

Blyth, E. (2003) Access to information about gamete and embryo donors in the UK. *Obs & Gynae Today* VIII(3): 109-112 (ISSN 0971 8133)

In December 2001 the UK government instituted a public consultation on what information – if any – people born as a result of donor conception should be permitted to learn about their genetic origins¹. The consultation ended on 1 July 2002 and the government response to the consultation is expected by February 2003².

The context in which this consultation has taken place is provided by the Human Fertilisation and Embryology Act 1990 which came into force in 1991. The Act established a statutory regulatory body, the Human Fertilisation and Embryology Authority (HFEA), with responsibilities to license centres providing assisted conception services and undertaking associated research. The HFEA also has responsibility to maintain a Register of Information about donors of gametes or embryos used for the treatment of others, recipients of donated gametes or embryos and children born as a result of donation - and arranging for access to information held on the Register by a donor-conceived person.

When the Human Fertilisation and Embryology Act was being debated in Parliament during 1989 and 1990, there was overwhelming support for the principle of donor anonymity. This reflected the recommendations of the Warnock Committee³, the government-appointed

¹ Department of Health. Donor information consultation: Providing information about gamete or embryo donors. London: Department of Health, 2001.

² Liberty (2002, May 20) Homepage of Liberty [Online]. Available: <http://www.liberty-human-rights.org.uk/> (2002, July 9).

³ Department of Health and Social Security. Report of the Committee of Inquiry into

Committee of Inquiry whose report formed the basis of the Act. It needs to be borne in mind that the Warnock Committee's deliberations on donor-assisted conception were, in essence, focused on donor insemination (DI) – although it also considered surrogacy arrangements – since at that time oocyte and embryo donation were innovatory and rare occurrences. The Warnock Committee itself had proposed a shift from complete secrecy in donor-assisted conception, which still characterised much practice⁴, because it recognised that family secrets could 'undermine the whole network of family relationships' and that it was 'wrong to deceive children about their origins'⁵. Nevertheless, voicing misgivings about the risk of 'introduc[ing] the donor as a person in his own right'⁶, the Committee thought that the donor's anonymity should be protected. The Committee's report itself does not elaborate the basis on which the Committee reached this decision. However, in 2002, Baroness Warnock, who chaired the Committee, indicated that while she and her colleagues believed that a donor-conceived person should be able to identify his or her donor, they had been persuaded that the loss of anonymity might result in fewer men offering to become donors and seriously jeopardising the supply of donated sperm⁷.

Human Fertilisation and Embryology (The Warnock Report). Cmnd. 9414. London: Department of Health and Social Security, 1984.

⁴ Royal College of Obstetricians and Gynaecologists. *Donor Insemination*. London: Royal College of Obstetricians and Gynaecologists, 1987.

⁵ Department of Health and Social Security, op. cit. p.21

⁶ Department of Health and Social Security, op. cit. p.24

⁷ Warnock M. Donor conceived people: a revised view of their information, needs and rights, keynote speech at *Donor Information Consultation – Providing Information About sperm, Egg and Embryo Donors*, conference organised by the

The only circumstances under which the Act permits the identity of a donor to be revealed are by order of a court in the 'interests of justice' or in connection with any legal proceedings resulting from the birth of a child with a congenital disability. The latter provision is to ascertain whether the donor had withheld any relevant personal information that might have contributed to the child's disability.

The HFEA's Register of Information was set up in August 1991. Up until 31 March 1999 (the latest date for which data are available), nearly 18,000 births had been recorded on the Register and, with approximately 2,000 donor-conceived births annually in the UK, it is reasonable to assume that over 20,000 births are now recorded on the Register. However, official statistics underestimate the total number of such births because they depend on the recipients of successful treatment providing notification of any birth. The HFEA itself acknowledges that the outcome in 3.8 percent of all clinical pregnancies resulting from DI in the UK is unknown⁸. Further, the official statistics do not take account of births resulting from a 'private' arrangement (such as private insemination or a private genetic surrogacy arrangement). What is important to note, however, is that unless the HFEA is notified of the birth of a child following donor conception provided by a licensed treatment centres, that child will never be able to make any connection with information held on the Register about his or her donor or genetic origins. It is also axiomatic that an individual would have to know – or have suspicions - about the nature of his or her conception – in order to

Project Group on Assisted Reproduction (PROGAR), London, 2002 May 16.

