Submission
No 13

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Name: Mrs Christine Whipp

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The following are my thoughts on the issues that are raised in managing information related to donor conception:

I firmly believe that as a matter of basic human rights, nobody should be deliberately deprived of access to information about their full biological identity, regardless of the inconvenience or embarrassment this may cause to any other persons or bodies. Regrettably, the early protocols of secrecy and donor anonymity which were established in donor conception, were at best misguided and at worst, unnecessarily cruel and inhuman. It is unfortunate for a whole generation of donor conceived people that it has taken so long to begin to address the situation that this unfair system has imposed.

An awareness of how a lack of full identity can create fundamental problems, affecting both physical, emotional and psychological health, has led to many world jurisdictions recognising that donor conceived people need and should have access to identifying information about their gamete donor/s, on reaching the age of majority, or sooner. While that principle is easy to implement by regulations for future generations, the implications and remedy for those already conceived have received less attention than those unfortunate people deserve, so I welcome this inquiry and hope that NSW will set a worthwhile precedent with respect to addressing the injustice that donor conceived people have suffered.

Legislation providing retrospective access to donor information will only be of use to those donor conceived people who have been made aware of their medically assisted conception. As a result of clinicians encouraging recipient parents to keep their use of donor gametes secret and governments colluding in such secrecy by allowing birth certificates to be representative of the *social* truth, rather than the *biological* truth about a donor conceived person's genetic parentage, there are many donor conceived people who are unaware that they have been duped about their full identity. This lack of awareness will continue and will impinge on the uptake of access to identifying information by future donor conceived adults to which such access has already been granted, unless legislation is implemented to ensure that birth certificates record that donor conception has taken place.

The haphazard way in which the medical profession has traditionally been allowed to control the use and growth of donor conception services had led to an appalling lack of proper record keeping, with few centralised repositories of records. Even for those people who know they are donor conceived, there is no guarantee that records of their conception and the identity of their biological donor parent, have survived.

Q. 1. Should donor conceived adults born prior to 2010 have retrospective access to donors' identifying details?

My answer to this question is an emphatic YES.

The benefits for the donor conceived person will outweigh any perceived negative effects for the gamete donor, as has already been demonstrated by the way in which adopted people have benefited from having access to their full adoption records.

There is growing evidence that donor conceived people also gain immense benefit from having contact with half siblings conceived through the same donor.

Q. 2. If retrospective access were granted what conditions should apply?

Around the world, a number of determined donor conceived adults have already sought out and found their sperm donor fathers, employing various means to do so, (including using the media, information technology, research, DNA technology, voluntary registers and educated guesses) both with and without the assistance of bodies dedicated to helping them. I am not aware of any incidences in which the donor conceived person has regretted seeking and making a connection with their donor father, or of the sperm donor vehemently resenting having been discovered. Similar accounts of meetings between donor conceived people who are biologically related as half siblings from conception though the same sperm donor, have all been entirely positive.

Based on these experiences, fears of catastrophe arising from the release of donor identifying information appear to be greatly out of proportion, if not entirely unfounded.

While concerns for potential negative outcome will remain, the little documented impact of allowing retrospective access to donor identifying information could theoretically be mitigated by imposing conditions on access similar to that of the Contact Veto system used in adoption, but it would be a further injustice to donor conceived people if some get to meet with their donor parent because he or she is open to the idea of contact, whilst others are prevented from doing so because their donor is less amenable. Equal opportunity demands that everyone gets the *same* chance to explore their full identity and biological family connections.

In the event that the need for a Contact Veto should became a sticking point on which the whole issue of allowing access to donor identifying information was hinged, it would be better for those donor conceived people born before 2010 to be burdened by a Contact Veto, rather than not to allow retrospective access to donor identifying information at all.

Q. 3. What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?

The granting of retrospective access would create a need for a centralised repository for records relating to past donor conceptions and the compilation of a register of information. A proactive approach to obtaining records and information from clinics would need to be taken, particularly towards clinics and hospitals who claim their records have been lost or destroyed.

Given the unique nature of donor conception it would be preferable for a dedicated body to be set up to manage both the records themselves and the process of access to information.

Q. 4 Which agency is best placed to manage the register of donor conception information (donor register)? Is the current management of the register adequate?

