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Donor insemination and the dilemma of the 'unknown father' (Der unbekannte Vater: Zum Problem der Samenspenderidentifizierung)

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Frankfurt: “Reproduction in 2007”

“Donor insemination and the dilemma of the ‘unknown father’ ”

Summary: this paper provides an analysis and commentary on the removal of donor anonymity in the UK

Background

As has been the pattern worldwide, donor insemination - and other forms of donor conception - in the UK has been characterised by anonymity between donors and recipients - and between donors and their donor-conceived offspring. In addition, donor-conceived people in the UK seemed rarely to be informed about the means by which their family was built. Later today we will be seeing Barry Stevens’ excellent documentary *Offspring* that provides an excellent commentary on DI as practiced in the UK until quite recently.

DI in the UK was totally unregulated until implementation of the Human Fertilisation and Embryology Act in 1991. At that time, the accepted wisdom that donor anonymity should be preserved was challenged by only a few dissenters, including the British Association of Social Workers’ Project Group on Assisted Reproduction (PROGAR) - of which both Marilyn Crawshaw and I are members - using professional and personal experiences of adoption and adopted people’s interests in their genetic roots. Combined medical and patient interests, anxious that removal of donor anonymity would compromise donor supply and therefore the availability of donor-assisted services, persuaded legislators formally to protect the identity of donors.

In the event, the Act provided donor-conceived people with limited opportunities to find out more about their genetic origins (always assuming that they knew that they were conceived as a result of donor conception in the first place). First, a donor-conceived person reaching the age of 18 years would be able to ask the state regulator, the Human Fertilisation and Embryology Authority - the HFEA - for non-identifying information about their donor that had been recorded on its Register of

Information. Second, anyone considering getting married would be able to ask the HFEA if its Register showed that they could be genetically related to their intended spouse.

The campaign against donor anonymity continued and several factors helped shift the balance of opinion during the 1990s and the early part of this century.

First, donor-conceived people themselves began publicly to articulate their experiences of anonymous donor conception. Without exception, they were severely critical of their inability to learn about their full genetic history. They were also supported by some users of donor conception who were beginning to realise the impact of anonymity on their donor-conceived children. I should say here that although sperm, egg and embryo donation are permitted in the UK, most of the active participants in this debate were involved in donor insemination.

Second, the United Nations Committee on the Rights of the Child formally questioned the compatibility of donor anonymity with the UK's endorsement of the UN Convention on the Rights of the Child (as it had done in a number of countries).

Third, in a high profile legal case, two donor-conceived people claimed that UK legislation contravened their right to "respect for private and family life" guaranteed by Article 8 of the 1950 European Convention on Human Rights and Fundamental Freedoms, although this case was not strictly concerned with donor anonymity *per se*. This case was adjourned pending the outcome of a government policy review, which led to a 2-stage change in donor-conceived people's access to information about their donor.

First, from July 2004, clinics were required to collect additional non-identifying information about donors and which could be accessed when the donor-conceived person reached the age of 18. Several research studies conducted during the 1990s had revealed the wide variations in donor information collected by clinics and this was an attempt to standardise this information.

Second, from April 2005, save for some specific transitional arrangements, all donors have been required to agree to the disclosure of their identity to any person conceived as a result of their donation who has reached the age of 18 who requests this information from the HFEA. These provisions have not been applied retrospectively.

The impact of the change in law on donor supply has been subject to claim and counter-claim. Predictions that donor numbers could fall by as much as 80% were augmented by newspaper headlines, such as “Infertile couples hit by big fall in sperm donors”, “Releasing donors’ names causes sperm bank crisis” and “Where have all the donors gone?”

A BBC survey of UK fertility clinics undertaken in 2006 claimed that two thirds of participant clinics were not recruiting new donors and that there was a solitary registered donor in Scotland, and none at all in Northern Ireland. On the other hand, the HFEA had undertaken its own clinic survey in 2004 in advance of the change in law and had indicated the difficulty of obtaining accurate statistics. More recent HFEA data, comparing registered donor numbers before and immediately after the change in law, suggest no change in donor recruitment. Recent UK studies of existing donors’ views have suggested that upwards of half of men and women recruited as anonymous sperm or egg donors would continue to donate as identifiable donors. In support of the notion that identifiable sperm donors can be recruited, two clinics in Manchester have claimed that they have no shortage of potential donors.

