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Donor Conception Practices: Past and Present

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Aspects pertaining to the practice of donor conception within Australia at present, in the past and in the future will be discussed while particularly addressing the terms of reference. When analysing the practice and its outcomes the most important factor to consider is the child. Legislation and regulation around Australia, while inconsistent and disjointed, often refers to the welfare of the child as being either paramount or 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.

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Executive Summary

It is recommended that:
1) Legislation and regulation must be uniform nationally to prevent disproportionate rights and discrimination from occurring across the country.

2) Payments of all forms to donors including reimbursement for time and expenses must cease at once. Payments transform gametes and embryos into commodities, thereby making the term donor an oxymoron.

3) All records (past, current and future) must be compulsorily acquired, preserved and centralised.

4) Accurate reporting from clinics to a central authority and finally to federal parliament must occur for transparency and auditing purposes.

5) A national register be implemented for collation of records and to allow people whose records have been destroyed the ability to connect to their biological family.

6) 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.

7) The number of offspring produced by donations be significantly reduced and capped. The numbers of families able to use the one donor must be reduced to help prevent consanguinity.

8) Access to identifying information on all biological parents must be a recognised right in law such that access to this information is made retrospective to all offspring, bringing this right in line with current adoption practices.

9) Offspring have a right to access identifying information on their half-siblings on kinship and consanguinity grounds.

10) Offspring have a right to an updated medical history on their donor(s) to ensure their own physical and psychological wellbeing. Access to such information must be automatic from birth.

11) Access to identifying information on the donor and half-sibling must occur before the age of 18 to reduce identity issues.

12) Counseling must be improved, that it becomes an on-going process and that it be independent from the clinics to abrogate vested interests.

13) Current practices must be altered to reflect an actual manifestation of the welfare of the child being the paramount concern. In essence any model that is to be implemented must be child centric rather than the adult centric one currently employed.

The past and present practices of donor conception in Australia, with particular reference to:

(a) donor conception regulation and legislation across federal and state jurisdictions;

Currently legislation varies across the states creating a patchwork of practices and rights afforded to each member of the donor conception triad (parents, donors and offspring). The ability to access treatment in each state has seen an increase in the incidence of fertility tourism whereby people will travel interstate to receive treatment that they were not entitled to in their own state. The rights of offspring differs markedly across state borders such that children conceived after 1995 in Victoria have access to identifying information on their donor while their contemporaries in the other Australian states 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.

Legislation and regulation must be federally institutionalised to ensure uniformity in the provision and control of the practice such that fairness and equality are applied to every Australian, not just those lucky to either live or be conceived in specific states. Administration of the legislation and regulation in regard to the licensing of clinics/providers and ensuring that the licensing conditions are met should be conducted by an appropriately independent body that reports back to parliament.

(b) the conduct of clinics and medical services, including:

(i) payments for donors,

Firstly, as donors are currently paid reimbursement for their time and expenses such that there is a financial transaction occurring between said donor and a clinic or institution, then the term donor is a misnomer. In simple terms they are currently being paid and a better term would be “vendor”. Donations of other bodily parts such as blood, marrow, kidneys and partial livers is strictly prohibited to prevent the commodification of the human body and thereby also preventing the ability to take advantage of those that may be less well off.

Payments devalue the gift of donation on a theoretical level as it is no longer donation. It is not quintessentially altruism either as something has been received in return.
As someone who has been through university and seen the advertisements calling for donors and knowing for a fact that others (through personal communication) had described it simply as a means of obtaining beer money for the weekend, gametes have become a commodity. Gametes that will become their biological children are quickly forgotten through a drunken haze. Knowing that I was essentially sold by my biological father as I do know that donors were paid at the time of my conception, makes me physically ill.

I am vehemently opposed to any payment to donors (even expenses) such that the implementation of these incentives should be stopped. Whenever we donate blood we are not paid to cover our time and expenses, it is done through pure altruism and the same dogma should apply in this instance. The recruitment of donors which previously focused on young university students who needed some extra money, must be refocused on a different demographic, one which acknowledges the link that they have with the child that is created, as well as the significance that child may place on them. We are already seeing a trend to older donors that have already started their own families.

