

**Submission
No 33**

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Organisation: Plunkett Centre for Ethics
Name: Dr Bernadette Tobin
Position: Director
Date Received: 17/02/2013

Plunkett Centre for Ethics

A joint centre of St Vincents & Mater Health and Australian Catholic University

St Vincent's Hospital
Victoria Street
Darlinghurst NSW 2010

15.2.13

The Honorable Mr Barilaro
The Chair, Committee on Law and Safety
Parliament House
Macquarie Street
Sydney NSW 2000
Email lawsafety@parliament.nsw.gov.au

Submission to Inquiry into Managing Information Related to Donor Conception.

Dear Mr Barilaro

Thank you for the opportunity to make a submission to the inquiry into managing information related to donor conception.

The Plunkett Centre is a joint centre of St Vincents & Mater Health in Sydney and Australian Catholic University. Its mission is to promote the values of compassion and fellowship, intellectual and professional excellence, and fairness and justice, primarily in the provision and allocation of health care. It expresses this commitment through research, teaching and community engagement, as these are informed by the Catholic tradition.

I congratulate you on conducting this inquiry. For it concerns the significance of a fundamental moral and social truth: that all children are entitled to know their biological parents.

We should not need to be reminded of this ('moral' or 'ethical') entitlement (which is expressed in the UN Convention on the Rights of the Child). But the fact is that we do need to be so reminded. In recent decades we not only allowed the anonymous donation of sperm to occur; we also allowed doctors and clinics to promise that that anonymity would be guaranteed. And, in some cases, further steps may have been taken, such as the mixing of sperm from two or more donors, so as to make it difficult to identify the actual donor.

The entitlement to know one's biological parents (or, as the National Health and Medical Research Council's *Ethical Guidelines on the use of Assisted Reproductive Technology in*

¹*Clinical Practice and Research*) put it, one's 'genetic' parents) should be understood primarily as a (moral) right to know the truth about one's conception as a (or, perhaps, the) fundamental aspect of knowledge of one's own identity. So whether or not it is useful, the information is knowledge to which every human being is entitled.

Of course, that knowledge may be useful: for understanding one's medical history (particularly in these days of personalized genetic medicine), for reducing the risk that a donor-conceived person will enter into a consanguineous relationship, for enabling opportunities for a donor-conceived person come to know his or her half siblings and other members of his or her biological family including the donor, to reduce the risk that the donor-conceived person will be burdened by psychological distress, etc. Your own very useful issues papers points all this out.

Your paper goes on to claim that 'equally, there are arguments for maintaining anonymity' (emphasis added).

It is true that there are arguments which can be advanced for maintaining anonymity: promises made, donor resentment at intrusion into their present lives of matters they consider to be in their past, etc. In fact, and even more seriously, some donors may actually be harmed by their identity being revealed and their being approached by a person or persons conceived as a result of their donation: fragile donors (the elderly, the cognitively impaired, those whose donation has led to the birth of very many children, etc) could be overwhelmed by such approaches.

But, with respect, they are not of equal importance with the argument for ensuring access to identifying information.

There are various ways in which this can be seen.

Here is one way. Over human history, the idea that children are entitled to knowledge of, and contact with, their biological parents has been taken for granted. Of course, there have always been exceptions, but that's the point: they were exceptions to a fundamental fact about human social life which was not only assumed but enshrined in law and public policy. (Certainly, adoption arrangements have sometimes failed to pay due regard to this entitlement, but in recent years policies have been adopted to rectify this oversight.)

Or, again. The principle of 'anticipated consent' requires that, when a person seriously affected by a decision cannot give consent, we must ask whether we can reasonably anticipate that he or she would consent if able to do so. If not, it is unethical to proceed. It follows that the views of donor-conceived adults are ethically-relevant to an enquiry into managing information related to donor conception. And they speak of a profound sense of loss, a loss which goes beyond an inability to access medical information about themselves,

¹ In addition, since donor-conceived person should have the same rights as adopted people, identifying information about every person who had or has a role in the 'parenting' of a donor-conceived person - biological parents, the gestational or birth mother, social parents, should be registered with the Registrar of Births, Deaths and Marriages and included on the birth certificate.

a loss which goes beyond a fear of consanguinity in their adult relationships, a loss which goes beyond the desire to know their biological relatives. It is the loss of knowledge of something critical to their sense of themselves: their personal identity.²

But it is only in recent years that there has been a need to spell out the idea that people are entitled to knowledge of, and contact with, their biological parents. For it is only with the invention of technologies to circumvent infertility that that taken-for-granted assumption has been ignored. The practice of seeking the donation of sperm – with the promise of anonymity to the donor – developed in response to the (understandable) desires of adults to have children, but it developed in a manner which ignored the child's entitlement to knowledge of his or her own biological parents.