Where government funded Voluntary Registers have operated, around the world, it could be argued that these have not acted sufficiently proactively to attract gamete donor registrants. There has been little campaigning to educate former gamete donors, recipient parents and the general public about the reasons why donor conceived people need identifying information relating to their conception and there has little encouragement for former donors to come forward.

Whatever agency is chosen to manage the register of donor information, the staff at that agency would need to be knowledgeable about donor conception issues and both empathetic and understanding of how the information might impact on those who are seeking it.

Q. 5. Should a standalone body be established to manage the register? What other areas could it have responsibility for?

Ideally a standalone body dedicated to managing the register and access to donor conception information would be best placed to offer a rounded, quality service. Such a body would develop experience and insights that would ensure that information gathering, processing and delivery of access was handled with sensitivity as well as efficiency.

Q. 6. Should counselling and support services be offered to those seeking donor conception information from the donor register?

The experience of those who have gone through adoption reunion suggests that counselling can have a very positive role in the process and the same will probably hold true for donor conception connections. Counselling can provide a positive framework through which to guide and facilitate those in the donor conception connection process to make the necessary transition from being biologically related strangers, to forming a meaningful familial relationship.

It would be appropriate for the body managing the access to donor conception information to be able to provide information about access to suitable counselling services for both donor conceived people, gamete donors and recipient parents along with anyone else (for example, members of the donor’s own family) who might be emotionally affected by the donor conception connection process. However, mandatory counselling should not be a pre-requisite for anyone wishing to access information. Donor conceived people should not be expected to fund their own counselling as they were not the architects of the situation which they seek to remedy through access to information.

Q. 7. Are there other types of support that could be offered?

The opening up of retrospective donor conception records will allow access to donor identifying information, where such information is available, but that information in itself may not be sufficient for the donor conceived person to make contact with their biological parent. Many adopted people have been disappointed to find that regardless of well kept records, their birth family is untraceable, for various reasons. It would be appropriate for greater help to be given to donor conceived people in the process of searching for their gamete donor parent.

Where there is a lack of donor conception records caused by past protocols that were short sighted, if not deliberately obstructive, there needs to be some remedy for the donor conceived people unfortunate enough to be affected. It would be appropriate for these donor conceived people to be offered, by way of some compensation, state funded DNA testing with one of the major companies offering genealogical genetic matching, which can provide some answers about genetic background.

A “letterboxing” service by which information can be exchanged through a third party, prior to contact, might be helpful, especially between half siblings conceived through the same gamete donor.

Q. 8. How would support services be funded? By the government, the individual seeking the service, or by ART clinics?

Donor conceived people did not ask to be put in the position of being deliberately separated, before birth, from one or both of their biological parents. It would be inappropriate to expect them to pay for the expense of having their severed kinship bonds repaired. If former donors were expected to contribute to the cost of the record keeping and information service it might deter some from coming forward and therefore be counterproductive.

It would be appropriate for those who assist in the creation of people through means which cause a deliberate separation between biological parenting and social / legal parenting to fund at least some part of the service designed to repair that situation, just as it would be befitting that any government that allowed the medical profession to create children in that way should take responsibility for dealing with the consequences.

Q 9. How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?

In order to give the best continuity of service it would be appropriate for the body managing the register to provide access to both information and all the additional services which would make the process of connecting donors with their offspring and offspring with their siblings, as seamless as possible.

Q 10. How long should ART clinics be required to retain records?

All information relating to donor gamete conceptions should be kept indefinitely.

Q 11. What should happen to records if a clinic closes?

It is not sufficient for a clinic or hospital to hold their own records, given that so many such records in the past have been destroyed, either deliberately or accidentally. Copies of all donor conception records should be lodged in a central repository for safe keeping.

Q 12. How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.

With one set of records being held by the clinic and a further set being lodged with an appropriate controlling body, the integrity of donor conception records would be reasonably assured, but legislation to specifically protect such records from misuse, interference or destruction, with penalties for non-compliance, would provide an additional safeguard. There is a possibility that some commissioning parents may not report a successful donor conception to their clinic, so it would also be necessary, for future reference, to keep records of treatment cycles that had not been notified as successful.

Mrs Christine Whipp

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