Those arguing for an increase in payment as a means for increasing the number of donors have no concept of the effect donation can have on an offspring, nor an understanding of what is required of current donors (must be willing to be known) and therefore which demographic of the population donors are recruited from (the so called altruistic donor). Placing a price on gametes and what is essentially the creation of life is dangerous ground to cover. The closest analogy to this and the only time money has changed hands in regard to human life in the history of the world is slavery. We do not want to be creating a system whereby children are created as slaves to a laissez faire marketplace.

(ii) management of data relating to donor conception, and

A central register must be set-up, maintained and run by a central authority. It should not be run as multiple registers by clinics or states.
These registers must contain:

a) numbers and types of all treatments administered,
b) financial statements of all payments and fundings received to cover treatments as funded by tax payers,
c) donor records must include number of donations, payments made to the donor, identifying and non-identifying information, a photograph of the donor, and an updated medical history which must be updated periodically,
d) records of the numbers of children born as a result of treatment,
e) identity of all children born through donor conception,
f) establishment of a DNA register to allow those with no records or records that have been destroyed the ability to connect with their biological family.

All existing records must be compulsorily acquired for entry into the central register such that donor offspring previously conceived have access to identifying information on the donor, an updated health history and the identity of any half-siblings born as a result of other donations. All existing records must not be destroyed but kept indefinitely. For those triad members whose records have been destroyed they should be allowed to voluntarily submit their information to the register. These registers and the provisions allowed for previously involved people to submit information must be significantly advertised, encouraging parents to disclose to their children and for donors to come forward.

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.

(iii) provision of appropriate counseling and support services;

Appropriate counseling should be provided for all parties in the donor conception triad, recipient parents, donors and offspring. While there is counseling provided for recipients in the lead up to treatment, clinics and counselors do not follow up after the birth of the child and there is no follow up years down the track to see how these families and children are coping. The same can be said for donors, once they have been screened and cleared for donation that is all the counseling that they will receive. The level of counseling does not cater for developing and changing emotions and situations in the lives of these people, which can be difficult for them at a later stage. At no time are offspring ever monitored or asked how they are dealing with the situation and whether or not the parents have followed through with disclosure to the child or if they have maintained the secret.

Of particular concern is that counselors are supplied and paid for by the clinics. Their duty of care to ensure that people receiving treatment or those donating are suitable has the potential to be tainted due to the vested interest by the counselor in allowing enough people through the door to ensure the required cash flow for the clinics which are run as businesses and not purely as health care providers.

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

Consanguineous relationships which are prohibited under Commonwealth legislation (Australian Marriage Act, 1961), are also looked upon with disdain by our society. The ability of a donor conceived person to ascertain the biological relatedness of any partner that they may have can be extremely difficult for numerous reasons. Not only must the offspring know accurately their conception status but also the potential partner must also know their conception status in addition to whether or not one or both of their biological parents were a gamete or embryo donor.

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 prevent a consanguineous event from occurring.

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 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.

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.

Currently the limits on the number of offspring allowed for each donor is left to the discretion of Australian clinics who are instructed to take into account the possibility of consanguinity (NHMRC 2004). Previously it was a laissez faire situation and the number of offspring was not capped resulting in some offspring having 50 or more half-siblings. While the UK has limited their donations to 10 families for the one donor (HFEA 2009), as have some Australian states, if we are to consider that most families will have 2 or 3 offspring we can easily see that each offspring potentially has 20-30 half-siblings not including any children the donor has from within their own relationships. Without proper dialogue and central registers, a clinic will be unaware if a donor has donated at other clinics within a given state or in other states as has occurred and therefore such limits may not be strictly adhered to increasing the number of half-siblings an offspring may have.

Personally I am deeply traumatised that there could even be one half-sibling that I have never known and will never get to know, let alone the fact that there could easily be dozens. While never being able to know your own family is emotional enough, the fact that there may be numerous half-siblings is deeply disturbing on a level akin to being manufactured to appease the masses. We are human beings with biological and social families yet the ability to produce so many siblings is actually dehumanizing. Therefore it is suggested that the limit to donations should be capped to 3 families and or a total of 6 offspring not only to help prevent the potential of a consanguineous event but to also reduce the psychological burden on offspring of having so many siblings out there that they will never know.

(d) the rights of donor conceived individuals.

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. This 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.

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.

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.

Concluding Remarks

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.

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