

Submission to Federal Inquiry into Donor Conception in Australia

Capacity in which I am writing

I am a donor conceived adult. I was conceived, born and raised in the UK, but hold dual Australian/British citizenship (my mother was Australian). More importantly, I think the views and experiences of those involved in Donor Conception are relevant, regardless of nationality.

I am also a member of the **International Donor Offspring Alliance (IDOA)**, a group of donor conceived adults across several countries (including Australia) which campaigns for reform of donor conception practices (see <http://www.idoalliance.org/> and attached briefing paper, which sets out IDOA's arguments in some detail). **Whilst my submission draws on my own first-hand experience, it is also submitted on behalf of IDOA.** I believe that other members of the alliance have also submitted evidence. (My response to (b)(i), Payments to Donors, purely reflects my own views, as IDOA has campaigned primarily in the areas of openness and counselling/support.)

This submission majors primarily, but not exclusively, on item (d) from the Inquiry's terms of reference, "the rights of donor conceived individuals". I address this item first, and then move on to selected items from (b), and finally to (c).

(d) the rights of donor conceived individuals

Openness – Birth Certification

It is essential for the mental/emotional health of donor conceived people that they be told about their origins. Keeping family secrets does not work – far from protecting the child, it leaves them guessing as to the nature of the contradictions, tensions etc which they perceive but cannot identify.

I would go so far as to argue that donor conceived people have a right to this information. The analogy is often drawn with those conceived eg through casual "one night stands". However, it is a false analogy, as if frequency of occurrence can somehow render an unfortunate occurrence right or desirable. Moreover, one night stands do not occur with State sanction.

The decision to "tell" should not be left to parental discretion. Experience shows that the majority of parents still do not tell. However, there is in any case a point of principle. It is not right that information about a person should be held by clinic, authorities and parents, but not by the person themselves. In countries which have acknowledged adopted people's right to information, good models of birth certification apply, protecting families' privacy, whilst ensuring that the truth of their adoption cannot be withheld from adoptees themselves. A similar model needs to be applied to birth certification for those born from assisted reproductive technologies¹.

¹ This principle was accepted by the Joint Lords/Commons Committee in the UK in 2008 which carried out the pre-legislative scrutiny process for the Human Fertilisation and Embryology Act. The Committee's report emphasised its concern that the birth certificates of donor offspring amounted to a legally-sanctioned fraud, and that the government was colluding in an act of deception.

In regimes where adult offspring have been awarded the legal right to access donor identity, birth certificate reform is essential to prevent such reforms remaining a dead letter for the majority of offspring (at present the majority of donor conceived people, on reaching 18 years of age, will simply not know about their origins, and will therefore take no steps to access the donor information to which they are entitled).

In purely physical, health-related terms, there is also no effective substitute for donor conceived people having reliable information from the outset. I, and other donor conceived adults I know, lived in fear that we had inherited health problems from our “social” fathers.

Openness – Anonymous versus Identifiable Donors

While I never for one moment regretted having been told about my conception, it was extremely painful knowing for several years that I had no legal or practical hope of uncovering the missing half of my identity.

Many donor conceived people campaigned long and hard for the lifting of donor anonymity within the UK. I have been a direct beneficiary of this reform, in that the voluntary DNA registry, UK DonorLink was set up at the same time, through which I was put in touch with several half-siblings, including the son by marriage of my donor. I was therefore able to learn, not only the identity of my natural father (long deceased), but also the narrative of his life, interests, beliefs, ethnicity, family etc. **It is impossible for me to over-emphasise the positive significance this has had in my life.** In place of confusion and self-hatred, I now have a far greater sense of identity and feel far more grounded, confident and tranquil. It would be my dearly held wish that no donor conceived person should have to endure the mental and emotional pain which is so often associated with a “closed” regime of donor anonymity.

While the British reform in 2004 was welcome, it did not go as far as it might have done. Birth certification, as already discussed, remains an issue. There was also no discussion of possible retrospective lifting of anonymity. In this respect, donor conception in the UK remains out of step with adoption, where records were retrospectively opened. The creation of UK DonorLink was a useful halfway house, but lack of funding and publicity have hampered its effectiveness both in terms of public awareness (vital if donors and donor conceived people are to be able to access its services) and of quality of technical service.

