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# **Written Submission from the British Association for Adoption and Fostering to the Joint Committee on the Draft Human Tissue and Embryos Bill**

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June 2007



## 1: Background

- 1.1. BAAF is the leading charity and membership organisation in adoption and fostering in the UK. BAAF's main activities are the development, promotion and advocacy of best policy and practice; the provision of advice and information to our members and to the general public; training, consultancy and seminars; child placement services including the publication of our flagship monthly newspaper, Be My Parent. We also publish a quarterly professional journal, *Adoption and Fostering*, books and guides for professionals, academics, parents and carers and research studies. The main users of our services are our members comprising local authorities across England, Scotland Wales and Northern Ireland, voluntary adoption agencies, independent fostering agencies and also individual social work, legal and medical professionals and carers. We are a child-centred organisation, and have a vast amount of knowledge and experience about the needs of children and young people who are brought up with parents and carers who are not genetically related.
- 1.2. We have learned a great deal from adopted adults about their experiences of being adopted and the importance of having the opportunity and choice to obtain more information about their genetic background. We hope that our input can help ensure that future legislation strikes the right balance, so that not only are prospective parents receiving help and support, but also that the life long needs of people born as a result of donor conceived are not overlooked. We have a longstanding interest in this area, with the BAAF Medical Group raising concerns about the implications of what was then only AID, even before the establishment of the Warnock Committee. The BAAF Health Group, which is also a Special Interest Group of the Royal College of Paediatrics and Child Health, continues to review relevant developments in the area of donor conception.

## 2: Comments on Draft Bill

- 2.1. We are limiting our comments to those areas in the draft bill on which we have relevant input.

BAAF welcomes some of the proposals in the draft Bill and is pleased that it is building on the decision to promote the rights of donor conceived people to information, including identifying information, about their origins as in the HFEA (Disclosure of Donor Information) Regulations 2004. However, we are concerned that the draft Bill does not include any measure to ensure that donor conceived people will be able to utilise this right, since they may never be informed of their donor conceived status.

### **We support the following (in no particular order of priority):**

- 2.2 **Affirmation of the need for statutory regulation of treatment and Research**, particularly where this involves the use of donor gametes, and for this duty to be transferred to the RATE.
- 2.3 **Welfare of the child**. We welcome the proposal to retain a duty for treatment centres to consider the welfare of the child who may be born as a result of treatment, or any other child who may be affected, before offering treatment, and

the decision to remove the reference to the need for a father in the current legislation. However we do not consider that this is sufficient. **See 3.4.**

- 2.4 **Information for donor-conceived people regarding genetic half siblings.** We welcome the new provisions that will create opportunities for a donor-conceived person to ascertain the existence and (by mutual agreement) the identity of donor-conceived genetic half siblings. However we are very concerned that donor conceived people will not be able to take up this opportunity if they have not been informed of their donor conceived status.
- 2.5. **Donors' rights to information.** We welcome the extension of donors' rights to information about those conceived from their donation.
- 2.6. **Voluntary Contact Register.** We support the proposal to give power of authority to RATE to provide, or arrange to have provided, Register services to those genetically related through donor conception if conceived prior to the enactment of the HFE Act.
- 2.7 **Counselling.** We support recognition of the need for counselling to be made available for those seeking treatment services and for those proposing to donate their gametes. However we consider that this needs to be obligatory for prospective parents of donor conceived children as well as for people proposing to donate their gametes. **See 3.5.**
- 2.8 **Not-for-profit surrogacy agencies.** We welcome the provisions to clarify the operation of not-for-profit agencies facilitating surrogacy arrangements, but see our further comments in **3.13.**

### **3: Areas that we would like to see included**

- 3.1. **Statement of principles.** We believe that the Bill should include an explicit statement of core principles. We would like to see that one of the core and underlying principles of the Act is to ensure that donor conceived people are able to have the choice and opportunity to access information and this should be recognised within the statement of principles.
- 3.2 **The right for donor conceived people to know their genetic origins.** The draft Bill does not address the issue of the importance of the child being told the truth about his/ her genetic origins. Living with the burden of deceit can impact on family functioning and family relationships. The experience of donor conceived adults who have found out later in life about their donor status shows that it is very distressing to discover they have been misled. Donor conceived people have a basic right to know their genetic origins. Without this they will not have the opportunity to access information that may have a profound impact on their life, for example medical information. The significance of genetic inheritance in health, well being and the body of knowledge about predisposition to illness and treatment is growing, and therefore it is irresponsible to ignore this. Advances in medical science and the importance of genetic testing in diagnosing and treating medical conditions, underlines the importance of donor-conceived people being informed of their donor status.

