

## Parliamentary Briefing on Human Fertilisation and Embryology Bill

**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), Donor Conception  
Network, National Association for Guardian *ad litem*s and Reporting  
Officers (NAGALRO) and UK DonorLink (UKDL)  
May 2008**

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.

Additionally, we welcome the government's decision to retain the requirement placed on clinics to consider the **welfare of the child** that may be born, and any existing children, prior to offering treatment. We welcome the amendments brought forward in the Bill in the House of Lords that will require the HFEA to produce guidance in the Code of Practice about how to offer **counselling** when prospective parents are contemplating the use of donated gamete(s) and the **information** that should be provided, including the **need to inform a child at an early age** - and to make this a licence condition.

However, there are some important gaps in the Bill that, drawing on our areas of shared interest and concern, we would wish to be addressed as a matter of urgency. Please note that these are not presented in order of priority as we consider each of the issues presented to be of prime importance:

### **1. Inclusion in the Bill of an explicit statement of core principles**

We believe that the Act should contain a **statement of core principles** that must be applied in administering the Act, in the performance of functions under this Act, and in the performance of activities regulated by this Act. Such statements are evident in similar legislation in other jurisdictions (e.g. Human Reproductive Technology Act 1991 - Western Australia; Infertility Treatment Act 1995 – Victoria; Assisted Human Reproduction Act 2004 – Canada; Human Assisted Reproductive Technology Act 2004 - New Zealand; Assisted Reproductive Technology Act 2007 - New South Wales – see Appendix A).

We suggest that the following statement of core principles should be considered for inclusion:

1. The **best interests of children** affected by the application of assisted human reproductive procedures both during their childhood and throughout their lives should be protected and promoted;
2. Appropriate measures should be taken to **protect and promote human health, safety, dignity and rights** in the use of assisted human reproductive procedures, recognising that **women, more than men**, are directly and significantly affected by the application of such procedures;
3. The principle of **free and informed consent** should be a fundamental condition of the use of assisted human reproductive procedures;
4. The **reproductive capacities of both women and men should not be subject to commercial exploitation**.
5. The different **ethical, spiritual, and cultural perspectives in society should be considered and treated with respect**.

## 2. Need for intermediary services

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 may include professional counselling as one part of their service, the provision of counselling alone is not sufficient in this context. It is essential that this is 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.<sup>1</sup>

## 3. Unique donor identifier number

It is essential that each donor has a unique identifier number that can be provided to:

- any recipient of eggs, sperm or embryos provided by the donor and
- any person conceived as a result of the donation of eggs, sperm or embryos by the donor, when seeking identifying information from the Register of Information

This **number should be assigned by the HFEA** rather than the treatment centre in order that the same identifier is not given to more than one donor and the number could not lead to identification of the donor.

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<sup>1</sup> British Infertility Counselling Association 2003; Clapton 2006; Crawshaw and Marshall *accepted for publication*; Crawshaw *et al.*, 2007; Howe and Feast 2000; Trinder *et al.*, 2004.

#### 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. We welcome the government's recognition of the inadequacy of this provision. However 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 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.**

## **8. Surrogacy arrangements**

Progar considers surrogacy arrangements to be **among the most complex** for those contemplating parenthood and for the families thus formed or affected. As stated at the beginning of this Briefing, we support the Bill's proposals to strengthen the counselling and information requirements for those considering the use of donor assisted conception and believe that this **should apply in all cases where surrogacy is contemplated, regardless of whether the use of donated gamete is proposed.**

Additionally, Progar urges that the **grounds for the making of a parental order should be amended** to mirror those pertaining to adoption. In particular, the law should **enable an application for a parental order to be made (subject to the order continuing to be in the child's best interests) in the rare event of the death of one of the commissioning parents** either before an application for the order has been made or the order has been granted.

All parental order applications **should be heard in County Courts** in England and Wales (and their equivalents in Scotland and Northern Ireland).

### **References**

British Infertility Counselling Association (2003) *Opening the Record* Sheffield, BICA Publications

Clapton G. (2006) 'Mediated contact – reflections on a piece of after-adoption intermediary practice' *Adoption and Fostering*, 30 (4) pp 53-63

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Crawshaw M. and Marshall L. 'Practice experiences of running a voluntary information exchange register for adults related through donor conception' *Human Fertility accepted for publication*

Howe D. and Feast J. (2000) *Adoption, search and reunion: the long term experience of adopted adults* London, The Children's Society

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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.

**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 pilot UK information exchange and contact voluntary register for adults genetically related through donor conception

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## Appendix A:

Included below are *selected* (but not necessarily complete) statements of principles from other countries' legislation:

### Victoria: Infertility Treatment Act 1995 - Guiding principles

(1) It is Parliament's intention that the following principles be given effect in administering this Act, carrying out functions under this Act, and in the carrying out of activities regulated by this Act—

- (a) the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount;
- (b) human life should be preserved and protected;
- (c) the interests of the family should be considered;
- (d) infertile couples should be assisted in fulfilling their desire to have children.

### Canada: Assisted Human Reproduction Act 2004

WHEREAS the Parliament of Canada

- acknowledges the benefits to individuals and to society in general of assisted human reproductive technologies;
- believes that those benefits can be most effectively secured by taking appropriate measures for the protection and promotion of human health, safety, dignity and rights in the use of such technologies;
- appreciates the paramount need for measures to protect and promote the best interests of children affected by the application of those technologies;
- recognizes that, while all persons are affected by those technologies, women more than men are directly and significantly affected by their application;
- wishes to promote the principle of free and informed consent as a fundamental condition of the use of human reproductive technologies;
- recognizes the health and ethical concerns inherent in the trade in the reproductive capacities of women and men, and in the exploitation of children, women and men for commercial ends;
- recognizes the importance of preserving and protecting human individuality and the integrity of the human genome

### New Zealand: Human Assisted Reproductive Technology Act 2004 - Four Principles

All persons exercising powers or performing functions under this Act must be guided by each of the following principles that is relevant to the particular power or function:

- (a) the health and wellbeing of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure:
- (b) the human health, safety, and dignity of present and future generations should be preserved and promoted:
- (c) while all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application, and the health and wellbeing of women must be protected in the use of these procedures:
- (d) no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent:
- (e) donor offspring should be made aware of their genetic origins and be able to access information about those origins:
- (f) the needs, values, and beliefs of Maori should be considered and treated with respect:
- (g) the different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect.