

HFEA

WELFARE OF THE CHILD

## Consultation Response

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## **ABOUT BAAF**

The British Association for Adoption & Fostering (BAAF) is pleased to respond to this consultation.

BAAF is the leading charity and membership organisation in fostering and adoption in the UK. We:

- promote the highest standards of child-centred policies and services
- speak out on behalf of looked-after children
- influence UK-wide policy and legislation
- provide much-needed information and advice
- promote greater public understanding of adoption and fostering
- support our members in their work

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 and Wales, voluntary adoption agencies, independent fostering agencies and also individual social work, legal and medical professionals and carers. We are currently developing our service to Northern Ireland.

## **GENERAL**

### **Question 1:**

**Please give any general comments you might have about the current guidance in the code of practice regarding the welfare of the child assessment.**

At present within the HFEA guidance, the welfare of the child is one factor that clinics are required to take into account. We think that it needs to be the first consideration. We believe, however, that there is an important distinction between cases using the parents' own gametes and those who use donated gametes.

For children who have been created as a result of using donated gametes, we believe that more responsibility and emphasis needs to be taken when making an assessment of the future emotional and psychological well-being of the child to ensure their needs will be met.

We accept that current legislation is not completely satisfactory. In both adoption and surrogacy the system of registration of births makes it apparent that the child was born to a parent other than the one named on the certificate, so there is no

encouragement of secrecy. But when a child is born using donor gametes or donated embryo, details of its genetic origins are discretionary and optional. In the past, parents were often encouraged not to disclose the truth to their child. We believe that attitudes have changed (as exemplified by the recent regulations entitling a donor conceived adult to identifying information about the donor in the future) and it is much easier than it perhaps was in the past to encourage parents to be open with their child. Honesty should therefore be promoted, with an expectation that parents will tell the child the truth about his or her origins.

## **ENQUIRIES TO BE MADE**

### **Question 2:**

**Which of the following options best reflects your view on the enquiries that clinics should be expected to make in order to gather relevant information for the welfare of the child assessment?**

- a) No welfare of the child enquiries should be made**
- b) Information about risk factors should be provided by the patient(s) themselves**
- c) Information about risk factors provided by the patient, plus follow-up to a third party if a problem is identified**
- d) Information about risk factors provided by the patient, plus follow-up to the GP routinely**
- e) Information about risk factors provided by the patient, plus follow-up to the GP and other agencies routinely**
- f) None of the above**

We recommend a combination of D and E.

D. When there is a full genetic relationship between both parents and gamete.

E. Should apply when there is a donated gamete or surrogacy.

We base this response on our extensive experience of working with children, young people and adults who have been raised by people other than their genetic parents. Experience and research has shown that social parenting presents additional challenges and these should not be ignored when assisting prospective parents to create a family using donated gametes. These challenges include:

- parenting a child with genetic traits and characteristics which may be very different from the social parents and with which they may feel uncomfortable;
- assisting a child feel comfortable with these differences and accept them;
- ensuring the wider family understands the child's different origins and that it does not become a "family secret" with all the risks this may present; and
- the impact on the couple's relationship where only one partner may be the genetic parent.

Not to do this is irresponsible and wrong as without such checks, how can we say that proper consideration has been given to the welfare of the child. In adoption, it is always necessary to involve the prospective adopter's GP. BAAF supports a network of advice and involvement from Medical Advisors to adoption agencies who have a wealth of expertise in these matters.

**Question 3:**

**Do you think that refusal by a patient to give consent for a centre to contact their GP should be taken into account when deciding whether or not to provide treatment?**

Yes most certainly when using donated gametes. Creating a child from donor-assisted conception has profound implications for the donor-conceived child, the prospective parent and other family members. As state intervention is needed to help these prospective parents conceive, it cannot be viewed as an entirely private decision. We would have concerns about the reasons for the prospective parents' unwillingness for the GP to be contacted. If a clear explanation is given by the clinic, we consider prospective parents should accept the reason for this enquiry.

