

A.R.T Act Review

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What is your association to assisted reproductive treatment?



Donor Conceived Person. (Conceived 1993, Reproductive Medicine Clinic at Monash Medical Center via Dr Kovacs)

Two full siblings (Conceived 1991 and 1997) from same sperm and same mother.

Do you make this submission in your individual or professional capacity?

Individual

Please comment upon the requirement within the Act that the welfare of any child born as a consequence of assisted reproductive treatment (A.R.T.) is treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of assisted reproductive treatment.



The following 3 points outlines laws and experiences which apply to me and my siblings, conceived from sperm donation as early as as from 1991, and perhaps up to 1997. My birth and upbringing was in the country town Mt Gambier, despite being conceived in Melbourne, Victoria. My mother and legal father divorced when I was 12. I moved to Adelaide to live independently and terminated contact with my legal father at 19 years age.

1. Non mandated disclosure of genetic origins to DC people

The lack of mandated notification to DC people is a direct breach of the welfare of child principle.

No laws in place require the children to know about their true biological heritage, giving the power over to the parents. Male infertility/sterility is linked to lower self esteem¹ and is likely a contributing factor to the large percentage of fathers not telling their children about their genetic origins. Often for ultimately self interested reasons, and at the expense of vital knowledge for the child.

In my case, an extremely insecure and controlling legal father projected his insecurities onto myself and my two siblings. With proper parental counselling, this may have not been the case. Had it not been for my mother insisting on telling us in private when we were as young as we were able to understand the concept, I would not know this fundamental piece of my identity. The rare occasion that this topic was raised with my legal father, it was met with verbal hostility. This led to absolutely zero amounts of intelligible discussion on the topic with the legal father throughout the 18 years I had contact with him. Chronic guilt, identity and self esteem issues throughout childhood were a direct manifestation of this.

Obtaining information about ones anonymous conception is extremely difficult, and in some cases impossible to access, due to the non mandated disclosure of genetic origins to DC children. One such example would be where a child is unable to access their parents legal records due to unreachable location, destruction of evidence, or being unsafe to access due to social environment. Likely leading to the child never knowing of their biological heritage, as evidence of this does not exist on more accessible documents such as a birth certificate.

2. Medical history

The well being of the DC child is not considered through the lack of access to medical history.

I believe that the story surrounding Narelle Grech serves to illustrate why disclosure of medical of information is of paramount importance and feel that all has been said on this topic - I will however share my personal experience.

The following anecdotes express how lack of medical history made diagnosis and treatment of various physical and mental health issues far more difficult. With the information, they may have been avoidable and preventable.

My mother was constantly frustrated by lack of ability to access medical records of her childrens' biological father, meaning potentially foreseeable and avoidable problems would instead run their course. This has frequently, and may continue to, put our well being and lives into question.

My younger brother and myself had complications both at birth and within the first few months of life, causing an inability to get adequate amounts of food necessary for health, there was a high risk of death. We would lead our formative primary school years with a diagnosis of aspergers syndrome and subsequent intervention with Autism SA. The existential, emotional and identity issues one experiences as a DC child, combined with the emotional hypersensitivity of people with aspergers, was likely increased by lack of DC psychological intervention and lack of understanding of unique DC children emotional experiences by the general public and professional settings. I would eventually be diagnosed with major depression disorder in my late teenage years and continue to fight it. My sister (23), would fight through glandular fever, several years of debilitating chronic fatigue, major depression disorder and various body image issues which were linked to her struggles with bulimia and anorexia. During her university studies, my mother has, on more than one occasion, cancel work and book a plane to fly 1200km from Mt Gambier to Sydney within several hours of receiving a call from her indicating a suicide attempt.

It has taken a significant amount of resources to work around such issues over the past 2 decades. The cost of a last minute return plane trip to Sydney alone would have covered several much needed psychological intervention sessions 20 years prior, when it was originally needed.

Further, if we had the other 50% of our medical history, some of this may have been foreseeable and avoided, as troubleshooting medication and diagnosis would have more genetic history to ground it. We were informed that each of the donors was put through a 'health screening' before donating sperm, unfortunately the lies this industry gives makes this impossible to know for certain as there is zero paperwork to back it up.

