

**Submission to**  
**Legal Affairs and Safety Committee**  
**Inquiry into matters relating to donor conception information**

**By**

**Trevor L Jordan, BA, BD, PhD**  


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## **Background**

This submission relates to the inquiry into matters relating to donor conception information.

I make this submission as a Queensland citizen who has been profoundly impacted by past closed adoption policies. My status as an adopted person was only revealed to me as an adult. I believe my experience was in many ways similar to that of donor offspring who find out later in life the mode of their conception. These impacts and their similarities have been well documented by my former colleague Dr Helen Riley (2008, 2009, 2012 & 2013)

### *Not repeating the mistakes of the past*

For over twenty years, I taught public and professional ethics in the Applied Ethics program at the Queensland University of Technology and developed a particular interest in ethics and adoption. As well as interacting with donor-conceived adults from Australia, the USA, Canada and Britain, I supervised graduate students who researched the ethical issues around the impact of late discovery and donor conception. Through that interest and my involvement in many national and international conferences, I met people affected by donor conception practices, who also suffered under a system which denied them access to the truth about their biological origins. It became clear to me that while there had been reform of adoption policy in many jurisdictions, little was being done to address the needs of donor-conceived adults. Paternalistic practices of secrecy long abandoned in adoption were being perpetuated in the field of Assisted Reproductive Technology (ART).

### *Respecting the voices of donor-conceived adults*

I believe it is important to listen to the voices of those directly impacted, most of whom are now adults. I encourage the committee to not only listen but also give added weight to the voices of donor-conceived people. However, it is a cruel irony that many of those voices will never be heard because perpetuating secrecy remains the default position for many families created by donor conception (Riley, 2002, 36; Warnock, 64).

### *The availability of commercial DNA kits erodes secrecy and anonymity*

It must be acknowledged that past contractual arrangements promoting donor anonymity and secrecy have been disrupted by the easily available commercial DNA tests linked to popular widely-used genealogical websites. Families formed by donor conception will experience future disruption. The time to act is now, by supporting the right of donor-conceived persons to access information and through the provision of services that provide trustworthy and informed emotional support.

### *Principles for moving forward*

I have found three principles to be important when advocating for reforms in adoption policy and practice, and I believe they are also important when assessing the rights of donor-conceived persons to access information about their origins.

- Openness and honesty
- Commitment to the lifelong best interests of the child
- Provision of adequate information and support services

### *Openness and honesty*

Openness and honesty form the basis of sound familial relationships and encourage socially responsible institutional practices. Deception undermines caring, accountability, fairness and integrity in relationships.

Past policies and practices of secrecy were often promulgated by professional hubris. For example, Dame Mary Warnock, who chaired the U.K. Committee on Human Fertilisation and Embryology, had this to say about the fact that the majority of couples then, as now, intended not to tell their children about their mode of conception:

Such concealment of the facts of a child's birth seems intrinsically wrong, though, astonishingly, as recently as the 1970s, the British Medical association's advice to women seeking AID [Artificial Insemination by Donor, as it was called then] was to go home after treatment and forget it, or even to have sexual intercourse with the infertile husband immediately, so that if a pregnancy is achieved, it will not be absolutely clear that the husband is not, after all, the father of the child. Their pamphlet ends with the words 'No one need ever know'. This seems to me a blatant case of neglecting the 'good of the child'. The child was to be brought up in a cloud of deception: she [sic] was to know neither the identity of her father, nor that her father was a donor. (Warnock, 65).

Dame Mary continued:

It is undermining to any relationship between two people if one knows a salient fact about the other which is not divulged .... If he [sic] accidentally discovers that truth, he may feel diminished. He will be anxious about his own identity once he discovers that, in an important sense, he is not who he thought he was. Moreover, he was not trusted with the information he may feel he was all along entitled to: he has been used by his parents to conceal their infertility, or simply as an instrument by which to satisfy their craving to be like other people and have a child. (Warnock, 66)

As attitudes towards secrecy have changed in the general community (in part based on the experience of adoption) justifications of the need for secrecy have sometimes shifted to the issues of 'supply' -- there would not be enough donors to meet the 'demand'. This merely underscored that the relationships between adults involved in ARTs were commercial and contractual in nature, with little regard to the impact this might have on the 'product' of the transaction: a person with future rights and interests. The impact of such commodification, then, becomes an issue to be faced (Riley, 2002, 186-187).

