

Submission to Victorian Parliament's Law Reform Committee Inquiry into Access by Donor-Conceived People to Information About Donors.

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Aspects pertaining to the practice of donor conception within Victoria at present, in the past and in the future will be discussed particularly in relation to the child's ability to access information on their donor (biological father/mother). When analysing the practice and its outcomes the most important factor to consider is the child. Legislation in Victoria refers to the welfare of the child as being paramount. In addressing this aspect the voices of those most affected must be heard and that is the voices of the donor conceived offspring themselves. They are the ones left to live with the consequences of other people's actions and decisions everyday, decisions that were made on their behalf and ones which they were not a party to nor had any control over. These decisions have the potential to adversely affect their psychological and physical well-being. Current and previous models implemented which have in many instances caused pain and trauma to offspring have resulted from the paternalism of the medical big business fertility industry catering to the desires of adults while at times neglecting the needs and welfare of the children they are creating. The consequences of these practices are not only restricted to the current generation of offspring but have the potential to be felt in and passed on to future generations that will be born to donor conceived people. As such there is a duty of care to a far greater proportion of the population than just the figures of donor conceived people would lead one to believe.

Damian Adams is an adult donor offspring who was conceived during the early stages of the practice. He is a published medical research scientist with numerous articles in peer reviewed journals, and has presented at conferences on the subject of the ethical practice of donor conception. As a father himself, he has a unique insight into the ramifications that have and are currently being made on behalf of the Donated Generation.

Introduction

The rights of donor conceived individuals encompass such factors as the right to trace your biological genealogy (Daniels 1995), which involves not only the donor but also their immediate family in addition to any other half-siblings created as a result of other donations. It also involves access to a medical history such that the physical wellbeing of any offspring may hinge on an ability to find out such information about their progenitor (Rowland 1985, Vetri 1988). These rights are enshrined in international conventions and Commonwealth law, yet are systematically deprived of donor offspring.

The United Nations Conventions of the Rights of the Child is the most widely and rapidly ratified convention with 192 countries as signatories including Australia.

It has several articles germane to the issue of donor conceived rights.

Article 2 deals with discrimination and in particular references birth status as not being grounds for discrimination.

Article 3 describes the preservation of a child's best interests irrespective of court, institution or government involvement, such that these bodies cannot adversely affect the welfare of the child.

Article 7 specifies that every child has a right to know and be cared for by their parents. From the UNICEF implementation handbook the original intent for this is described as meaning biological parents.

Article 8 states that every child has a right to a name, identity, family relations and nationality. All of which can be adversely affected through donor conception. It also specifies the responsibility of the state to speedily re-establish these if removed which has not happened anywhere in Australia.

Article 13 deals with the right to information affecting the child so that the child can maintain their autonomy. The information deprived through donor conception seriously diminishes this component.

The Commonwealth Family Law Act (1975), states that a child has the right to know and be cared for by their parents irrespective of the parent's relationship. The wording implies that parentage under this act is biological and of vital importance to the child. While this legislation was enacted prior to reproductive technologies becoming mainstream, altering this fundamental ethos due to medical innovation irreversibly destabilises the family construct by making it malleable to the desires of the clinics and the infertile rather than preserving the best interest of the child. This does not mean that donor conception cannot exist under this legal definition rather that the welfare of the child in particular regard to the knowledge of their progenitors is of fundamental importance.

The right to this knowledge is important for the offspring for numerous reasons which have been supported by research and some of which will be presented here. Donor offspring suffer from issues of identity formation and loss which is associated with the loss of kinship (Weigert and Hastings 1977). Identity formation occurs throughout a lifetime, however a critical window is in adolescence (Erikson 1968). If one of the child's biological links is removed then the process can become clouded as they will lack the mirror that they would see in both progenitors that would normally raise them. When genealogy is unclear then a person may suffer from genetic bewilderment (Sants 1964), whereby a person's place in the world remains unclear to them and this genetic void may cause psychological harm (Cooper and Glazer 2004). Late discovery of their mode of conception which frequently occurs for many varied reasons changes a person's perceptions of identity and family, thereby introducing distrust, confusion, and possibly anger between themselves and those that deceived them (McWhinnie 2000, Turner and Coyle 2000). If these factors are to be considered, then the current practice of only allowing donor offspring access to identifying information once they reach the age of 18 may cause irreparable damage as the vital identity construct window has passed. And as such it would be prudent to recommend that the age at which an offspring is able to access such information should be substantially lowered. This is supported by reports that less damage occurs when a child is told of their conception at an early age (Hewitt 2002, Jadvá et al 2009), and that it is certainly more beneficial to occur before the identity construct window of adolescence occurs (Kirkman 2003). So not only should a child be told of their conception at an early age, but they should have access to the identity of their progenitor from a much early time point than what is currently allowed to ensure that the welfare of the child is appropriately protected.

