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### Original Citation

Blyth, Eric (2005) Follow-up of gamete donation families. In: Serono Ovum Donation Symposium , 30th September 2005, Vantaa, Finland. (Unpublished)

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## **Follow-up of gamete donation families**

Ovum Donation Symposium

Tamro House Auditorium Vantaa

30 September 2005

**Eric Blyth**

### **Introduction**

It is estimated that over one million children have been conceived worldwide through various forms of assisted reproductive technology, although this is a 'ballpark' figure because few countries maintain accurate statistics. In most industrialized countries children conceived through assisted reproductive technology represent about 1% of all births, although in Nordic countries the figure is higher – 3.9% of all births in Denmark, 3.2% of all births in Sweden, 2.8% of all births in Iceland and 2.4% of all births in Finland<sup>1</sup>. Quite how many of these children will have been conceived as a result of gamete donation is equally hard to estimate; before the advent of technologies that increase the chances of a couple conceiving their own genetic children such as ICSI, donor insemination was the principal method of assisted conception, and therefore accounted for a high proportion of all assisted conception births. This will now be much lower. Nevertheless, a considerable number of children will have been conceived, and continue to be conceived, as a consequence of gamete donation.

### **Who's who in gamete donation and collaborative reproduction**

Reproductive technology has the capacity to completely revolutionize parent-child relationships. First, let us consider the range of adult-child relationships that may result from the application of reproductive technology:

A = genetic mother (provider of the egg)

B = genetic father (provider of the sperm)

C = gestational mother (who may be single or in a heterosexual relationship with a man or in a lesbian relationship with another woman)

D = social mother (who may be single or in a heterosexual relationship with a man or in a lesbian relationship with another woman)

E = social father/or mother (co-mother) in a lesbian relationship

If D (the child's social mother) forms a new relationship with another man or woman (F), this person may assume a parental relationship with the child.

In many countries, a child's mother is regarded as the woman who gives birth to a child. Where a child is conceived as the result of a surrogacy arrangement and the surrogate is married, her husband may be regarded as the child's legal father even though he is not the child's genetic father and has no intention of caring for the child after she is born.

The use of technology adds a further dimension to existing social and family relationships when a family member acts as a donor; this is not uncommon in surrogacy or egg donation. In sister-to-sister egg donation, the child's genetic mother would also be her aunt. In a mother-to-daughter gestational surrogacy arrangement, the child's genetic mother would also be her grandmother. In a daughter-to-mother gestational surrogacy arrangement the child's genetic mother would also be her sister. Some possible arrangements would give the impression of infringing consanguineous relationships, if not actually doing so; for example, brother-to-sister sperm donation (where a sister uses a donated egg) and sister-for-brother gestational surrogacy (where a sister gestates an embryo created from her brother's sperm and her sister-in-law's egg). Others would actually involve the combination of gametes from consanguineous relationships, such as brother-to-sister sperm donation, sister-to-sister-in law (brother's wife) egg donation and sister-for-brother genetic surrogacy.

Social relationships can be made even more complex when a sperm or egg donor contributes to the conception of more than one child; when a woman acts as a serial surrogate or - if a couple have frozen embryos in store that they no longer need because they have achieved their desired family – when they donate their “spare” embryos to other women or couples. If these different children live in different families, the constellation of potential inter-personal relationships takes on a character that has not been experienced hitherto.

In the UK before legislation was introduced which, among other things, limited the number of children who could be born from the eggs or sperm of a single donor to ten, there were no limits at all, and one woman in the UK claimed that her deceased father, who had been a sperm donor at a London clinic in the 1940s and 1950s had been told by the clinic that he had produced over 100 children<sup>ii</sup>.

While a number of countries have imposed formal limits on the number of offspring that may be conceived from the gametes or embryos of a single donor, such restrictions are of comparatively recent origin and still permit the possibility of extensive kinship networks.

Given the potentially massive personal, family and social implications that this technology threatens to unleash, it is understandable that in many countries a number of these practices are prohibited by law.

Where such practices were not expressly prohibited, for many years, proponents urged discretion, if not absolute secrecy, on the part of those who used them. One effect of this is that it has been exceptionally difficult for researchers to study the lives of children conceived by gamete donation and their families. However, changing attitudes towards donor conception in recent years have created a climate in which some research has been possible.

