

Written submission from the British Association of Social Workers Project Group on Assisted Reproduction (PROGAR) to the Joint Committee on the Draft Human Tissue and Embryos Bill – June 2007

1: Background

1.1. The British Association of Social Workers Project Group on Assisted Reproduction (PROGAR) was established in the 1980s originally to provide evidence on behalf of BASW to the Warnock Committee of Inquiry into Human Fertilisation and Embryology. Since then PROGAR has consistently contributed to policy discussions and policy formation in assisted conception, working in partnership with British Association for Adoption and Fostering, the British Infertility Counselling Association, and the Donor Conception Network.

1.2. The principles underlying PROGAR's work are that people with a personal involvement with fertility problems, especially those conceived as a result of donor procedures, donors of gametes and embryos and people undergoing investigation and treatment should receive the best care possible, including access to information, counselling and support.

2: Comments on Draft Bill

2.1. PROGAR welcomes many of the provisions in the Draft Bill, especially those that build on the HFEA (Disclosure of Donor Information) Regulations 2004, and those that:

- revise **status and legal parenthood** provisions to enable a greater range of persons to be recognised as legal parents following surrogacy and donor conception
- prohibit **sex selection** for non-medical purposes
- bring within the regulatory framework **fresh gamete and internet supply services**.

In addition, we support the following (in no particular order of priority):

2.2 **Affirmation of the need for statutory regulation of treatment and research** – 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.

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.

2.5. Donors' rights to information – we welcome the extension of donors' rights to information about those conceived from their donation and donors' rights to be informed when anyone thus conceived approaches the HFEA for identifying information about them.

2.6 Extension of rights to information for people contemplating entering marriage/ civil partnership – we consider this to be appropriate.

2.7. 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.

2.8 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 gamete.

2.9 Not-for-profit surrogacy agencies - we welcome the provisions to clarify the operation of not-for-profit agencies facilitating surrogacy arrangements.

2.10. Capacity and consent for storage of gametes – we welcome the proposals to enable those, including legal minors, that lack the capacity or competence to consent to storage of their gametes to be enabled to access storage until such time as they are able to provide consent as to its ongoing storage or use. We support the proposal that consent to treatment using such stored material should only be with the explicit consent of the person from whom the gamete is obtained.

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. Such statements are evident in similar legislation in other jurisdictions.

3.2 Welfare of the child: We consider that reformulated 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.

3.3 Age at which (a) donor-conceived people can access identifying and non-identifying donor information on the RATE Register of Information and (b) people subject to a Parental Order can access information about their birth – we believe that the age at which this information should be accessible should be reduced from 18 to 16 years. Retaining the status quo maintains anomalies regarding access to information concerning Adoption and Parental Orders in Scotland compared to the other UK nations. While we accept that this matter is made complex by issues relating to devolved powers and to adoption provisions, we consider that the opportunity should be taken to ensure more coherent UK-wide

arrangements for accessing personal information in the case of gamete and embryo donation, surrogacy and adoption. Such anomalies are inconsistent with the government's wider agenda to promote young people's autonomy.

3.4 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.

3.5 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.

3.6 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.

3.7 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. A smaller number may require therapeutic counselling services. This has also been found to be the case by UK DonorLink, who is running the pilot Voluntary Contact Register for those conceived through donor conception prior to August 1991.

3.8 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.

3.9 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 that those for later treatments. All possible steps should be taken to protect from the risk of destruction all existing records of donor procedures undertaken in the UK before implementation of the Human Fertilisation and Embryology Act.

3.10 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.

3.11 Consent to disclosure requirements

Existing 'consent to disclosure' requirements are inimical to effective patient care and are out of step with the climate of openness promoted by the Government through the 2004 Regulations. In our view, they should therefore be removed from the current legislation.

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