3. *Socio-emotional wellbeing*

The lack of consideration and subsequent intervention for the unique emotional experiences faced by DC children directly undermines their well being.

Being emotional and sociological in nature, this is a complicated, multi-layered and speculative issue. My fundamental point is that DC children express a unique set of emotional complexities in comparison to what is typically experienced by children, and that there is not adequate support from DC services in helping understand and navigate through these mental maps. Leading to confusion, alienation and lower self esteem of the DC children.

I would express frequently to my mother from the age of 5 this feeling that “Something is missing” and that “I don't belong”, often in relation to my legal father. This was left unchecked and would be a significant component of my diagnosis of major depression disorder in my teenage years. I believe a large part of this recurring depression to stem from a lack of personal identity with an entire line of genetics. To this day, I am in constant preparation to be stolen into overwhelming month long phases of apathy and suicide ideation. Longing for a state of belonging that may well never exist.

There are countless ways of perceiving the world that one is unaware of if discussion does not take place with other people who going through similar experiences. It wasn't until talking with another DC person (The first other I would ever meet who knew he was DC) at the age of 21 that I discovered the similarities of our emotional experiences, and between adopted and DC children. This small insight relieved one of the many cognitively demanding questions I have asked my entire life on why I feel the way I do. If I had of known this in the beginning, it would have alleviated much of the suffering associated in trying to understand myself. I am sure this process will continue as I meet other DC children, other people who were never told may not have been so fortunate.

My experience is that there is not enough psychological support to assist DC children and families. 3 psychologists and a psychiatrist did not once explore the fact that I did not know my genetic father during sessions, despite me explaining it to them on the onset every time.

This may support the thought that even trained professionals will not intuitively pick up on the subtle but overarching unique emotional experiences faced by DC children – potentially indicating that there is inadequate information in literature and training for mental health staff to work with such issues. This affects direct family as well. My mother, as the main caregiver for most of our childhood, would go on to feel perpetual guilt for the various emotional troubles we faced through the decades, going as far as to completely blame herself.

Ethics and its implications on a DC individual apart of society

One final point that I am sure many have always felt, but may not be able to articulate; the paradoxical notion of being bought into the world under bio-ethical circumstances that one fundamentally disagrees with. Every time I make an argument against Assisted Reproductive Technology, I am essentially attacking the integrity of my own conditions of existence and so I must be willing to submit my own life - in all of its laughter, sorrows and adventure - in the name of an ethical ideal.

I plead that we can collect the suffering experienced by the thousands of individuals at heed of this social experiment, extract it into knowledge which we can learn from, and move on.

Please comment on the effectiveness and operation of the legislation regarding access to assisted reproductive treatment in South Australia. In particular, the conditions set out in the Act and in the regulations that relate to the circumstances in which, and to whom, A.R.T. may be provided.

Potential risk of passing on infertility:

Meta-analysis shows a statistical significantly higher chance of birth defects on children born with IVF⁷. Using IVF to assist in reproducing using genes which the phenotype is not able to pass on through physical means likely leads to a higher probability of the offspring having infertility. As sterility is linked to damaged DNA², it would be predicted that there is a host of yet to be seen health risks associated with passing on damaged genes. Are we knowingly allowing birth defected children for the sake of allowing parents, unaware of the literature, to use such technologies in the name of a extremely profitable business model?

If A.R.T is being used to pass on genes in due to impotence/erectile dysfunction or other related physical barriers, the emotional well being of the child is put into question as they are potentially being passed on these genes, which has shown to be linked to a number of negative physical and emotional health markers³. This is all speculative as there is not enough literature on the topic of psychological outcomes of infertility⁶. I personally consider one should have the ability to be sexually expressive, and have their own children without the use of medical business intervention – because of the risks to having a fully functioning sexual system, I am very sceptical of people knowingly passing on infertility/impotence related genetics as it relates to the well being of the child.