Some of the major issues on which researchers have focused have been the effect of unequal genetic relationships on personal relationships between parents and between parents and children; the impact of secrecy in such families, or conversely, the impact of disclosure to the child and/or to others - and the impact this may have on the child's sense of identity and psychological wellbeing, and the availability of information about the donor.

In the remainder of this presentation, I propose to summarize what we currently know about:

- Heterosexual families that have used donor insemination
- DI families headed by single heterosexual mothers
- DI families headed by lesbian mothers
- Heterosexual families that have used egg donation
- Heterosexual families that have used embryo donation
- Heterosexual families that have used surrogacy
- Donor-conceived people's perceptions concerning their conception

First, it is important to make some general observations about the available evidence, and the limitations on applying the findings to larger populations.

People who have achieved parenthood by means of assisted conception are a selective group to start with; their commitment to having and rearing children may be higher than parents of naturally conceived children. Parents of donor-conceived children who are most concerned about maintaining secrecy are least likely to participate in research studies, so the available research evidence is biased in favour of families where parents are willing to disclose their recourse to donor conception to researchers.

Most studies have been conducted with families with very young children – very little research has been conducted beyond early adolescence, although some studies of

families headed by lesbian mothers have included teenage and young adult donor-conceived children.

Most studies have been based on small samples.

Most studies have been conducted with families following DI, and a number of studies of families headed by heterosexual couples have used mothers as the principal source of information, so there is limited direct evidence about fathers in DI research. Little research has been conducted with families created following egg donation, embryo donation or surrogacy arrangements – whether or not involving a friend or family member – families of donors and recipients involved in egg sharing, or families headed by single heterosexual women who have used donor conception. And no research has been conducted with donors' families.

Very few DI-conceived children living in families headed by a heterosexual couple that have participated in research studies have been told about their conception. Few studies, have investigated donor-conceived people's perspectives of donor conception – our understanding of the impact that knowledge of their conception may exert on the donor-conceived person's identity, their interest in knowing about the donor and any other genetic relations they may have, and the relationship between donor-conceived children and their parents remain rudimentary, and is largely derived from sources other than formal research.

There is little research of a qualitative nature, providing in depth exploration of those who have been personally involved in donor conception.

### **Heterosexual families that have used donor insemination**

Studies have generally found no evidence of any cognitive and socio-emotional developmental problems experienced by DI-conceived children raised in heterosexual families or in parent-child relationships<sup>iii</sup>.

While there is some recent evidence suggesting an increased inclination among heterosexual parents to inform their DI-conceived children about their conception<sup>iv</sup>, it seems that many parents continue to withhold this information from their children<sup>v</sup>. A variety of reasons appear to be behind parental decisions not to inform their children, including protecting the child from the potential stigma associated with DI, fears of the impact of acknowledging the father's fertility difficulties and the absent genetic relationship with the child on family relationships, uncertainty about how and when to tell the child, and lack of information to give the child about the donor<sup>vi</sup>.

Consequently most published research concerns families where the children are unaware of the nature of their conception, and very little research involving families that have disclosed to their children the nature of their conception exists<sup>vii</sup>. One recent British study has specifically compared and contrasted "disclosing" and "non-disclosing" heterosexual DI families<sup>viii</sup>. Mothers from disclosing families reported significantly less frequent and less severe arguments with their children and considered their children showed a lower level of conduct problems and to be less of a strain than did non-disclosing mothers. However, no significant differences regarding the children's socio-emotional or cognitive development were found between the two family types. Another recent British study of donor-conception families found no differences in parent-child relationships between families where parents intended to tell their child about her conception and those where parents favoured non-disclosure or were still undecided<sup>ix</sup>.

### **DI families headed by single heterosexual mothers**

Few studies have focused on single heterosexual women who have used DI and none have investigated the development or experiences of children. Important reasons for single women's choice of DI appear to be their wish to avoid both using a man to conceive a child without his knowledge or consent and sharing their parental rights and responsibilities with a man with whom they had no emotional relationship<sup>x</sup>. Single heterosexual women appear more likely than heterosexual couples to tell their child about her conception<sup>xi</sup>.