The negative impacts of secrecy were also detailed by Annette Baran and Reuben Pannor in their groundbreaking book, *Lethal Secrets: The Psychology of Donor Insemination* (1993). Having interviewed members of families created by donor conception, their view was that secrecy blocks families off from the support they may need to negotiate the dilemmas and burdens that maintaining secrets has created. Given the strong, but misguided, professional advice in the past to maintain the secrets, family members will be reluctant to seek out help from that source. 'The fear of ever telling the truth deprived some families of the opportunity to seek adequate help for their problems' (Baran, 153). Eventually, the secret becomes known, usually at a time when the family system has broken down for other reasons (Baran, 71). Revealing the secret is rarely planned, is usually forced by circumstance and inevitably creates a family crisis.

#### *Commitment to the lifelong interests of the child.*

Assisted Reproductive Technology practice is a transaction between adults, in the course of which the lifelong interests of the child are often overlooked. The interests of the donor, the recipient family and the service provider are usually foregrounded with scant recognition of the need to respect the autonomy and future rights of the person so created. Practices of secrecy deny donor-conceived adults full access to those rights. Rather than being respected as persons capable of making their own decisions and judgments, they are treated paternalistically throughout their life and denied the same rights as other persons to have knowledge of their origins.

Each individual should be entitled to know the truth of his [sic] conception and his genetic heritage. Essentially, donor offspring are a deprived group who are denied access to information available to the rest of the population. (Baran 153-154)

Donor-conceived adults have faced many of the same lifelong issues as adopted persons. Their *narrative sense of self is diminished* because they are missing the first chapters of their life or are presented with a false version. Their *social sense of self is diminished* because they cannot place themselves securely within a known network of biological and social relationships, leading to genealogical bewilderment and anxieties about potential consanguinity. Depending on when and where they were born they may have hundreds of half-siblings. Their *moral self is diminished* because they have been systematically lied to, not trusted with key information, and have been subject, even as an adult, to arrangements that they did not consent to. With some justification, they can feel used, betrayed, hurt, and angry.

The right to access information about one's origin, whether one chooses to exercise it or not, is an important step towards moral repair. I believe that to rebalance the scales of justice in this situation, more recognition should be given to the rights of donor-conceived adults. The imbalances created by systemic practices of secrecy were already weighted in the favour of the adults at the time of conception. While the current interests of all stakeholders must be recognised, those of the donor-conceived must be prioritised.

#### *Provision of adequate support services*

Potentially, providing donor-conceived adults with access to information will lead to some challenges in relationships. Crucially, many of these challenges will arise from the way in which secrecy has distorted family interactions, rather than from the disclosure of information. The provision of affordable, accessible and adequate services is vital when introducing policies that address past social practices and are likely to have significant personal impacts. The provision of such services is a concrete acknowledgement of the

deficiencies of the past and a means of making amends by addressing the lifelong impacts of those past practices. It also provides an opportunity to address the current needs of families as they negotiate the impacts of changing policy.

Applying our experience with adoption to the donor conception domain, information and emotional support should be accessible, affordable and specific to the issue of donor conception. As one size usually does not fit all, there should be *a range of services -- government, professional and peer support*. Providing donor-conceived adults access to information will require the cooperation of existing clinics and service providers, but I also believe that some independence from the professional contexts that previously encouraged secrecy is important to maintain trust as a reliable source of information and emotional support.

*Accessibility* will also require both web-based and telephone-based support services and familiarity with the relevant legislation and policies in each state.

*Affordability* will require some financial commitment from the government and previous service providers to ensure equitable access to information and support.

Lastly, support services must be *adequate*; that is, *informed and knowledgeable about the specific impacts of past practice on donor-conceived adults* and the ability to provide search and intermediary support that sensitively addresses the needs of all concerned parties.

As previously mentioned, the time to act is now. It is time to grant donor-conceived persons the right to access information and to provide them with the informational and emotional support services necessary to manage the impacts.

Trevor L Jordan

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