

Joint Committee on the Draft Human Tissue and Embryos Bill

Memorandum of Evidence

from

Donor Conception Network

Introduction

1. The Donor Conception Network is a voluntary self-help charitable organisation supporting donor conceived families; those who are considering or undergoing treatment; and donor conceived individuals. The Network was founded 14 years ago and numbers over 1,000 member families, including many single women and lesbian couples. Our philosophy is that families should be encouraged to be open with their children about the facts of their conception. We believe that secrecy over a matter as central to personal identity as one's origins is an insecure basis for a lasting and loving family relationship, and poses potential threats to children's welfare. When the issue of changing the law on donor anonymity was raised in 2002, we supported the ending of secrecy about the identity of future donors while not breaching the promise of anonymity made to past donors.
2. We continue to regard the access to origins information made possible by the ending of donor anonymity as the right policy for the 21st century. By 2023 when it will be fully effective, the UK will be seen to have made the right move, putting in place a consent-based regime that respects the rights of the next generation. If other jurisdictions have not by then done something similar, they will be faced with even more difficult policy choices. The change has not given rise to the negative consequences predicted by some. While it is true that waiting lists for treatment with donor sperm have lengthened in some areas, it looks likely that this is a temporary phenomenon as clinics develop more sophisticated strategies for recruiting identifiable sperm donors. Nor have most of those seeking donor treatment found the idea that their children could contact the donor a threatening one.
3. This memorandum centres on the issues in Clause 32 of the draft Bill concerning the Register of information and the rights of donors and donor conceived people.

The donor conceived population

4. Since the HFE Act came into force, up until 2004, recently published data from the register shows that 16,836 children have been born as a result of donor insemination, 4,506 from egg donation and 413 from embryo donation. In addition 4,568 children were born from IVF using donor sperm. This would mean a total of 17,775 donor conceived children between the ages of 3 and 16.
5. There is no data on the number of individuals born as a result of donor treatment prior to 1991; however in the first full year after the Act came into force 1,760 children were born following the use of donated sperm, and it

seems likely that similar numbers of donor children were being born in the decade prior to the Act. Taking a conservative estimate of 1,500 children a year during that decade would suggest around 15,000 donor conceived individuals who are now between the ages of 26 and 16.

6. Donor insemination has been practised since the Second World War, and we are in contact with donor conceived individuals now in their 60's – conceived in the 1940's. Little is known about the scale of activity in DI clinics in the 1950's, 1960's or 1970's, but a conservative estimate would suggest that there are at least 5,000 individuals between the ages of 26 and 65 alive today who were conceived by DI during this period. The vast majority of the latter group are unaware of their origin.

Donor information and genetic relationship requests

7. Inserted Clause 31ZA repeats the relevant provisions of the current Act and Regulations as regards identifiable and non identifiable information about donors. We support these provisions and believe that the broad framework should remain unchanged, subject to a change to provide for information for descendants of donor conceived people.
8. If for instance a woman aged 40 with a young family learns that she was donor conceived, but dies before making an information request, there would appear to be no power for the Authority ever to provide information to her children, even when they are of age.
9. **We recommend** that provision however ought to be made for the descendants of donor conceived people to obtain information.

Civil partners and others contemplating intimate relationships

10. One change of significance is made in the draft Bill, namely to allow those planning to enter a civil partnership with a specified individual the same right as those planning to marry – namely to find out if they would or might be related. And the question arises as to whether those simply living together in a sexually intimate relationship (whether or not they intend to legitimate this by marrying or becoming civil partners) should have similar rights.
11. These provisions of the 1990 Act about Register requests have not yet been tested in practice since no donor conceived person born after the Act came into force has attained sufficient age to marry. The inhibitions about the incest taboo are felt just as much by lesbian and gay individuals as by heterosexual people – whether or not they are hoping to have children. So it is right that a gay or lesbian person intending to enter a civil partnership should be able to check whether they are or might be related to their proposed partner.
12. So far the provisions appear to be designed for the protection of the intending partners (to a marriage or civil partnership) so that they can avoid finding themselves in an incestuous relationship. The limitation to proposed legal partners however seems anomalous, given that other provisions of the Act recognise unmarried partners in the context of treatment and legal parentage. Nor can this limitation be particularly helpful administratively to RATE in checking whether information requests are validly made since the applicant has only to state that he or she proposes to marry or enter a civil partnership, and no evidence of this is required.