### **DI families headed by lesbian mother**

The main issues that have been subject to research interest in DI families headed by lesbian mothers have been the quality of parenting, the child's emotional well-being and gender development, the relationship between the child and her genetically unrelated mother ("co-mother") and informing the child about her conception<sup>xii</sup>.

The research shows that lesbian parents generally provide good quality parenting experiences for their children. Lesbian couples seeking to pursue parenthood through donor conception are likely to face a more difficult task than heterosexual couples, so are likely to be especially strongly motivated. The quality of the relationship between the child and co-mother has generally been found to be good. Most notably, where comparisons have been made with DI families headed by a heterosexual couple, co-mothers in two-parent lesbian families were more involved with their children than were fathers in two-parent heterosexual families.

The research indicates that neither DI-conceived boys nor girls in lesbian headed families differ from their peers in heterosexual families regarding either their gender development or emotional well-being.

A key issue that sets apart DI-conceived children of lesbian mothers and DI-conceived children in two parent heterosexual families is that the former are more likely to be told

about their conception by their parents. Neither disclosure itself nor the nature of their conception appears to be experienced as problematic by either parents or children.

### **Heterosexual families that have used egg donation**

Limited research has been undertaken involving families that have been created using egg donation. So far, this has been conducted in families with children up to the age of eight years. Studies investigating the health<sup>xiii</sup> or cognitive and socio-emotional development<sup>xiv</sup> of children conceived following egg donation have provided no evidence of health problems or cognitive or socio-emotional problems for the children. Few studies have explored issues for donors or recipients or their families where the donor has been a friend or family member. Known donation is considerably more prevalent in egg donation than in DI and in countries where donors may not be financially rewarded may represent a significant element in egg donation - so the absence of relevant research evidence represents a notable knowledge gap. One Finnish study<sup>xv</sup> included eight families where a sister or friend had acted as an egg donor and saw the child regularly. The study reported no difficulties in the donor-mother relationship or differences in the proportion of children with eating or sleeping difficulties compared with children conceived following IVF; the egg donation parents expressed less concern than the IVF parents about their child's behaviour.

To date there have been no studies investigating outcomes for either donors' or recipients' families or children involved in "egg sharing" - an arrangement in which a woman who is herself undergoing IVF agrees to donate eggs to another woman who subsidises the donor's treatment. "Egg sharing" is not permitted in many countries, although it is claimed to provide the main source of donor eggs in the UK<sup>xvi</sup>.

### **Heterosexual families that have used embryo donation**

Children conceived through embryo donation have no genetic relationship to either of their social parents and, since a major source of donated embryos is so-called “surplus” embryos donated by couples who have completed their families, most children conceived through embryo donation are likely to have older, full genetic siblings who have been reared by their genetic parents. So far, only one study has reported on the psychological development of children conceived through embryo donation<sup>xvii</sup>. This study found no differences in respect of child psychological problems between matched groups of adopted, IVF-conceived and children conceived through embryo donation aged between 2 and 5 years.

### **Heterosexual families that have used surrogacy**

While a number of studies have investigated the motives of surrogates and commissioning or intended parents, there has been limited research concerning either the families of surrogates or of commissioning or intended parents. Studies involving infants conceived following a surrogacy arrangement have provided no evidence of adverse speech, motor impairment<sup>xviii</sup> or infant temperament<sup>xix</sup>.

### **Donor-conceived people’s perceptions concerning their conception**

Almost without exception, our knowledge of donor-conceived people’s perceptions is confined to DI-conceived individuals. This evidence is provided by a small number of academic research studies investigating the experiences of DI-conceived children and adults<sup>xx</sup>. Other sources include letters<sup>xxi</sup>, biographical accounts<sup>xxii</sup>, videos<sup>xxiii</sup>, proceedings of conferences<sup>xxiv</sup>, individual projects conducted by donor-conceived people<sup>xxv</sup>, emails and information on internet web sites. Numerous newspaper and

magazine articles and TV documentaries have also reported on donor-conceived individuals' experiences and views. For the most part, the focus of interest has been the donor-conceived person's knowledge about their conception and information about their donor and other people to whom they may be genetically related, and the impact of this knowledge on their self-identity and relationships with significant others.