No matter whether an offspring is aware of their conception or not, they all currently have incomplete medical histories. Those conceived from anonymous donations will have no medical history to go on, while those conceived through identity release donations will most probably have outdated histories as it is not compulsory for donors to update their medical profiles on a regular basis. In any scenario above, the offspring is at a severe disadvantage in the clinical setting which can lead to poor diagnosis, inappropriate treatments and wasted time. A lack of a complete and updated medical history has serious implications for early diagnosis (Hastrup 1985, Centers for Disease Control and Prevention 2004) and it can affect the life-style choices these offspring make. Access to such information is vital to the well being of the person affected right from birth and as such must be available from birth.

The physical and psychological welfare of the donor offspring is further highlighted by the study of Marquardt et al (2010). This study showed that donor offspring suffer from greater levels of depression, delinquency and substance abuse. They also feel more isolated from and confused about their families when compared to children raised by both biological parents. These issues are serious areas of concern when addressing the welfare of the child principle. Additionally it shows the importance of genetic connections for the wellbeing of an individual. It is these genetic relationships that go to our deepest roots of who we are and to whom we bond (Somerville 2007), it is our basic humanity.

The argument of many proponents of secrecy and the right to privacy is untenable on ethical and legal grounds. If we are to balance opposing rights, at all times we must provide protection to the party that is most vulnerable, which in donor conception is clearly the child. The child's rights must take precedence and override those of the adult's as a principle of welfare. Concerns about privacy and other agendas of adults are outweighed by possible negative consequences of withholding such information and it is a clear violation of the offspring's autonomy (McGee et al 2001).

Secrecy is not only constructed through the clinical practice of donor conception but more fundamentally occurs within the home. Several studies (Golombok et al, 1996, 2002, Broderick and Walker 2001, Brewaeys 1997, Rumball 1999 and Lycett 2005) have shown that the majority of parents hide the child's conception from them, preferring to keep the secret. While the current consensus is that the child should be informed and the parents are advised of this it is clear that they are not following through even when the family is initially in favour of telling the truth (Blyth and Ryll 2005). This leaves us with a situation in which the majority of offspring will not be aware that they are donor conceived and therefore are unable to accurately construct their place in the world during identity formation but they also cannot take appropriate steps to prevent a consanguineous event from occurring which is prohibited under Commonwealth legislation (Australian Marriage Act, 1961),.

The ability for recipient parents to conceal the truth is made easier for them due to the fact that they are allowed through the institutionalisation of donor conception practices to create fraudulent birth certificates. Birth certificates are factual documents that record a person's pedigree, their genealogy, nothing more, nothing less. They are not certificates of ownership, a deed or title entitling the parent to special privileges. No-one owns a child, they are not pets to be bought and sold. Legal parentage can and is describe through other legislation such as the Status of Children Act and it should be further enshrined in such legislation such that recipient parents do receive full protection under the law to enable them to parent with the same authority as those that conceive children under normal conditions. Under no circumstances should a factual document be altered in an attempt to assist the recipient parents in their parenting duties or to make them feel better about their relationship to a child. Replacing biological parents with non-biological parents on a birth certificate and allowing it to occur enshrines deception into the law (Rowland 1985). While several models can be put forward that can cater for all parties (multiple certificates, annotated certificates, multiple listings on a certificate not restricted to just father and mother), the purpose of which is not to go through those here, it should be a fundamental principle that birth certificates remain truthful and factual, thereby preventing deception and also aiding in preventing consanguineous relationships as a donor conceived offspring will be able to determine their biological relationship to another person.