**FACTORS TO BE TAKEN INTO ACCOUNT**

**Question 4:**

**Which of the following options best reflects your view on the factors that should be taken into account during the welfare of the child assessment?**

- a) Only risk factors for medical harm should be taken into account.
- b) Risk factors for medical, physical and psychological harm should be taken into account.
- c) Risk factors for medical, physical and psychological harm and social circumstances should be taken into account.

C. Social circumstances are significant and must be addressed because these will impact on the child's well being. For example, in situations where there are concerns about age, we consider it important to ensure that the parent(s) have the necessary health and vigour to parent the child through childhood to adulthood, or that there should be a supportive network of family and friends available where some health risks are identified.

A thorough assessment of risk factors is crucial and necessary to ensure that people who are convicted or suspected of paedophilia, or who have failed to parent safely other children, leading to the statutory involvement of other agencies, are not assisted to produce children who may subsequently be at risk of abuse.

It is important to minimise the possibility of a child being conceived purely to meet the needs of others.

**Question 5:**

**Would you welcome guidance from the HFEA on how to take into account the factors mentioned above?**

Yes. These are very complex issues and considerable insight is needed to fully understand the implications.

The guidance needs to be informed by multi-disciplinary input, not just the views of the medical and scientific professions. There needs to be standardised application of protocols in fertility clinics to ensure that practice and services are consistent and that time is not wasted in developing and testing procedures and documentation that has already been brought into effective use elsewhere.

We would like the guidance to address the need for role models of both genders for every child who is created and also identify the long-term care plan of a child that may be orphaned.

**WELFARE OF THE CHILD ASSESSMENTS FOR PARTICULAR TREATMENTS**

**Question 6:**

**Which of the following options best reflects your view on the assessment that should be carried out during donor conception treatment?**

- a) When patients are having donor conception treatment, the same welfare of the child assessment as patients using their own gametes should be used and no extra information should be provided.
- b) When patients are having donor conception treatment, the same welfare of the child assessment as patients using their own gametes should be used. However, donor conception patients should receive extra information and preparation for becoming the parent(s) of a donor conceived child.
- c) When patients are having donor conception treatment, a more thorough welfare of the child assessment should be made and patients should receive extra information and preparation for becoming the parent(s) of a donor conceived child.

We believe that C is appropriate. Research has shown that both adoptive and step-parent families are often unprepared for the particular challenges, differences and difficulties that can present themselves when parenting a child to whom there is no genetic relationship.

This has been recognised in recent adoption legislation through the provision of post adoption support.

In situations where prospective parents need to use donated gametes, at least one parent will face these additional parenting challenges. Both parents need to have addressed the additional tasks and emotional issues involved in parenting a child who is not genetically related to one or both parents. They should be given the opportunity to obtain more knowledge and a greater understanding of what is involved so that they can understand the child's perspective and feel comfortable and able to answer the child's questions.

#### **Question 7:**

**If you opted for either 6b or c what kind of assessment and or preparation for the donor conception patients is desirable?**

We consider that not only is assessment necessary and crucial but that a sound assessment can only be made if preparation has been provided to the potential patient. The preparation should precede the assessment. People can then make an informed choice about whether to proceed.

The preparation should promote a spirit of openness. The preparation could also include the opportunity to provide a forum, which would allow potential patients to meet with other people in a similar situation. It would be helpful to include parents of donor conceived children, and also donor conceived young people and adults, so that they can hear the perspective of the various parties and learn from these. Within this forum they could also learn of other sources of support and information available, such as reading lists, videos, DI networks etc and how to access a support group.

The preparation process could help prospective parents understand the importance of being open with the child about his or her origins and introduce them to the support services available to help them manage this. It will prepare them for the fact that their children may look physically different from them and may also have very different characteristics. Children need to be celebrated for their individuality and unique characteristics where heredity may have played a part.

