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Toronto Clinic Round 25 April 2006

Donor conception: International trends and practices in disclosure of genetic origins information

Eric Blyth

I am going to provide a brief overview of trends in various countries regarding the provision of donor-related information in donor conception. I will be looking at the underlying issues concerning rights to information and the implications of increased information-disclosure. Finally, I will provide an update on the experience of the UK voluntary register, "UK Donorlink".

Donor insemination has been practiced for many years. From its earliest beginnings, it was assumed that it was best for all concerned if the donor and recipient did not know each other's identity, and that any child conceived as a result of donor insemination did not know about the nature of his or her

conception. It was generally considered appropriate to apply a similar approach to egg and embryo donation as these became available during the 1980s. One consequence of this is that we do not know how many people involved in donor conception, although worldwide it is likely to result in the birth of many thousands of children each year.

However, in the last twenty years or so, different views have developed, so that - in some countries and among some groups of people - the justifications for donor anonymity and secrecy concerning donor conception are no longer invariably regarded as self evident.

In 1985, Sweden was the first country in the world to introduce legislation requiring donors to agree to their identity being disclosed to any person conceived as a result of their donation, and has been followed by Austria, Germany, the Netherlands,

New Zealand, Norway, Switzerland, the United Kingdom and the Australian states of Victoria and Western Australia. In Finland in February this year, the government introduced legislation that will mandate the abolition of donor anonymity if it is approved by Parliament.

However, in most other countries where donor conception takes place, donor anonymity either enjoys legal protection or simply characterises practice because that is how the service has always been provided. In some of these countries, it is possible for a donor-conceived person to obtain some non-identifying information about his or her donor. This is usually health information and a pen portrait of the donor - providing a brief physical description and information about education, interests and employment. A small number of countries that generally protect the donor's identity, nevertheless provide for disclosure of the donor's identity - usually by order of a court - in case of "medical emergency"

In some countries where neither anonymity nor identification is mandated, both anonymous and identifiable donation may be available.

Voluntary registers that enable the collection and sharing of information between different parties involved in donor conception have also been established. I will talk about these later.

Three major models of donor conception appear to be in operation:

1. Anonymity and secrecy: where donors are anonymous and it is considered best not to disclose the fact of donation.
2. Anonymity and disclosure: where donors are anonymous but it is considered best to inform children about the nature of their conception - and some non-identifying information about the donor may be available.
3. Identity disclosure: where the identity of the donor is made available to the donor-conceived person and where it is

considered best that he or she is aware of the nature of his or her conception.

Of course, the real world does not operate so neatly. For example, a donor's identity may be potentially available, but if the donor-conceived person is unaware of the nature of his or her conception he or she will know neither of the existence nor the identity of the donor - we know that many parents say that they do not intend to tell their child. Or secrecy may be intended, but the donor-conceived person may find out about the nature of his or her conception anyway, perhaps as the result of a family argument or because someone else who knows about the nature of the child's conception has told him or her - we also know that many parents who would not tell their child about their conception, nevertheless tell other people.

Several reasons have been identified for promoting the donor-conceived persons' access to identifying information:

- The donor-conceived person's 'right to know' - usually articulated within a human rights framework such as domestic law or international conventions such as the European Charter on Human Rights and Fundamental Freedoms or the United Nations Convention on the Rights of the Child.
- The experiences of parents, who may also think that their child has a right to know, but who have either experienced the stress of maintaining the secret of the child's conception or - having told their child about his or her conception - find that they do not have enough information about the donor to satisfy their child's inquiries.
- The experiences of donor-conceived people who may consider that they have both a right to know and a need to know to enable them to develop a full sense of their own identity.

Since the ability of donor-conceived people to know the identity of their donor is a very recent phenomenon, and has been enjoyed by very few, we know very little about their experiences. We

know a bit more about the experiences of donor-conceived people who are aware of their conception but have limited information about their donor - and about the experiences of their parents. Generally, parents have developed successful ways of telling their children - even very young children - about their conception without harming family relationships. Indeed, making children aware of the nature of their conception seems to strengthen relationships within families. The lack of information about the donor seems to be experienced differently by different individuals and there is some evidence from the accounts of older donor-conceived people that this will be experienced differently by the same individual at different times in their life.

The principal fear about removing donor anonymity of course, is that there will be fewer donors. The evidence from countries that have abolished anonymity seems to support this at least initially. However, some donors recruited as anonymous donors say they would be willing to donate if their anonymity is no longer protected, and there are potential donors who would not donate anonymously but would be willing to donate as identifiable donors.

The important challenge for service providers is to access such donors.