The right to know who your biological parents are, is a prima facie right, a right that is denied of those who are donor conceived (Gollancz 2001). A group of other disenfranchisees, adopted people, also suffered from forced kinship separation but have since had this prima facie right recognized and they are allowed to know who their biological parents are (Pannor and Baran 1984, MacIntyre and Donovan 1990). These rights and access to information has been made retrospectively in countries such as England, Scotland, Australia, some states of the United States and some provinces of Canada (Carp, 2007). There are several similarities between adoption and donor conception and the effects it can have on the child and as such the practices of donor conception should implement the same policies that entitles the adopted child to knowledge of their biological parents (Triseliotis 1993, Evan B Donaldson Adoption Institute 2009). By not providing donor conceived people with the same rights as adoptees and in fact every other member of our society we are in effect creating a group of second class citizens. Unlike adoption which is typically a last resort, donor conception is a systematic and institutionalised means of severing genetic ties (Rose 2009). This intentionality can also be a factor that offspring feel is hurtful, creating a sense of abandonment by their donor, and a sense of inconsideration by their parents, clinics and government.

The bizarre twist is that we clearly recognise the tragedy when a conventionally conceived child has somehow had their biological father or mother separated from them through unfortunate circumstances. Paradoxically however, we are unable to recognize the same tragedy when a child has been “half-donated”. Yet at the same time it is the systematic institutionalisation of planned and deliberate kinship separation that perhaps makes the fragmentation occurring within donor conception even more of a tragedy.

Currently legislation in Victoria as applied to donor conception is dependent on when a child was conceived, creating a patchwork of practices and rights afforded to each member of the donor conception triad (parents, donors and offspring). The rights of offspring differs markedly across these time spans such that children conceived after 1995 in Victoria have access to identifying information on their donor while their predecessors do not enjoy the same right. This thereby creates inequality and an unethical treatment towards offspring on a matter that was clearly identified as being important in the adoption community nearly 20 years previously.

The denial to a child of knowledge of their mode of conception in addition to the knowledge of the donor progenitor and associated kinship is harmful psychologically and physically. This knowledge is a right enshrined in international conventions and federal legislation. Currently access to this right is either non-existent or poorly administered through institutionalisation and current family constructs. Donor conceived offspring are being discriminated against due to their mode of conception and in some instances due to their age. Australia and Victoria has created a generation of second class citizens with inferior rights to the rest of society. Donor conception practices, legislation and regulation must be changed to cater for the welfare of past and future offspring giving them equal rights to every other Australian such that they are not only acknowledged through law that they are entitled to identifying information on their biological family but that this entitlement is put into practice and is enacted retrospectively.

Terms of Reference

Referred by the Legislative Council on 23 June 2010.

To inquire into, consider, and provide an interim report by September 2010 and a final report by 2011 on --

1. the legal, practical and other issues that would arise if all donor-conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made;

Over-riding any legal or practical concerns, the heart of the matter is that it is an ethical issue. Firstly that donor offspring have a right to knowledge about their donors and biological family including half-siblings. As stated previously this knowledge is enshrined in international and national responsibilities as well as being encapsulated in the NH&MRC guidelines (2004). By not affording donor offspring this right in a practical and accessible manner we create inequality and discrimination which is also ethically unacceptable. Precedent has been set with the adopted community being afforded this right retrospectively even when the relinquishing parents still wished for anonymity. Privacy concerns are also overridden in our court systems all the time when it is deemed that the welfare of the child may be adversely affected as a result of maintaining privacy. Such agreements made about privacy in regard to the donor, a clinic and recipient parents involve another person (the conceived) who was not a party to the decision. It is inappropriate to make such a decision on behalf of this other person when it potentially can be damaging to their welfare.

One of the single biggest arguments against release of such information is that the donor may then be liable financially to the child. While this is easily remedied under legislation, this concern is not borne out through fact but rather is a phallacy. It has not been recorded that this is a matter that offspring seek when looking for their donors, instead they are only looking for familial links, their kinship, genealogy, a heritage, their identity and a health history.

In conclusion of these factors, any stance in regard to maintaining privacy is on shaky ground and does not stand up to scrutiny. Legislation allowing ALL offspring access to identifying information on their donors and half-siblings must be implemented and done so retrospectively.

2. the relevance of a donor's consent or otherwise to the release of identifying information and the National Health and Medical Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research;

Please see argument 1 above. Additionally while in theory it would be nice if every donor gave their consent to the release of information, it does create stratification whereby we create the “haves” and the “have nots”. By seeking consent which is then rejected can cause even greater trauma for the offspring. Potentially an offspring may view this as a second rejection, the first being the act of donation and the second when the request for information was denied. Psychologically this can be very damaging. In the interests of the child as being paramount I do not believe that consent should be sought but rather that the information was provided irrespective of any wishes of the donor and as preceded by the adoption model.

