

**Parliamentary Briefing on
Human Fertilisation and Embryology Bill
October 2008**

**Issued by the British Association of Social Workers Project
Group on Assisted Reproduction (BASW PROGAR)**

in conjunction with **British Association for Adoption and Fostering (BAAF), British Infertility Counselling Association (BICA),
Children and Family Court Advisory Support Service (CAFCASS), Donor Conception Network, National Association for Guardian *ad litem* and Reporting Officers (NAGALRO) and UK DonorLink (UKDL)**

We welcome the publication of the Human Fertilisation and Embryology Bill. In particular, we welcome the government's ongoing commitment to **greater openness around the use of donated gametes**. The removal of donor anonymity in April 2005 was well received by many donor conceived people, donors, parents of donor conceived people and professionals.

We have previously issued Parliamentary Briefings outlining a number of areas where we believe that the Bill could be strengthened¹. In this Briefing, we have selected a smaller number to reflect the fact that the Bill is now entering its Report Stage.

1. Continuing support for the rights of donor conceived people to know of their genetic origins

We are aware that there continues to be debate in some quarters about the lifting of donor anonymity. As organisations with **professional and personal interests** in the well-being of those directly affected – i.e. donor conceived people, parents, donors and other family members – we are firmly of the view that the current **commitment to openness is socially, psychologically and morally crucial**. The limited opposition to this policy has tended to come from two main sources:

1. 'supply and demand' – in other words, whether the openness policy will affect the supply of donor gamete(s)?.

¹ Please contact us if you require any previous versions – Marilyn Crawshaw, mac7@york.ac.uk; 01904 321254

2. parents' willingness to be open – whether an open policy will drive parents towards not disclosing to their donor-conceived children so that they are not tempted to later search for their genetic parent, i.e. the donor.

With regard to the 'supply and demand' question, we believe that a policy dealing with access to information about genetic origins must be based on the **rights and well-being of those directly affected** – i.e. those conceived through the use of donated gamete(s) – not on grounds of the supply of gamete(s) to *prospective* parents. **We support the Government's view that the case for this has been made.**

With regard to the impact of the openness policy on parents, our experience is that the introduction of the policy has been accompanied by **greater numbers of parents telling or intending to tell their children of their origins** (as referenced for example by the increased membership of DC Network, take up of their current programmes of 'Telling and Talking' and 'Preparation for Parenthood' workshops; and by the recent study by Crawshaw (2008)). Parents also appear to be making **constructive use in their parenting of the non-identifying information** about the donor that they now receive when a pregnancy is confirmed. It is likely that some of these offspring will wish to seek identifying information as adults. Additionally, the experience of UK DonorLink is that there continue to be donor conceived adults who find out their origins in a planned or unplanned way as adults, including those finding out as a result of **genetic screening**. These numbers are likely to rise, especially with the planned expansion of genetic screening. UK DonorLink's experience is that the **distress of late disclosure may be eased where information about the donor and siblings is available together with access to professional support services.**

2. Need for the power of authority to run the Voluntary Register service to be extended to cover the HFEA Register service for those seeking information and contact

The HFE Bill as drafted will afford the HFEA the power of authority to run the Voluntary Register (currently managed by UKDL and applying to those conceived prior to August 1991), including through delegation. However in relation to the HFEA Register itself (i.e. for those conceived post August 1991), there is only the requirement for the HFEA to *offer* suitable counselling. **We believe that the HFEA should be afforded the power of authority to run the service (including through delegation) to those approaching its own Register in order for parties to be treated equably, regardless of whether they were conceived pre or post 1991.** Without such a clause, we have grave concerns that no funding will be made available for such a service and that the HFEA will be deemed to have met its obligations by providing the contact details of counsellors.

3. Need for intermediary services

We believe that those directly affected by donor assisted conception should be given a **statutory right to receive professional intermediary services** when seeking the release of information and any subsequent contact with genetic relatives. While intermediary services should include second tier professional counselling services, the provision of counselling *alone* is not sufficient in this context and this should be reflected in the Bill. Intermediary services should be **free at the point of delivery**.

All our organisations have experience of assisting people who are seeking contact with genetic relatives as adults. Our practice experience, together with research studies of post adoption 'search and reunion' work make it clear that **intermediary services have a vital role to play**, where necessary, in assisting donor conceived adults, donors and their genetic relatives to exchange information and/or make contact.²

4. Rights of access to HFEA Register of Information at age 16

Under existing legislation, anyone aged between 16 and 18 can only seek information from the Register if they are intending to marry. While welcoming the government's recognition of the inadequacy of this provision, we believe that the **proposed replacement is unnecessarily complex and is likely to prove unworkable**. The new provision extends the right to seek information to (a) people contemplating a civil partnership and (b) those entering or already in an "intimate" relationship. It is not at all clear to Progar how the HFEA will determine eligibility for information under the "intimate" relationship clause.

Progar would prefer this to be **amended to allow any two people over the age of 16 to jointly request information from the HFEA as to whether the information on the Register suggests that they are genetically related**.

5. Rights of children of donors to have access to information from the HFEA Register of Information

We welcome the recognition in the Bill of the importance of donor conceived people being able to receive information about their donor conceived half siblings. We have consistently advocated that similar rights should be extended to **the children of donors**, i.e. those who are not conceived through donor assisted treatment. The Bill establishes as an important principle that there may be Information needs concerning those to whom one is related as a result of donor conception that can be addressed by the provision of such information as is held on the HFEA Register of Information. To exclude the children of donors from this is illogical as, without such information, **they too carry the risk of (i) entering**

² British Infertility Counselling Association 2003; Clapton 2006; Crawshaw and Marshall *in press*; Crawshaw *et al.*, 2007; Howe and Feast 2000; Trinder *et al.*, 2004.

consanguineous relationships and (ii) experiencing distress or disadvantage as a result of such information being withheld.

6. Protection from inheritance or other liabilities to gamete donors who donated prior to the implementation of the Human Fertilisation and Embryology Act 1990

Donors who donated prior to the implementation of the Human Fertilisation and Embryology Act 1990 appear to have **limited legal protection from inheritance or other liabilities in all UK jurisdictions**. This may prevent some from registering with the Voluntary Register or otherwise being open to approaches from anyone conceived as a result of their donation **Pre 1990 Act donors should be afforded similar levels of protection to post Act donors**.

7. Protection of records relating to donor-assisted conceptions prior to the implementation of the Human Fertilisation and Embryology Act 1990

There is an urgent need to **protect records** that relate to donor-assisted conceptions prior to the implementation of the Human Fertilisation and Embryology Act 1990 by **making it an offence to destroy them**. Additionally, the **HFEA should be mandated to take active steps to secure such records and to make non-identifying information available to those seeking donor information from them**.

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Notes

British Association of Social Workers is the professional body for registered Social Workers in the UK

British Infertility Counselling Association is the professional association for infertility counselling and allied research in the UK.

British Association for Adoption and Fostering is the leading charity working in adoption. It also runs the Adoption Register for England and Wales.

Children and Family Court Advisory Support Service (CAFCASS) is the non-departmental public body providing family court services and accountable to the Secretary of State for Children, Schools and Families.

Donor Conception Network is a self-help support group and registered charity of over 1,000 member families throughout the UK.

National Association for Guardian ad litem and Reporting Officers (NAGALRO) is the Professional Association for Family Court Advisers and Independent Social Work Practitioners and Consultants.

UK DonorLink runs the Department of Health funded UK information exchange and contact voluntary register for adults genetically related through donor conception.

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