The UK's voluntary contact register, UK Donorlink, is one of several voluntary contact registers, allowing for the recording and sharing of information between people that have been personally involved in a donor procedure, that have been established.

Some registers have been set up by parents of donor-conceived children and are principally directed at people involved in donor procedures taking place in the United States; however, they are accessible globally via the internet. The largest of these, the Donor Sibling Registry, has 7466 registrations and matches between 1632 half-siblings and/or donors have been facilitated. Other voluntary registers have been set up by governments.

Since 1991, when the UK's current legislation was implemented, a statutory register, which includes donor conception, has been operational. However, since donor anonymity was protected until 2005, non-identifying donor information only can be made available for donor procedures between 1991 and 2005.

UK Donorlink was established in 2004 as a means of facilitating contact between people involved in donor procedures that took place **before** 1991. As of 13 March 2006, 118 individuals had completed full registrations, i.e. had completed DNA testing. Of these, 41 are donor-conceived adults, 14 are donors, 2 are genetic siblings of donors and 25 are birth mothers. In addition a further 125 individuals have made initial enquiries and are at varying stages of considering or actually registering with UK Donorlink. Matches have been made so far between three groups of individuals sharing the same donor/genetic father:

- 8 half siblings and 1 birth child of the donor
- 3 half siblings and one birth son of the donor.

- 2 half siblings and possibly a third half sibling, subject to completion of tests.

In conclusion

The international trend in donor conception appears to be towards increasing disclosure, ranging from the family level of parents sharing information with their children to governments introducing legislation to abolish donor's rights to anonymity.

Given the various changes taking place in different countries, we have much to learn from each other on how best to develop donor conception services.

Donor Anonymity in the UK

1. From 1 April 2005, all NEWLY-RECRUITED gamete and embryo donors will be required, as part of the consent requirements under the Human Fertilisation and Embryology Act 1990, to agree to their identity being disclosed to any person conceived as a result of their donation.
2. specified NON IDENTIFYING DONOR INFORMATION will also be provided to recipients and to offspring.
3. At present, both IDENTIFYING and NON IDENTIFYING DONOR INFORMATION may be made available upon request to a donor-conceived person reaching the age of 18. The government is currently consulting on whether this age limit should be reduced to 16.
4. The new legislation provided for the continuing use of ANONYMOUS donors for a transitional period up to 31

March 2006. Two exceptions where donations from anonymous donors can be used AFTER 31 March 2006:

- (a) where patients have 'reserved' anonymously-donated gametes for future use to conceive a sibling for an existing child conceived from the same donation.
- (b) where the patient's own gametes have been used to create an embryo with anonymously-donated sperm or eggs, where the embryo can be used until the expiry of the maximum storage period.

Donor Compensation in the UK

The UK's attitude towards donor compensation has always been somewhat ambiguous. While not permitting the untrammelled operation of the market it has, nevertheless, eschewed an exclusively altruistic approach to gamete donation.

Since 1991, when the Human Fertilisation and Embryology Act 1990 became operational, sperm donors have been able to claim a fee of £15 per donation, in addition to expenses. This was the "going rate" in 1991, but the statutory regulatory body, the Human Fertilisation and Embryology Authority has never approved its uprating. Under the HFEA regulations, a similar fee would be available to egg donors, although in practice, egg donors do not receive this. In 1998, the HFEA set out to remove donor payment over and above reimbursement of expenses, but backed down in the face of strong opposition from clinics claiming that

this would irreparably compromise donor supply. At the same time, the HFEA gave equivocal endorsement of "egg sharing", in which female patients receive free or discounted treatment in exchange for sharing their eggs with another patient. In addition, although certain commercial activities connected with surrogacy are prohibited, it is generally accepted that surrogacy in the UK operates on a quasi-market basis under the guises of expenses.

During 2005, the HFEA undertook a further review of donor reimbursement which was required to accommodate the European Union's *Tissues and Cells Directive* (European Union, 2004), which the UK is obligated to enforce. Article 12(1) of the Directive provides that:

"Donors may receive compensation which is strictly limited to making good the expenses and inconveniences related to the

donation. In that case, Member States define the conditions under which compensation is paid."

The HFEA decided that there should be no compensation for inconvenience. The new provisions endorse the principle of 'cost neutrality', by which donors should neither profit nor lose out financially from their donation. The HFEA proposes that donors will be reimbursed out-of-pocket expenses only and compensated for loss of earnings; the latter to a maximum of £55.19 per day - the current rate for jury service - but with an absolute limit of £250 for each course of sperm donation or cycle of egg donation. The HFEA has still to clarify how it intends to verify a donor's loss of earnings and protect the donor's confidentiality.