3. any practical difficulties in releasing information about donors who provided their gametes before 1 July 1988, because in many cases records are not available either because the procedure was carried out privately or records were not stored centrally;

In instances whereby records are unavailable for whatever reason, sufficient advertising must be conducted to encourage previous donors to come forward to provide their information in the best interest of the child. This advertising must also be structured such that recipient parents are also strongly encouraged to tell their children that they are donor conceived so that their family unit is not based on lies and deception which is never a good foundation to build a family on.

A DNA database should also be implemented to assist in matching those people who do not have appropriate records. The CODIS markers can be used for matching the donor to offspring as well as offspring to half-siblings.

5. the impact that any such changes may have on the donor, the donor-conceived person and future donor programs;

Evidence suggests that the release of information and even meeting of biological family (donors and half-siblings) is a positive event for all parties involved (Scheib and Ruby 2008, Freeman et al 2009, Jadvá et al 2010). There is evidence to also suggest that all parties involved in donor conception transition to a position of more openness over time (Crawshaw et al 2007, Daniels et al 2005, Daniels et al 2009). This coupled with the fact that this knowledge acquisition by offspring may help ameliorate some of the trauma associated with being donor conceived, makes changes allowing retrospective access to information to be seen as a positive step forward. This is mirrored in the adoption community whereby people were initially hesitant about retrospective access but now it is widely acknowledged as being beneficial.

6. the impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the registrar of births, deaths and marriages; and

The registers should be maintained by an authority that has experience in this field rather than an authority with no practical knowledge about the intricacies of donor conception or the running of such a register.

References

Blyth E, Ryll I (2005). Why Wouldn't You Tell? Telling donor-conceived children about their conception. *Health Ethics Today* 15(1):4.

Brewaeyns A, Golombok S, Naaktgeboren N, de Bruyn JK, van Hall EV. Donor insemination: Dutch parents' opinions about confidentiality and donor anonymity and the emotional adjustment of their children. *Hum Reprod* 1997 12:1591–1597.

Broderick P, Walker I. Donor gametes and embryos: who wants to know what about whom, and why? *Politics Life Sci.* 2001 Mar;20(1):29-42.

Carp, E.W. (2007). Does opening adoption records have an adverse social impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2007. *Adoption Quarterly*, 10 (3-4), 29.

Centers for Disease Control and Prevention (CDC). Awareness of family health history as a risk factor for disease--United States, 2004. *MMWR Morb Mortal Wkly Rep.* 2004 Nov 12;53(44):1044-7.

Commonwealth of Australia. Federal Marriage Act 1961 s 23B.

Commonwealth of Australia. Federal Family Law Act 1975 s 60B.

Cooper SL and Glazer ES. (1994). *Beyond Infertility: The New Paths to Parenthood.* (p. 351). Lanham, Maryland: Lexington Books.

Crawshaw MA, Blyth ED, Daniels KD. Past semen donors' views about the use of a voluntary contact register. *Reprod Biomed Online.* 2007 Apr;14(4):411-7.

Daniels KR. Information sharing in donor insemination: a conflict of rights and needs. *Camb Q Healthc Ethics.* 1995 Spring;4(2):217-24.

Daniels K, Blyth E, Crawshaw M, Curson R. Short communication: previous semen donors and their views regarding the sharing of information with offspring. *Hum Reprod.* 2005 Jun;20(6):1670-5. Epub 2005 Mar 10.

Daniels K, Gillett W, Grace V. Parental information sharing with donor insemination conceived offspring: a follow-up study. *Hum Reprod.* 2009 May;24(5):1099-105. Epub 2009 Jan 21.

Erikson, E. (1968). *Identity: Youth in Crisis* (p. 94). New York: W.W. Norton.

Evan B Donaldson Adoption Institute (2009). *Old Lessons for a New World: Applying Adoption Research and Experience to Assisted Reproductive Technologies*.

Retrieved September 6, 2009 from:

http://www.adoptioninstitute.org/policy/2009_02_oldlessons.php

Freeman T, Jadvá V, Kramer W, Golombok S. Gamete donation: parents' experiences of searching for their child's donor siblings and donor. *Hum Reprod*. 2009 Mar;24(3):505-16.