Thus it was that, in 2004, in setting out the ethical basis of its guidelines, the NHMRC explicitly stated its acknowledgment of this fundamental fact about human social life: *In these guidelines, the Australian Health Ethics Committee has recognized that the welfare of people who may be born as a result of the use of assisted reproductive technology is paramount*³ (emphasis added). 'Paramount' means that it 'comes first', 'is first in order of importance', etc.

So it follows that arguments for making identifying information accessible, and not so doing, are not 'equal'.

Your committee now has the opportunity to make a significant contribution to rectifying this wrong. I urge you to recommend to the NSW Parliament that identifying information of donors should be made available to donor-conceived persons.

That is the main point I wish to make. Of course, careful thought will need to be given to how this entitlement should be enabled. Unless a mature young person's 'social parents' give their consent to the release of identifying information, perhaps access should be available only when a donor-conceived person reaches adulthood. And careful thought needs to go into the best arrangements for ensuring that this information is accessible; a register will need to be established and run at a State or Commonwealth level.

There are several possible objections to this recommendation. I will outline them and indicate how I think they can be answered:

Objection 1: Some donors may be harmed by having their identity revealed. Some may be harmed by being approached by one or more people conceived as a result of their donation of sperm many years ago.

Reply: This is true and important. However it can be managed by an arrangement which enables a donor who wishes to decline to allow identifying information to be made available

² Margaret Somerville. 'Brave new babies: children's human rights with respect to the biological origins and family structure', Published as 'From homo sapiens to Techno sapiens: Children's Human Rights to Natural Human Origins', Proceedings of the 14th World Congress on Reproductive Technologies, Montreal, 17th to 20th September, 2007). Submission No 2 to Senate Inquiry into Donor Conception in Australia.

³ *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research*, 2004, p 9

to a donor-conceived person or persons to have the substance of his reasons reviewed by a Panel. The Panel would assess his claim that he would be seriously harmed by the disclosure of identifying information to the donor-conceived person(s) and, if the claim is substantiated, the information could be withheld.

Objection 2: People made anonymous donations in good faith and may have been explicitly promised anonymity. Promises, undertakings, contracts, were (or may have been) made with donors that their privacy would be respected by their donation being anonymous. Release of identifying information would be an infringement of their privacy.

Reply: No such promises, undertakings or 'contracts' should ever have been made. Since such promises or 'contracts' would have a profound effect on the rights of a third party, or indeed multiple third parties, they were not validly made. Clinicians had no right to make such promises or to enter into such contracts because the profoundly-affected third party (or parties) was not represented when the agreements were entered into. The 'contracts' are void. So there is no such right as a 'donor's right to privacy' which must be respected.

Objection 3. It will not always be possible for donor-conceived persons to access identifying information. Records may have not been kept. Records may have been lost. Records may have been deliberately destroyed. It may be costly or onerous for clinics to retrieve identifying information.

Reply. It is true that there may be difficulties encountered in identifying and securing records. For this reason, registers will need to be established, at the State or Commonwealth level. Public resources will need to be devoted to the gathering of data from clinics and other repositories as best as is possible.

Now that it is illegal in New South Wales to facilitate donor conception unless potential donors agree to having identifying information kept accessible for donor-conceived people, the parliament has put in place arrangements which ensure that, in the future, donor-conceived people will not have inflicted on them the gross injustice of not being able to know who is one of their biological parents. The parliament should now authorize arrangements to address the injustice inflicted on donor-conceived people in the past. The Parliament will need courage to do this: it will most certainly be resisted by some if not all of the 'providers' of assisted reproductive technologies. A useful first step may be a public campaign which encourages donors voluntarily to come forward and register the relevant details about themselves on a public register.

Once again, I thank you for the opportunity to contribute to your deliberations, and I would be very happy to try to answer any questions you may have about this submission.

Yours sincerely

A solid black rectangular box redacting the signature of Bernadette Tobin.

Bernadette Tobin
Director