Submission
No 1

INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

Name: Mr Damian Adams

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Inclusion of donor details on the register of births

Prepared by Damian Adams
B.Biotech (Hons)

Introduction

When analysing the practice of donor conception and its outcomes the most important factor to consider is the child. Legislation and regulation in New South Wales is a relatively recent occurance. NH&MRC regulations refer to the welfare of the child as being of significant importance. 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. The current 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.

Executive Summary

It is recommended that:

Birth certificates must be a truthful and accurate record of genealogy as they were designed to be, rather than the fraudulent documents that are currently being created.

In recognising this all progenitors (biological parents) must be included on the birth certificate.

Whether or not additional social or non-biological parents are to be placed on the certificate and register is a decision for the legislature. Whichever model is chosen, it must not conceal the truth.

The Importance of Records

If we look at previous record keeping practices, the standard that was set has been appalling. That record keeping and making in the early seventies in the hospitals were excellent. Everything that could be recorded was recorded and the records were kept. This is clinical best practice that allows for medicine to be practiced with the greatest care on the day and also in the future as we are able to track down causation and effect events to improve subsequent treatment. An example of this is the post-natal treatment records for most children and mothers of the day which are large enough to fill their own small book. In regard to donor conception records, the only documents that are in existence from the seventies if they haven't already been destroyed are generally contained on a few pieces of paper with a paucity of information and the volume of which wouldn't even be enough to fill up your back pocket. This is true in the case of myself, and other donor offspring that I have spoken to.

The question must be asked "Why would the clinic go strictly against best clinical practices in not creating and keeping appropriate detailed records, and or destroying them?" It goes directly against everything doctors and nurses are taught from day one of their training. While these clinics were operating in a hospital environment and in a clinical setting, the early seventies represent donor conception in its infancy and we could perhaps assume that they were operating more as a research facility undertaking experiments in medical and social science. As a scientist myself, I know for a fact that any research that is conducted now and in the past must be appropriately documented so that experiments can be verified and repeated as required. So what we have is a scenario in which the documentation that was being made within donor conception falling outside the accepted norm within either the medical or scientific fields. For something that was so important and supposedly ground breaking it is mind boggling to think that inappropriate documentation occurred. If the manner in which these records were taken and kept was not a deliberate act to maintain that anonymity was ensured, as was the order of the day, then the record keeping was surely incompetent and must not be allowed to happen again.

One specific reason for the NSW Registrar of Births, Deaths and Marriages to hold donor information is to ensure the safety of such records. A single location for a record does not provide backup measures in case of flood, fire or intentional destruction. The latter is a matter which historically has occurred throughout Australia. And while there may now be restrictions on the destruction of records, it does not prevent accidental destruction.

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 cannot take appropriate steps to be proactive in their health care (inherited disorders – family health history).

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 Family Relationships acts (South Australia) 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, 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.

Additionally there are other factors to consider in regard to consanguinity when a person is unaware of their full kinship. Many of these children are born within defined geographical boundaries and relatively short time-spans. As approximately 41% of our behaviours are inherited (Malouff et al 2008), it is highly feasible that these children may have similar interests and therefore move in similar circles. Compounding this further is the phenomenon known as Genetic Sexual Attraction (Gonyo 1987, Greenberg 1993), which can occur when kin who have been separated shortly after birth have met later in life and become sexually attracted to each other through similar looks and attributes. This effect has been known to occur within the adopted community. Normally GSA is prevented from occurring within our society due to the Westermarck effect (Westermarck 1921), which occurs during cohabitation during early childhood. This kin recognition effect is something which is non-conscious and is not based on beliefs but rather whether people have cohabitated (Leiberman et al 2003). These things are removed when donor conception occurs and therefore it makes it increasingly difficult for donor offspring to prevent consanguinity from occurring unwittingly.

I personally despise my birth certificate as it is an erroneous document. I love my parents very much and what they did in raising me, but it does not change biological fact. My birth certificate does not accurately describe who I am, as components of our identity are a result of our heritage.

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 persons 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, which can be assisted through truthful birth certificates. This early disclosure is supported by reports that less damage occurs when a child is told of their conception at an early age (Hewitt 2002, Jadva 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. Changing the paradigm of allowing the recipient parents to decide if they will choose to disclose the child's conception to one that is more of a matter of when it will be disclosed, as the birth certificate will detail that information, will help to ensure that all parties are aware of the need for this health history. Secrecy and deception in the family will only hide these histories.

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).

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 Donavan 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. Creating a system of honouring the truth and providing the ability for offspring to discover this information is vital in easing this conflict.

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.

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 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.

Summary

By creating a factual document that the child will have legal access to, it will be impossible for the recipient parents to actively deceive the child. The family foundation should never be based on lies and deception, but rather truth. Having donor identifying information kept in this manner provides a central location where all offspring can go to discover their kinship and therefore their heritage, which is vital for their psychological wellbeing and identity formation. It safeguards against record destruction and loss, and also provides another avenue to prevent consanguineous relationships. It is vital that the Registrar of Births, Deaths and Marriages implements the appropriate systems, procedures and certification to foster the welfare of the child principle.

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