13. But if the interests of potential children are taken into account, indeed treated as potentially more important, it is clear that the provision ought to go wider. The psychological effect on individuals who discover that they have been conceived in an incestuous relationship is bound to be damaging, so the union of such people should be avoided so far as possible.
14. **We recommend** that the provision allowing for information checks should therefore be extended from merely those proposing to marry or form civil partnerships to those intending to form sexually intimate relationships.
15. An odd omission from the statutory framework, inherited from the HFE Act, is the lack of any requirement of consent from the named person specified in the request. We would not wish to see the system for responding to information requests from the Register being abused or exploited for journalistic or mischievous purposes – or generally brought into disrepute. Those administering the system ought to be able to concentrate on the business of answering requests made in good faith for whom the information will be of serious relevance. As the Bill stands, any person who is a relevant individual (has been born in consequence of licensed treatment) will, it seems, after an opportunity to receive counselling, be able to make an unlimited number of requests against the names of anyone without their knowledge or consent. This could include individuals towards whom applicants may have formed an obsession, celebrities or even members of the Royal Family.
16. **We recommend** that the consent of the named person specified in the request should be essential. The Authority should also have a power to decline frivolous, vexatious or repeated requests, or those not apparently made in good faith.

Withholding information

17. Paragraph (3) provides the Authority with a discretion not to supply information if there are special circumstances making it more likely that donors or half-siblings could be identified. It is difficult to see how this provision could operate fairly and justly – or be other than extremely difficult for the Authority to administer. Donors who donated anonymously, and those who donate now but whose identity is protected for 18 years, were and are encouraged to provide background information about themselves, and some have given a good deal of information about their education and interests. Information about a donor's education (if for example it involved unusual combinations of degree courses) would "increase the likelihood" of being able to identify the donor, without actually being able to lead to an identification. The drafting of this provision seems too wide.
18. We have recommended above that the Authority should have power to decline certain information requests. **We recommend** that the Government should clarify the need for the provision in paragraph (3) and should in any event re-draft it.

Age of entitlement to information, and information for minors

19. The provisions entitling donor conceived individuals to information about themselves, or their half-siblings are limited to those over 18. There is a strong case for those aged 16 and above to be able to access such information with their parents' consent and support. Paragraph (5) provides that information about proposed marital or civil partners can be given to those

under the age of 18 – no doubt on the basis that the HFE Act appears to provide for this and that people are free to marry and form civil partnerships at 16. An odd feature of the current provision – and of that reproduced in the Bill – is that it is not confined to those aged 16 and above. A child of 10 could theoretically make a request.

20. **We recommend** that the age of 16, and no less, should be that at which donor conceived people can make information requests, provided that those between 16 and 18 should have the consent and support of their parents.

Information about half-siblings

21. The Clause also provides for donor conceived individuals to have access to information about the number and ages of any half-siblings. Our experience is that many donor conceived individuals have at least as much, if not more, interest in finding out about how many half-siblings they have, as in information about donors. Clause 31ZD provides that where donor conceived half-siblings register a wish to be put in contact with another donor-conceived half-sibling, this can be facilitated and we support this.

Information for donors

22. Inserted Clauses 31ZB and 31ZC gives donors a right to information about children who have resulted from their donation (information that the HFEA is already providing but not under statutory provisions), and also a right to be informed if the Authority is about to comply with requests about them. We strongly support these proposals. Potential donors need to be reassured that they will have some idea of the outcome of their donation, and that offspring will not contact them before they are aware that this contact might take place. These are assurances that any prospective donor would wish to see before agreeing to donate. But in our view the provisions do not go far enough. It is not enough for a donor simply to be informed that an offspring has now been told of one's identity and therefore may make contact. Such a contact may be fraught with emotion and both parties need to be helped to prepare for it. In the field of adoption there are intermediary services to ensure that contacts and meetings between adopted people and their birth parents are arranged by trained intermediaries – counsellors or social workers familiar with such contacts. UK DonorLink, the organisation that operates the voluntary register has already recruited and trained a team to offer this service to those making use of its register.

23. **We recommend** that RATE be empowered to ensure that intermediary services, and potentially counselling, are available to facilitate contacts between donors, donor conceived people and half-siblings.

Provisions relating to those conceived before 1991

24. Inserted Clause 31ZE makes provision for a voluntary contact register in relation to individuals who were donor conceived before the HFE Act came into force in 1991. While we support this provision, other measures are needed to protect the position of those conceived before 1991. The most important of these would be a provision to prevent the destruction of records. Before 1991, donor conception services were totally unregulated and the records of such treatments are at risk. Some are held by doctors who practised privately and never became regulated. Others are held by organisations such as the British Pregnancy Advisory Service which offered donor treatment in the 1980's, but chose not to become regulated.

25. **We recommend** that it should become an offence to destroy such records, and the Authority should be empowered to receive them and to incorporate relevant material onto the Register so far as possible.

Walter Merricks, Chairman
DONOR CONCEPTION NETWORK
Registered in England and Wales: Charity No 1041297

Contact details
32 Cholmeley Crescent
London
N6 5HA

enquiries@dcnetwork.org
mobile 07718 658301
landline 020 8245 4369