In my experience, and from my discussions with other donor conceived adults, it is the issue of identity which dominates. However, as already mentioned with reference to birth certification, accuracy of health information is also important. Inasmuch as donor conceived people ought not to be misled into thinking they are genetically predisposed to their social fathers’ health problems, they ought also to have access to accurate health information about their donor parent. It is not adequate that this be a “one-off” pen picture or clean bill of health from the time of donating. Up-to-date and relevant health information is a natural consequence of using identifiable donors.

I would urge the Australian Federal Government to look broadly at the needs and interests both of those yet to be conceived, and of those already conceived under regimes of anonymity.

(b) (i) payments for donors

Assisted reproduction is already big business, and the voices of the fertility industry have generally, over the decades, prevailed over the best long term interests of donor conceived people – and, indeed of their wider families, since secrecy and anonymity do nothing to enhance long term family wellbeing. The issue of the commodification of life does not, therefore, hinge on whether or not donors are paid.

Moreover, while I appreciate that many donors operate out of altruistic care, this may or may not be perceived as altruistic by donor offspring struggling to come to terms with separation from a biological parent (I know that donor conceived adults hold a range of views and emotions on this issue).

Therefore, whilst donor payments would undoubtedly serve only to intensify the sense of babies as commodities, the absence of payment does not of itself eliminate the inherent complexities in the donor/recipient parent/offspring “triangle” (see comments in bold under next section). Adequate and appropriate counselling is essential.

The argument that payment is needed as incentive should be resisted. Any potential donor requiring such incentive would appear poorly placed to appreciate the enormous long term personal and emotional significance (for others, and in all likelihood themselves) of their action.

(b) (iii) provision of appropriate counselling and support services

Assisted reproduction is classically treated as a purely medical procedure (one might remark in this context that the catch-all term “fertility treatment” is generally a misnomer, as the infertility is not being treated, but circumvented).

Again, comparison with adoption is helpful. Parents wishing to adopt nowadays are required to accept their child’s own history and heritage. No longer is a child or baby considered a “clean slate”. There is a thorough vetting and preparation process, whereby would-be adoptive parents must work through their own motivations, acknowledge the separate identity of the child/ren they wish to adopt, and recognise the grief and loss already experienced by the child/ren.

How much more should this be the case in donor conception, where the situation is arguably even more complex (owing to the innate imbalance between the mother/father genetic/adoptive relationships).

I think about my own family of origin, and the often agonising dynamics between family members, both before and after I was told the truth. In my experience, there are as many extraordinarily complex, and often very painful variations on the theme of family relationships as there are donor conceived people. I cannot emphasise strongly enough the need for thorough and well-informed counselling for recipient parents and donors. The emphasis for too long has been on producing healthy babies. Thereafter, research has focused unduly on attachment theory, and considered the developmental progress of young children *before the relevant issues of identity kick in at or after adolescence*.

I believe that donor conception is **inherently complex** and that **no model, however enlightened, can ever eliminate the difficulties and complexity**. This is because the practice is a kind of cross between adoption and step-parenthood, neither of which is generally easy. However, there are steps to make it less painful for the people conceived. In addition to the issues of openness already discussed, it is essential that parents be well-

informed, and understand that their child has their own inalienable genetic identity, deriving in part from the donor. Similarly, donors – for their own long term wellbeing, as well as their offspring’s – need to understand that they are not simply “helping an infertile couple”, but themselves reproducing, helping to create individuals whose own sense of identity may well hinge on the option of knowing of and/or actually knowing their natural father.

As for donor conceived people, I think the surface has scarcely been scratched of their potential needs for counselling/therapeutic help. I am concerned at the lack widespread understanding and expertise in this area.

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

While statistically the probability of inadvertent consanguine relationships may reduce the more donations from each donor are limited, the only way to eliminate the danger is to make birth certification transparent, as already argued.

It is, moreover, absurd to me that authorities should use donation limitation to address this danger. Part of the discomfort of being donor conceived is the extent to which decisions pertaining to one’s life and identity are decided on one’s behalf, often before birth. This would seem to me an example of medical/civil authorities deciding how best to protect donor conceived people, without according us the dignity of full and necessary information on our origins and identity. If there is fear of consanguinity, then give donor conceived people the necessary information, so they themselves can responsibly avoid it.

Please Note: I understand that the terms of reference of this enquiry relate to donor conception. I would hope, however, that the principles I and other similar individuals or interest groups make might equally be taken into consideration when thinking about people born from various forms of surrogacy, egg donation, embryo adoption etc. I am deeply concerned that the long term effects are simply of these are not known, yet they widely practised, and rarely questioned.