**3.3 Registration of donor conceived births.** BAAF would like to see an urgent review of how children born as a result of donor-assisted conception have their status reflected in official records. This proposed legislation provides an opportunity to consider whether the existing method of birth registration is still the most suitable way of officially recording information about a person's birth and status. Until 1987 the Register of Births was, except where individuals knowingly or unknowingly gave false or incomplete information, by and large an accurate record of the child's genetic origin. Subsequent developments in the technology of human fertilisation and legislation have brought about a situation where, quite legally, the Register may record a legal fiction, and there is no presumption that the person shown as a parent in the Register is genetically related to the child. In the case of adoption, a separate Register exists, and access to the link between the identity of an adopted person as shown in the Adopted Children Register and his or her original identity as shown in the Register of Births is restricted to those who have a personal right to that information. While the method of recording the fact that a child has been born as the result of the use of donated gametes, without unnecessarily intruding on the privacy of each family, needs sensitive consideration, we would like to see a debate about the way to ensure that donor conceived people have the necessary information about the circumstances of their birth to enable them to make further enquiries – if they so wish – as to their genetic origins.

**3.4 Welfare of the child.** In other family legislation the child's welfare is regarded as the paramount consideration. This is not to say that the rights of parents are ignored, but they, as adults, are able to make informed choices; the child has not made the choice and his or her position and rights need to be especially respected. We consider that there needs to a regulated and standardised requirement for clinics to ensure that the child's welfare has been properly addressed.

The welfare requirements should be specified in primary legislation to require a treatment centre to take all reasonable steps to satisfy itself that neither the child to be conceived, nor any existing child affected by that child's birth (i.e. any existing child in the family of the recipient(s), donor or surrogate) is likely to experience *significant harm* as a result of providing the treatment.

While we acknowledge that there are many differences between adoption and assisted reproduction using donor gametes, there is a strikingly wide contrast between the stringent requirements and enquiries in the case of a proposed adoption, and the very much looser obligations in respect of enquiries into the welfare of a child in assisted reproduction. We note, for example, the comment in the Explanatory Notes on clauses 42 and 43 (paragraph 156) in connection with the appropriate consent for the purpose of identifying the father of a child, which implies that the woman concerned may have identified a string of different potential fathers at different stages of her treatment, surely raising questions about the stability of the relationship into which the child is to be born, in contrast with the requirement in the Adoption and Children Act 2002 for the adoption agency to consider the stability and permanence of the relationship of any couple who wish to adopt.

**3.5 Preparation and information for prospective parents of donor conceived children.** Although the draft Bill makes provision for prospective parents of donor

conceived children to be offered counselling, this is not obligatory and many may choose not to take up this offer. We cannot ignore the lessons we have learned from adoption. Parenting a child who is partially, or not at all, genetically related, raises unique issues and this should be acknowledged in legislation. BAAF would like to ensure that future legislation makes it obligatory for prospective parents to attend counselling, preparation and information sessions prior to receiving donated gametes so that they can think about the particular and pertinent issues relating to parenting a child who is not genetically related to either one or both of them.

We would like to see parents of donor conceived children supported and helped to be confident in telling the truth to their son/daughter about their genetic origins. Parents may be afraid that by telling the truth they will undermine the strength of their relationship with their son/daughter, but we know from adoption that this is not the case. Research has shown that adopted people develop loving, strong and enduring relationships with their adoptive parents.

- 3.6 Information for donor-conceived people regarding genetic half siblings.** In addition to the existing proposals, we consider that such entitlements (with similar safeguards) should be extended to (a) people conceived as the result of a surrogacy arrangement; (b) the children of donors and surrogates; (c) descendants of those in (a) and (b) above.
- 3.7 Access to information for people contemplating marriage/civil partnership.** In our view, the provisions currently enabling persons intending to marry to find out whether they are related as a result of gamete donation should be extended not only to persons intending to form a civil partnership – as is currently proposed – but also to any two persons aged over 16. Given that such a clause is primarily to do with risks of consanguinity, it is sexual activity rather than contemplation of marriage or a civil partnership that provides the risk and the law should reflect this.
- 3.8 Voluntary Contact Register.** We would like the voluntary register of donor conceived people and donors to be extended to people born after August 1991 and before April 2005, and also for people who donated during that period.
- 3.9 Recipients to be notified when a donor re-registers as 'willing to be known'.** Revised legislation should make provision for formal notification of a previously-anonymous donor's re-registration as 'willing to be known' to be provided to all persons who have conceived children using the gametes or embryos of that donor.
- 3.10 Provision of counselling and intermediary services.** We consider that the government has a responsibility to ensure that adequate counselling and intermediary services are available when individuals seek information from either the RATE Register of Information or the Voluntary Contact Register. This includes specifying both who should be responsible for providing such services and ensuring that they are adequately resourced. Experience from the field of adoption and other 'tracing' services suggests that the primary need for those seeking information and/or contact with genetic relatives is for implications counselling and support and for intermediary services.
- 3.11 Protection of "pre 1991 donors" from liability.** Reassurance to past donors and their families should be provided by affording them the same protection from

liability as is given to donors under the provisions of the Human Fertilisation and Embryology Act 1990.

- 3.12 **Protection of “pre 1991 records” from destruction.** Records that pre-date the enactment of the HFE Act are not afforded the same level of protection as are those for later treatments. All possible steps should be taken to protect from the risk of destruction of all existing records of donor procedures undertaken in the UK before implementation of the Human Fertilisation and Embryology Act.
- 3.13 **Operation of not-for-profit surrogacy agencies.** In addition to the existing proposals, we believe that adequate standards of care would be better assured if such agencies were to be formally registered with, and inspected by, the RATE.

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14 June 2007