⁸ Human Fertilisation and Embryology Authority. Ninth Annual Report. London: Human Fertilisation and Embryology Authority, 2000, p. 13

approach the HFEA for information. Such knowledge cannot be assumed since UK research evidence had indicated that the majority of recipients of donor gametes do not intend to tell any child about his or her origins, although many have told other members of their family so the long-term security of their child's ignorance is questionable⁹. However, some parents are known to have changed their views about disclosure when their child is growing up and a recent research study reports that 47% of mothers of donor conceived children stated their intention to tell their child about his or her status, while 24% were uncertain and 29% intended not to tell their child¹⁰. Other donor-conceived people may learn the truth of their origins inadvertently.

Assuming that a donor-conceived person is aware of his or her origins, the Human Fertilisation and Embryology Act provides for disclosure of the following information from the HFEA Register of Information. First, the Act permits an individual intending to marry to ascertain whether the Register provides any evidence of a genetic relationship to his or her intended spouse. (The earliest that anyone could request this information would be 2008, since 16 is the legal minimum age for marriage in the UK). This may be seen as a somewhat anachronistic device, designed to reduce the risks of consanguineous relationships, but could only do so in the strict legal sense and would not prevent a genetically-related couple from entering a sexual relationship and even producing a child.

⁹ Cook R, Golombok, S, Bish A and Murray, C. Disclosure of donor insemination: parental attitudes, *Am J Orthopsychiat*. 1995; 65(4): 549-59.

¹⁰ Golombok S. *Relationships in ART families*, paper given at annual meeting of the British Fertility Society, Oxford, 10-12 April 2002.

Second, anyone reaching the age of 18 (i.e. from 2010) may enquire if the Register shows that he or she had been conceived as a result of gamete or embryo donation.

Third, the Act permits the government to make Regulations specifying any additional information held on the Register that may be disclosed to a donor-conceived person aged at least 18. While this information could include the donor's identity, the Regulations cannot mandate retroactive disclosure of donor identity. Self-evidently, information can only be made available if it is recorded in the first place. The information collected by the HFEA includes details of the donor's ethnic group, religion, eye colour, hair colour, skin colour, occupation and interests and whether the donor has any children of her or his own. In addition the HFEA invites donors to provide 'a brief description' of themselves which could be made available to anyone using their gametes or embryos and to any child who may subsequently be born, although the space provided on the form for such information is comparatively small.

On the HFEA's own admission, the welfare of donor-conceived people was not a main priority in determining the nature of this information. Rather it was perceived as:

' the minimum necessary to allow the Authority to answer questions from children born as a consequence of treatment services about their genetic backgrounds..... Great importance was given in the design of the data collection system to avoid unnecessary intrusion into the personal lives of patients and donors, and to avoid unnecessary cost to centres and to the Authority' (my emphasis)¹¹.

¹¹ Human Fertilisation and Embryology Authority. Annual Report. London: Human

Furthermore, various research studies have shown that the nature and quality of data provided for the HFEA, and which form the basis of any information that may subsequently be released from the Register, are variable and to a large extent depend on the policy of the clinic at which the donor was recruited¹²¹³¹⁴. Such paucity of information will act as a major inhibitory factor regarding the release of non-identifying information. Limited information about the donor may also discourage parents from telling their donor-conceived children about their origins as they feel they are ill-equipped to answer any subsequent questions the child may have about the donor¹⁵. Conversely, the provision of detailed information about the donor, including details of the donor's identity, may encourage parents to be open about their recourse to donor conception¹⁶.

Fertilisation and Embryology Authority, 1992, p.23.

¹² Maclean S and Maclean M. Keeping Secrets in Assisted Reproduction – The Tension between donor anonymity and the need of the child for information. *Child and Family Law Quarterly*. 1996 8(3): 243-51.

¹³ Abdalla H, Shenfield F and Latache E. Statutory information for the children born of oocyte donation in the UK: What will they be told in 2008? *Hum Rep*. 1998; 13(4): 1106-9.

1998

¹⁴ Blyth E and Hunt J. Sharing genetic origins information in donor assisted conception: views from licensed centres on HFEA Donor Information Form (91) 4. *Hum Rep*. 1998; 13(11): 3274-77.