Gollancz D. Donor insemination: a question of rights. *Hum Fertil (Camb)*. 2001 4(3):164-7.

Golombok S, Brewaeys A, Cook R, Giavazzi MT, Guerra D, Mantovani A, van Hall E, Crosignani PG, Dexeus A. Children: the European study of assisted reproduction families: family functioning and child development. *Hum Reprod* 1996 11:2324–2331.

Golombok S, MacCallum F, Goodman E, Rutter M. Families with children conceived by donor insemination: a follow-up at age twelve. *Child Dev* 2002 73:952–968.

Greenberg M. Post adoption reunion – are we entering uncharted territory? *Adoption & Fostering*, 1993 17:5-17.

Hastrup JL. Inaccuracy of family health information: implications for prevention. *Health Psychol*. 1985 4(4):389-97.

Hewitt, G. Missing links: Identity issues of donor-conceived people. *J Fert Counsel* 2002 9(3), 14-20.

Jadvá V, Freeman T, Kramer W, Golombok S. The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type. *Hum Reprod*. 2009 Aug;24(8):1909-19. Epub 2009 Apr 27.

Jadvá V, Freeman T, Kramer W, Golombok S. Experiences of offspring searching for and contacting their donor siblings and donor. *Reprod Biomed Online*. 2010 Apr;20(4):523-532. Epub 2010 Jan 11.

Kirkman M. Parents' contributions to the narrative identity of offspring of donor-assisted conception. *Soc Sci Med*. 2003 Dec;57(11):2229-42.

Lycett E, Daniels K, Curson R, Golombok S. School-aged children of donor insemination: a study of parents' disclosure patterns. *Hum Reprod* 2005 20:810–819.

MacIntyre JC, Donovan DM. Resolved: children should be told of their adoption before they ask. *J Am Acad Child Adolesc Psychiatry*. 1990 Sep;29(5):828-33.

Marquardt E, Glenn ND, Clark K. (2010). *My daddy's name is donor: a new study of young adults conceived through sperm donation*. New York, Institute for American Values.

McGee G, Brakman SV, Gurmankin AD. Gamete donation and anonymity: disclosure to children conceived with donor gametes should not be optional. *Hum Reprod*. 2001 Oct;16(10):2033-6.

McWhinnie A. Families from assisted conception: ethical and psychological issues. *Hum Fertil (Camb)*. 2000 3(1):13-19.

National Health and Medical Research Council (2004). *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research*. Australian Government. Retrieved May 10, 2010 from:
http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/e78.pdf

Pannor R, Baran A. Open adoption as standard practice. *Child Welfare*. 1984 May-Jun;63(3):245-50.

Rose J. *A Critical Analysis of Sperm Donation Practices: The personal and social effects of disrupting the unity of biological and social relatedness for the offspring*. 2009. Doctor of Philosophy, Queensland University of Technology, Brisbane.

Rowland R. The social and psychological consequences of secrecy in artificial insemination by donor (AID) programmes. *Soc Sci Med*. 1985 21(4):391-6.

Rumball A, Adair V. Telling the story: parents' scripts for donor offspring. *Hum Reprod*. 1999 May;14(5):1392-9.

Sants HJ. Genealogical bewilderment in children with substitute parents. *Br J Med Psychol*. 1964 37:133-41.

Scheib JE, Ruby A. Contact among families who share the same sperm donor. *Fertil Steril*. 2008 Jul;90(1):33-43. Epub 2007 Nov 26.

Somerville, M. Dispossessed and forgotten: the new class of genetic orphans. September 19, 2007. Retrieved April 25, 2010 from:
http://www.mercatornet.com/articles/view/dispossessed_and_forgotten_the_new_class_of_genetic_orphans/

Triseliotis J. Donor insemination and the child. *Politics Life Sci*. 1993 Aug;12(2):195-7.

Turner AJ, Coyle A. What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum Reprod.* 2000 Sep;15(9):2041-51.

UNICEF. (2006). Who has not ratified the Convention on the Rights of the Child and why? Retrived May 13, 2010 from: http://www.unicef.org/crc/index_30229.html

United Nations (1989). *Convention on the Rights of the Child*. United Nations.

Vetri, D (1988) Reproductive technologies and United States law. *Int Comp Law Q.*, 37: 505-534.

Weigert AJ, Hastings R. Identity loss, family, and social change. *AJS.* 1977 May;82(6):1171-85.