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The British experience: the UK consultation on access to genetic origins information

Eric Blyth

In order to understand the current situation in the UK regarding the government consultation, it is necessary to set out the legislative context.

In 1991, the UK became one of the first countries to implement near-comprehensive legislation governing assisted conception treatment and associated research, the Human Fertilisation and Embryology Act 1990.

A key feature of this Act was the establishment of a regulatory body, the Human Fertilisation and Embryology Authority (HFEA), one of whose functions is to maintain a Register of Information about donors of gametes or embryos used for the treatment of others, recipients of such treatment and children born from those treatments - 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 Committee (Department of Health and Social Security, 1984), the government-appointed Committee of Inquiry whose report formed the basis of the Act, the views of many clinicians providing assisted conception services and, as far as could be ascertained, of recipients of donor treatment services. An alternative approach, that only people willing to be identified to their offspring should be recruited as donors – advocated by some social workers and adoption specialists, and supported by a couple of members of parliament, – was discounted. 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. Of course we might well ask why disclosure of the

donor's identity should be restricted to these circumstances.

The HFEA's Register of Information was set up in August 1991. Up until 31 March 1999, 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.

So what will donor conceived people be able to find out about their origins? First, of course, it depends on whether they know about the circumstances of their conception. UK research evidence has indicated that the majority of people receiving donor treatment 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 questionable. In addition, some parents are known to have changed their views about disclosure when their child is growing up and more recent research shows that possibly as few as a quarter of parents of donor-conceived parents remain intent on not telling their children. Other donor-conceived people may learn the truth of their origins 'by accident' or inadvertently.

Assuming that a donor-conceived person is aware of his or her origins, the Human Fertilisation and Embryology Act permits 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.

Second, anyone reaching the age of 18 (i.e. from 2010) may enquire if the Register shows that he or she was conceived following donor treatment.

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, retroactive disclosure of donor identity via Regulations is specifically prohibited. Clearly, information can only be made available if it is recorded in the first place. Various research studies have shown that the type of donor information recorded on the HFEA Register is highly variable and to a large extent depends on the policy of the clinic at which the donor was recruited and this will act as a major inhibitory factor regarding the release of non-identifying information.

In December 2001, the government published a public consultation paper to assist decision-making on what information – if any – should be made available to people born since August 1 1991 following donor treatment. The consultation period ends on July 1 2002.

The government is inviting comment on the following specified areas:

- Whether a donor conceived person should be able to obtain non-identifying information about the donor
- Whether a donor conceived person should be able to obtain identifying information about a future donor
- Whether future donors could specify whether identifying information should be made available (the so-called 'twin track' policy that would allow the future recruitment of both identifiable and non-identifiable donors).

Limitations to consultation

Because of the limited remit of the primary legislation, the consultation does not consider information about half siblings who may exist as a result of donor treatments. Neither does it discuss the possibility of arrangements for obtaining any further information from past donors who have donated under the existing regime of anonymity.

Context of Debate

As in other countries, access to genetic origins information in donor-assisted conception has

been vigorously debated. Some clinicians and consumer groups have argued that removal of donor anonymity would adversely impact on the recruitment of donors and would, therefore, compromise service provision. Donors' fears of being held accountable for their donations (actually an erroneous apprehension because the law specifically precludes a donor from financial liability towards any offspring) were articulated by an anonymous sperm donor writing in a London newspaper in March under the byline, 'WARNING: these sperm could sue you one day' (Anonymous, 2002). On the other hand, donor-conceived people themselves and parents of donor-conceived people – who were simply not in evidence at all when the original legislation was framed - are increasingly urging the recruitment of identifiable donors only.

Potentially of major significance, last month Baroness Warnock, who chaired the Warnock Committee, told a London conference audience that she considered it was 'no longer acceptable' that donor-conceived people should be denied knowledge of their genetic parents or of knowledge of 50% of their genetic heritage. This conference was organised by PROGAR, of which I am a member, and we had known for some time that Baroness Warnock was willing to lend support to our cause for the statutory removal of donor anonymity. The government consultation provided the opportunity for us to make our move and Baroness Warnock's 'public conversion' received considerable media coverage, including all the major national daily newspapers, radio and TV. Interestingly, Baroness Warnock acknowledged that both she and her Committee had been aware of the ethical case against anonymity but had been persuaded that the removal of donor anonymity would seriously jeopardize the supply of donors. She now conceded that taking the pragmatic option was an error.

What happens next is largely a matter of conjecture, although a case currently before the English High Court may well have a bearing on progress. In 2000 a new Human Rights Act – the first we have ever had – came into operation, incorporating the European Convention for the Protection of Human Rights and Fundamental Freedoms. This is usually referred to as the European Convention on Human Rights. Two donor-conceived people, an adult (Joanna Rose), and an unidentified six-year old girl, with the support of our national civil rights organisation, Liberty, have taken the government to the High Court, claiming that the

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endorsement of donor anonymity by the Human Fertilisation and Embryology Act is a breach of Article 8 of the European convention, which guarantees respect for private and family life, including the right to form a personal identity. The first stage of these proceedings took place on May 22 and 23, the purpose of which was to decide whether or not Article 8 of the European Court is ‘engaged’ (i.e. lawyer-speak for whether the issues are covered by Article 8). Having heard representations from all parties – the government and the Human Fertilisation and Embryology Authority are opposing the application – the judge is currently considering his verdict. This may take two to three months. If the judge determines that Article 8 is engaged, then a full hearing will ensue. So it may be that the Court may well take the matter out of the hands of politicians and professionals. In the meantime the government has stated that it will respond to the consultation by February 2003 while in practice, the Department of Health has confirmed that it will begin analysing responses to the consultation and seeking a way forward as soon as possible after the conclusion of the public consultation on July 1.

An additional point to make, and which may be indicative of the government’s responsiveness to this issue, is that the Department of Health has funded a separate but allied project being undertaken by the British Infertility Counselling Association. The Human Fertilisation and Embryology Act requires that counselling must be made available to anyone seeking information from the Register, although they are not required to accept counselling. The project is to identify the counselling needs of people seeking information from the Register and their families and how those providing counselling can best be equipped to provide this service.

Unless the High Court effectively takes the decision out of the hands of politicians, the decision will ultimately be a political one. The government has not yet ‘taken a view’ on the question of donor anonymity so it seems that all is still to play for. It is not too late to contribute to this Consultation. The deadline for responses to the Consultation is July 1 2002. Copies can be obtained from the Department of Health website: www.doh.gov.uk/gametedonors and responses can be returned by email to: gilson.charles@doh.gsi.gov.uk.

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References

Anonymous (2002) WARNING: these sperm could sue you one day, *Evening Standard*, 5 March.