Two specific observations need to be made about these sources. First, some donor-conceived people have participated in more than one research study – and have also contributed to other sources of available information; their story has been told and retold on more than one occasion. Consequently, the various sources cannot be relied upon to provide independent verification of each other. Second, we cannot extend the experiences of donor-conceived people who know about their conception to those who do not know.

Of donor-conceived people who are aware of their conception, it is possible to distinguish those who were informed about the nature of their conception at a relatively young age and those who discovered the nature of their conception in later life, sometimes by mischance or in an unplanned way. Apart from the basic facts of their conception, donor-conceived people may be able to access different types of information about their donor – ranging from no, or very little, information, to being able to learn his identity if they choose to do so.

What these sources indicate is that:

DI-conceived children can be informed about their origins in sensitive and age-appropriate ways without jeopardising the child's self-identity or family relationships.

A large proportion of those who were told as children described a sense of “always knowing” and being unable to recall a specific time when they were told. Those who

have learned earlier appear to have accommodated this information more readily than those told later. Those told early indicate that this knowledge made them feel wanted and loved by their family. However, appropriate disclosure is not a one-off event, but is rather a process that develops over time.

DI-conceived people who have learned about their conception in adolescence or adulthood not infrequently comment on their prior awareness of unexplained physical and/or temperamental differences between themselves and other members of their family - or of growing up sensing something being “different” within their family.

Sometimes information about the DI-conceived person’s conception is poorly managed and/or inadvertently disclosed. When this information is revealed later in life the individual may experience negative feelings about the prior concealment of this information, although not necessarily of their parents’ recourse to donor assisted conception.

Some DI-conceived people are interested in learning more about their donor. The sorts of information they want to know are wide ranging - including health and physical information, family history, whether the donor has other children, his job, hobbies, sports interests, personality and his motivation for donation. Those who would also like to make contact with their donor say they are not looking for a father, either to replace their existing father or to substitute for one they never had, nor are they planning to make financial or emotional demands on him. Most of those who are able have indicated their intention of learning their donor’s identity, but not necessarily as soon as they are legally or practically able to do so.

Lack of information about the donor is a source of concern, frustration and problems with identity for some DI-conceived people; some consider that only knowledge of the

donor's identity will help them to make sense of their own identity and that access to information about their identity is their fundamental civil right.

Some DI-conceived people want to identify and locate any other people sharing the same donor, either simply to avoid the risk of entering a consanguineous sexual relationship or to meet other people with whom they may feel a sense of shared kinship. However, some DI-conceived people have expressed being “deeply disturbed by the thought of almost a tribe of offspring from their provider”<sup>xxvi</sup>.

## **Conclusions**

The evidence that currently exists may offer some reassurance insofar as it suggests that neither the psychological development of donor-conceived children - up to early adolescence in the case of DI-conceived children, nor the quality of parenting appear to be compromised by the absence of a genetic link between parent and child. However, we need to keep an open mind about longer-term implications for three main reasons:

1. Most of the children in these studies are very young.
2. In most of the families headed by a heterosexual couple, the child had not been told about their conception, and so was unaware of the missing genetic relationship. While there is no research evidence of any adverse impact of successfully maintained secrecy in donor-conceived families, the longer-term effects of non-disclosure on parenting and family relationships remain to be evaluated. However, the experiences of older DI-conceived people indicate the potentially harmful consequences which can result from the exposure of such secrets and when disclosure is unplanned or is accompanied by negative circumstances. What is also evident is that limited information about the donor and the inability to learn the donor's identity can also be a source of distress to donor-conceived people.

3. The limited – and in some cases the almost complete lack of - research involving:

- families that have used egg donation, embryo donation or surrogacy arrangements – whether or not involving a friend or family member – and egg sharing;
- families headed by single heterosexual women who have used donor conception; fathers – especially in DI families, and
- families of donors.

Donor conception began with the best of intentions to relieve the misfortune of involuntary childlessness. Had it been perceived at the outset as providing the basis for family-building rather than merely as offering a technical solution to a biological problem, considerably different forms of practice might have developed. Belatedly, research is providing some information about the longer-term consequences of successful donor conception for the families it has helped to build. However, it is evident that there is still much that we do not know, and the considerable gaps in our knowledge mean that it is imperative that increased priority is given to research in this area both by research funders and by social science researchers.

Thank you for listening

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