¹⁵ Cook R, Golombok, S, Bish A and Murray, C. *op cit*.

¹⁶ Sperm Bank of California. Identity-release research. *Newsletter* vii(3) Fall, 2001

Through the consultation, the government has invited comment on three main issues. First, whether a donor-conceived person should be able to obtain non-identifying information about the donor. Second, whether a donor-conceived person should be able to obtain identifying information about a future donor and third whether future donors could specify whether to be anonymous or identifiable. The possibility of maximising donor and recipient choice and perhaps avoiding any potential problem with donor recruitment that this approach offers is superficially tantalising. However, while this would give both prospective donors and prospective recipients a choice regarding anonymity at the point of donation and at the outset of treatment, once this decision had been made, there would be no opportunity for a subsequent change of mind. Most significantly, however, the effect on donor-conceived individuals is invidious. It affords them no choice at all and would create two classes of donor-conceived people – those who could ascertain the identity of their donor and those who could not. It is hard to see how such a policy could be considered compatible with the recently-implemented Human Rights Act 1998.

The limitations of the consultation should also be noted. It does not consider the possibility of establishing procedures to obtain further information from past donors who have donated under the existing regime of anonymity. A model that could be adopted in the UK has been developed in the Australian state of Victoria, Until 1998, donors in Victoria were guaranteed anonymity but the law was then changed requiring all donors to agree to be identifiable. Where a person conceived following donor treatment that is occurred during the period when anonymity was protected wishes further information about the donor – including his or her identity – arrangements exist for counsellors in treatment centres to act

as mediators to facilitate the gathering of further information. Under these arrangements the donor is able to veto the disclosure of such information. Although there have been relatively few requests from donor-conceived people so far, it has been reported informally that erstwhile anonymous donors have been willing to provide the information requested, including details of their identity in most cases. The evidence from Australia, therefore, is that donors do not necessarily demand to remain anonymous. While there are no provisions in the Human Fertilisation and Embryology Act for accessing this information retrospectively, consideration should be given to instituting such arrangements.

Neither does the consultation acknowledge any interest that a donor-conceived person may have in identifying and making contact with any half siblings – either other donor-conceived individuals or the donor’s own children – or other genetic relatives. The state of Victoria has also developed a pioneering initiative in this respect. Under the state’s Infertility Treatment Act 1995 (Section 82), a Donor Treatment Procedure Information Register was established to allow anyone involved with a donor treatment since 1 July 1988 voluntarily to apply for inclusion in the Register to provide identifying information to be released to other people to whom they may be biologically linked, a photograph or any other information that may be of interest to anyone else who may be associated with the donor treatment¹⁷.

As in other countries, access to genetic origins information in donor-assisted conception has been vigorously debated. Medical practitioners’ traditional support for donor

¹⁷ Infertility Treatment Authority. *ITA News*. Melbourne: Infertility Treatment Authority, March 2001.

anonymity on the grounds that its removal would exercise an adverse impact on the recruitment of donors and would, therefore, compromise service provision has been endorsed by the British Medical Association, despite the Association's previous support for the identification of donors¹⁸. In this respect, the medical profession may be out of step not only with the views of donor-conceived people and parents of donor-conceived people who are urging the recruitment of identifiable donors only, but also with UK public opinion. In June 2002, a national children's charity commissioned a public opinion survey in which over 80% of respondents considered that donor-conceived people reaching the age of 18 should not only have access to their donor's genetic and medical history, but should also have a statutory right to and learn the donor's identity¹⁹.

The government consultation is also taking place within the context of a legal challenge to current legislation under the Human Rights Act. In this case a donor-conceived adult and an unidentified six-year old donor-conceived girl have argued that the endorsement of donor anonymity by the Human Fertilisation and Embryology Act is a breach of Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms, which guarantees respect for private and family life, including the right to form a personal identity. At the time of writing the judge hearing this case is considering whether Article 8 is engaged; if so a full hearing will ensue. So it may be that the Court may well take the matter

¹⁸ Carvel J. 'Named sperm means no sperm', doctors warn government, *The Guardian*, 2002; 5 July: 6.

¹⁹ The Children's Society British public back change in law to give children a right to their identity. London: The Children's Society, 2002

out of the hands of politicians and professionals²⁰

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²⁰ Liberty, op. cit.