth certificates. Many donor conceived people have very strong views about their birth certificates, some have called them sanctioned untruths. Some people, in particular donor-conceived people, and people involved in adoption, told me they believe that birth certificates should always display the names of a child's genetic parents, to reflect the biological truth about his or her parentage, and to guard against the secrecy that has historically accompanied donor conception and adoption.

The results of retrospective access to information can really only be looked at through what has happened in the state of Victoria where retrospective access became available in 2015. Since then, there have been numbers of contacts made between donors and DC people through The Victorian Assisted Reproductive Technology Authority.

A study published in 2019 concluded that:

The study's findings with regard to donor-initiated applications suggest that more research also needs to be conducted with donors. The LRC appears to have seriously underestimated pre-1988 donors' level of interest in their offspring and their willingness to initiate applications.

(From Stranger to Family or Something in Between: Donor Linking in an Era of Retrospective Access to Anonymous Sperm Donor Records in Victoria, Australia

Fiona Kelly, Deborah Dempsey, Jennifer Power, Kate Bourne, Karin Hammarberg, Louise Johnson
International Journal of Law, Policy and the Family, Volume 33, Issue 3, December 2019)

Access to support and counselling for donor-conceived persons and donors;

When people are referred to fertility clinics these days part of their acceptance onto a donor conception program is to have at least one session with a clinic counsellor. This is not compulsory but is it usual that most, but not all, doctors will encourage this. In the history of donor conception this is a very recent innovation. If you go back only a little over 20 years not all clinics even had counsellors and doctors were not encouraging patients to see them. While there are, no doubt, a great many excellent counsellors working in clinics we do need to make people aware they are in the employ of the industry.

To compare donor conception with adoption again in the area of family support; adoption has a long-standing tradition of helping adoptive families. All states usually have multiple sources of information. For example, within NSW adoptive families may access information and support from the Department of Community Services but also may go to the independent organisation the Post Adoption Resource Centre (PARC) which is funded by the Benevolent Society; these are apart from the smaller adoption organisations such as Anglicare and Barnardos. This is repeated in other states. There has been a realisation that adoptive families need ongoing support throughout their lives especially for such things as talking to children about adoption and exploring the issues of contact between adoptees and their biological families. The organisations that are available to adoptive families have decades of experience in adoption counselling and support.

What are donor conceived families supposed to do if they need support after the birth of their child. As it grows and what of adult donor conceived people? Parents can go back to the fertility clinic and possibly get help from the clinic counsellor (if this is made available to them by the clinic) but the counsellors in clinics are trained to deal with the issues surrounding infertility. So where else can families go? For many years they came to the DCSG a volunteer run organisation (where clinics referred quite a number of parents and DC people) but the DCSG closed a few years ago.

Counselling must be a mandatory part of entry onto a donor conception programme and made available through trained independent counsellors. The Authority that looks after the Register of DC records must make counsellors available to all people requesting information from the Register. In the event of making contact for the first time, counselling should be made compulsory.

Whether a register should be established;

There needs to be a Donor Conception Register independent of service providers that will store the identity of gamete and embryo donors, recipient parents and donor conceived people past and present.

The Register should be maintained by an Authority set up by the Queensland Government. Service providers must notify the Authority of all treatment procedures that use donated gametes and embryos.

There must be compulsory notification by the service providers to the Register of all births (where known) from donated gametes and embryos.

Parents be encouraged to also inform the Authority of all births from donated gametes or embryos.

Notification of births be linked to the Registers of Births, Deaths and Marriages so that Birth certificates of donor conceived people will have an appended note available only to the donor conceived person which gives information about the nature of their conception.

All records, where they still exist, of past gamete and embryo donations plus treatments with donated gametes should be compulsorily acquired by the Authority as these records contain the identity of donor conceived people that cannot be obtained any other way.

All records that will be stored on the Authority Register must be kept in perpetuity.