The subsequent assessment should evaluate the extent to which the patients have been able to grow in their understanding of these crucial issues and also assess whether the parents have any unresolved issues about their own infertility. These may emerge when the child reaches adolescence and becomes sexually potent.

#### **Question 8:**

**Which of the following options best reflects your view on the assessment that should be carried out for patients undergoing unlicensed treatments in licensed clinics?**

- a) When patients are undergoing unlicensed treatments, the same welfare of the child assessment as those undergoing licensed treatments should be used.**
- b) When patients are undergoing unlicensed treatments, a less thorough welfare of the child assessment than those undergoing licensed treatments should be used.**

We would suggest B.

**Question 9:**

**Please give any general comments you might have about the welfare of the child principle and its interpretation in clinical practice.**

We recognise that many patients requesting infertility treatment will feel concerned and unhappy about being subject to a “vetting” procedure which they feel is unfair because it is not applied to other prospective parents in the community. They already may be sensitive about their infertility and the intrusive treatment they require in order to allow them the opportunity of conceiving a child. However this cannot be sufficient reason for the state failing to take some responsibility for a decision which leads to the birth of a child which would otherwise not be born. It is possible to identify from relatively simple enquiries (i.e. health checks with GP or an assessment interview with the patient) whether there are factors which would seriously affect the welfare of any child which might be created, and we consider such checks should continue. There should, however, be greater clarity about the factors explored in this assessment and how they are recorded. It is not acceptable, for example, to create children whose development may be adversely affected by pre-natal maternal drug or alcohol abuse, whose parent(s) have a lifestyle which prevents them from being safe parents or whose parent(s) have already abused or neglected other children.

In addition, there needs to a real culture change if we are to ensure that the welfare of the child is properly addressed in situations when people have to use donated gametes to create a child. All children should have the opportunity to gain truthful information about their genetic origins, and the fact that s/he is not genetically related to one or both the parents who are named on the birth certificate. In our society, where great value is placed upon truth and honesty, the importance of honesty between parents and children should never be underestimated. If clinics fail to offer effective preparation the whole system of assessment becomes flawed and we are all complicit in promoting state sponsored lies. The inspection of clinics must be expected to check that the assessment of the child’s welfare is being properly carried out.

We believe that potential donors of gametes, who may later be traced by their adult genetic children, would not wish that gametes be given to such parents and

there could be a lot of anger from adults conceived in these circumstances towards their donors who made a “casual” decision without due regard to the welfare of their subsequent children.

There is a basic right for a child 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.

Part of the information, preparation and counselling process is to help assess the prospective parents’ ability to be open with the child about his or her genetic heritage. Equally important is ensuring the potential parents are aware of the complexity of the situation so they do not simply see the receipt of donor gametes as a routine treatment for infertility with no particular implications. The patients need full information in order to make an informed decision as to whether or not to proceed with this type of treatment.

Patients should be fully aware of the detrimental effect that maintaining the secret of the child’s genetic make up and donor conceived status can have on the family and particularly the child. Learning the truth about their donor conceived status, for example, at a time of a family crisis can have a profound and unsettling impact on the child and must be avoided. Patients/prospective parents should be given the support and help they need to tell the child about his or her genetic heritage. This help and support may need to be accessed at different times throughout the child’s childhood. It should be expected that the patients would bring the child up in a spirit of openness.

The code reads well and give the right pointers for undertaking the welfare of the child assessment but there needs to be a way of ensuring that treatment centres adhere to the practice that is promoted in the HFEA guidance and that further consideration is given to who should have responsibility for the assessment interview and how it should be recorded.

We are concerned by the complete absence of any consideration of “any other child who may be affected by the birth”. This is an ambiguous element of Section 13(5).

The failure to consider the provision of services to people in relation to the HFEA Register and to the needs of donor conception families over time is of great concern. It is a matter for regret that there is no statutory obligation on clinics – or on any other body - to provide support and counselling for parents and children as and when required. Pending any change in legislation, clinics should be encouraged to consider how they can best ensure that these continuing and future needs are met.

**BAAF April 2005**