Removal of mandatory counselling

It would appear that, due to the large amount of DC children not told about their conception, children are not being told information about their heritage. Sometimes the parents do this out of good intentions, however they are unlikely to have experienced DC related identity issues themselves and so should not be given the responsibility to make this decision. Some sort of counselling or information related intervention is vital to ensure that parents know the likely effects of holding back information. Or, ideally, parents don't have a choice in disclosure.

Removal of preventing people with child sexual abuse records to use infertility treatment

Considering the intergenerational links between child abusers, it is established that child sex offenders come as a result of both genetics and environment⁹. I strongly question the ethics of using such treatments to pass on the genetics of a child abuse criminal and then have them raised in an environment with the offender raising the child.

This of course, may be alleviated with appropriate intervention programs for previous offender parents in tandem with psychological intervention¹⁰. However this is not what I have seen in the proposed 2010 legislation changes and considering the lack of psychological intervention for A.R.T children in other realms, I am not confident that this is being applied in this situation. Again, at the risk of child well being, and potentially the wider community if left unchecked.

5. Please comment on the effectiveness and operation of the Act in relation to it providing for the establishment of a donor conception register.

I find it quite amazing that considering the almost half century long history of DC, that there is no South Australian register as of yet. At minimum, children should have access to:

Donor name

Donor medical history

Sibling medical information available to other siblings

Child medical information available to donor

Sibling personal information available to other siblings*

Child personal information available to donor*

[*A voluntary option with the option of opt out from the children]

DC children should have access to the register, parents of DC children may do so up until an time where the DC child claims independence and ownership of the information, in which the parents are no longer allowed access to the information.

DC children should have a means of being informed at 18 of their genetic heritage, lest they haven't been told. Also of the existence of a register, as it is likely that they might not know about it if they weren't even told of their genetic heritage.

Please comment on the effectiveness and operation of provisions within the Act for record keeping and confidentiality.

The records have been very successful at maintaining their confidentiality, as the only evidence I have of my genetic heratige is a letter from the Reproductive Medicine Clinic informing of my conception in the 4th cycle. About two sentences long.

Unfortunately this may be less to do with effective confidentiality and more so a collection of conflicting information, in which, depending on who was asked, one would be given information of the records being either not available, accessible, lost or even destroyed. There does not appear to be enough procedures to ensure uniformity in the record keeping and confidentiality for DC records.

Despite being anonymous, there should at least be a minimum amount of information available to DC children (Place of conception, basic visual information about donor, any information related to the medical procedure of the child). This would have been made to the children whilst still maintaining donor anonymity.

References

- [1] Kedem, Peri, et al. "Psychological aspects of male infertility." *British Journal of Medical Psychology* 63.1 (1990): 73-80.
- [2] Ji, Guixiang, et al. "Common variants in mismatch repair genes associated with increased risk of sperm DNA damage and male infertility." *BMC medicine* 10.1 (2012): 1.
- [3] Feldman, Henry A., et al. "Impotence and its medical and psychosocial correlates: results of the Massachusetts Male Aging Study." *The Journal of urology* 151.1 (1994): 54-61.
- [4] Patterson, Charlotte J. "Children of lesbian and gay parents." *Current directions in psychological science* 15.5 (2006): 241-244.
- [5] Rivers, Ian, V. Paul Poteat, and Nathalie Noret. "Victimization, social support, and psychosocial functioning among children of same-sex and opposite-sex couples in the United Kingdom." *Developmental psychology* 44.1 (2008): 127.
- [6] Greil, Arthur L. "Infertility and psychological distress: a critical review of the literature." *Social science & medicine* 45.11 (1997): 1679-1704.
- [7] Hansen, Michèle, et al. "Assisted reproductive technologies and the risk of birth defects—a systematic review." *Human Reproduction* 20.2 (2005): 328-338.
- [8] Beitchman, Joseph H., et al. "A review of the long-term effects of child sexual abuse." *Child abuse & neglect* 16.1 (1992): 101-118.
- [9] Wolfe, David A. "Child-abusive parents: An empirical review and analysis." *Psychological Bulletin* 97.3 (1985): 462.
- [10] Lundahl, Brad W., Janelle Nimer, and Bruce Parsons. "Preventing child abuse: A meta-analysis of parent training programs." *Research on Social Work Practice* 16.3 (2006): 251-262.