Other factors to bear in mind in trying to make sense of these trends are, first, that a much longer decline in DI is evident – mirrored by a rise in the use of ICSI and its emergence as the “treatment of choice” for heterosexual couples experiencing male factor fertility difficulties, and second, that countries where donor anonymity remains protected similarly report a long-term decline in DI.

While the principal focus of critics of the change in legislation has been donor supply, a second charge has been made that the change in law may actually make it **less likely** that parents of donor-conceived children will tell their children how their family was built. The rationale for this assertion has been poorly-articulated, which makes it difficult to take it seriously. Since research evidence suggests that one key reason why parents do not talk to their children about this is the absence of information about their donor, the suggestion that access to **more** information will make it **less** likely that parents will do so is less than convincing. What we do know is that while a number of research studies have shown that many parents do not tell their donor-conceived children about the way their family was built, recent research has suggested a growing trend towards disclosure. A Swedish study, the only one to compare parental disclosure practices before and after the removal of donor anonymity, indicates an increase in disclosure following the removal of anonymity.

Of further interest are the findings of a recent study showing that mothers who tell their DI-conceived children how their family was built report fewer child-related problems compared with non-disclosing mothers.

The UK government has recently proposed comprehensive revision of the Human Fertilisation and Embryology Act. Although this will not include revisiting donor identity *per se*, several proposals impact on managing donor conception. These have to be approved by parliament, and given the current state of British politics, there is no guarantee that the government's view will prevail.

Proposals directly regarding DI include:

Acknowledging reciprocal rights of donors to access limited non-identifying information regarding any offspring and in "some circumstances" (currently unspecified), allowing donors to be informed when details of the identity have been requested by any offspring.

Allowing donor-conceived people to find out if they have donor-conceived siblings, as part of the information accessible to them at age 18. There are no proposals to extend these rights to donors' children to ascertain if they have half-siblings as a result of a parent's donation or to extend them to donor-conceived people's own children. Although the government consulted on the possibility of reducing the age at which donor-conceived people should be allowed access to donor information from 18 to 16, it is currently proposing no change.

Following recent legislation allowing the formal registration of same sex relationships by means of a Civil Partnership, the government proposes to extend to persons intending to form a civil partnership the ability to check HFEA records to ascertain the possibility of a genetic relationship as a result of donor conception. Time will be made available to legislators to consider whether this provision should be further extended to cohabiting couples, although the government itself is not advocating this. There is an argument that this right should be extended to any individual aged 16 – the age of consent in the UK.

Finally, although the government consulted on whether any provisions should be introduced to compel parents to tell their donor-conceived children how their family was built (for example, by annotating birth records), it has decided that parents should be encouraged to tell their children rather than be compelled to do so.

Other issues that have not been addressed in the government review

The change in legislation has created four distinct "classes" of donor-conceived people with different rights to information about their origins. In addition to the most recent group who will have the opportunity to learn the identity of their donor, there are those for whom no statutory records exist, who were conceived as a result of a donor procedure taking place before 1991. UKDonorLink, a government-supported voluntary contact register, offers a service for these donor-conceived people as well as their parents and donors - and has already matched several donor siblings. Second, people conceived following a donor procedure undertaken between

August 1991 and July 2004 will have access to non-identifying information held on the HFEA Register. Third, a small group of people conceived following a donor procedure undertaken between July 2004 and April 2005 will have access to rather more non-identifying information held on the HFEA Register. For both these groups, the Register also contains details of the donor's identity - it is possible therefore that their continuing inability to access this information will be subject to a human rights challenge in the courts.

Since 1991, the HFEA has limited the number of offspring that may be conceived from the gametes or embryos of a single donor. Initially this was 10 "birth events" but has since been revised to children in 10 families. This represents a compromise between those who questioned whether limits that may have been appropriate within the context of anonymous donation are still appropriate when a donor is potentially identifiable and those who want to increase the number to mitigate donor shortages.

While the legislation provides for access to counselling when information is sought from the HFEA Register, it is not yet clear how this will be organised and managed, even though the first young people eligible to access non-identifying information will reach the age of 18 in 2010. The government commissioned a report on counselling services from the British Infertility Counselling Association in 2003, although to date the only practical effort to ensure adequate provision of services has been sponsored by PROGAR. It remains to be seen whether the government and the regulatory body will address these issues in time.