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7 April 2005

Consultation response to the Human Fertilization and Embryology Authority (HFEA)

Tomorrow's Children: A consultation on guidance to licensed fertility clinics on taking in account the welfare of children to be born of assisted conception treatment

The **Scottish Council on Human Bioethics** (SCHB) is grateful to the **Human Fertilisation and Embryology Authority** (HFEA) for this opportunity to respond to its consultation on guidance to licensed fertility clinics on taking in account the welfare of children to be born of assisted conception treatment entitled **Tomorrow's Children**. It welcomes the HFEA's intent to promote public understanding and discussion on this topic.

In addressing the consultation, the SCHB has formulated the following responses:

Applicable United Kingdom Legislation

Human Fertilisation and Embryology Act 1990:

The SCHB notes that the Human Fertilisation and Embryology Act 1990 has addressed the topic of taking into account the welfare of children to be born of assisted conception treatment with the following Sections:

Section 13:

(5) A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father) and of any other child who may be affected by the birth.

Section 25:

(1) The Authority shall maintain a code of practice giving guidance about the proper conduct of activities carried on in pursuance of a licence under this Act and the proper discharge of the functions of the person responsible and other persons to whom the licence applies.

(2) The guidance given by the code shall include guidance for those providing treatment services about the account to be taken of the welfare of children who may be born as a result of treatment services (including a child's need for a father), and of other children who may be affected by such births.

United Kingdom - Adoption and Children Act 2002:

The SCHB notes that the Adoption and Children Act 2002 has addressed the topic of adoption of children in the following Sections:

Section 1 - Considerations applying to the exercise of powers

Relevant paragraphs:

(2) The paramount consideration of the court or adoption agency must be the child's welfare, throughout his life.

(4) The court or adoption agency must have regard to the following matters (among others)-

> *(c) the likely effect on the child (throughout his life) of having ceased to be a member of the original family and become an adopted person,*
>
> *(e) any harm (within the meaning of the Children Act 1989 (c. 41)) which the child has suffered or is at risk of suffering,*
>
> *(f) the relationship which the child has with relatives, and with any other person in relation to whom the court or agency considers the relationship to be relevant, including-*
>
>> *(i) the likelihood of any such relationship continuing and the value to the child of its doing so,*
>>
>> *(ii) the ability and willingness of any of the child's relatives, or of any such person, to provide the child with a*

secure environment in which the child can develop, and otherwise to meet the child's needs,

(iii) the wishes and feelings of any of the child's relatives, or of any such person, regarding the child.

(5) In placing the child for adoption, the adoption agency must give due consideration to the child's religious persuasion, racial origin and cultural and linguistic background.

(8) For the purposes of this section-

(a) references to relationships are not confined to legal relationships,

(b) references to a relative, in relation to a child, include the child's mother and father.

Possible psychological harms to children born of assisted conception

The HFEA consultation document indicates that :

"Studies conducted over the past decade suggest that, despite initial concerns, children born to lesbian couples compare well with other assisted conception children in terms of emotional, behavioural and gender development."

However, the SCHB notes that such a statement could lead to misconceptions since it is not because children born to lesbian couples compare well, psychologically, with other assisted conception children that there will not be any possible complications in the future. The studies undertaken so far are incomplete and have often only examined pre-adolescent children. These may not be as concerned about their identity or their family circumstances as when they grow older. It is possible that these children may only become aware of any psychological problems when they become adults or consider having children of their own later on in life.

Concerning the welfare of children created through donated eggs or sperm, the SCHB is concerned with the confident manner in which the HFEA consultation document indicates that:

"the psychological wellbeing of children who are not genetically related to one or both of their parents compares well with that of their naturally-conceived counterparts."

Again, the SCHB notes that this statement could be misleading since all the evidence remains very preliminary .

The SCHB thus agrees with the HFEA that a lot more research is needed in these areas which should take place over a number of decades.

The SCHB notes, in addition, that there seems to be a lack of openness concerning assisted procreation through donated eggs or sperm. This apprehension is reflected in published reports which suggest, for example, that when Assisted Insemination by Donor (AID) has been used, the commissioning (non-genetic) father is significantly more reticent than the commissioning (genetic) mother of informing the child of its biological origins. Moreover, it has been indicated that only 21% of AID parents, in the Netherlands, have decided to inform their child of the way in which they were conceived compared to 94% of parents who have not used AID .

More recently, researchers found that in 46 families in England with a child up to age of eight who had been conceived through sperm donation only 13% of parents had already told their child of his or her conception circumstances with 26% saying that they intended to inform their child. But 43 % had decided against it and 17% were still unsure what they would do , .

And an earlier European study of donor insemination families in the UK, Italy, the Netherlands and Spain found that only 12% of the mothers had planned to tell the child about his or her conception procedure, while 75% had decided not to do so. By the time the children reached 11-12 years old, only 8.6% of parents had told their children about their conception procedure .

This is all the more worrying since 50% of donor insemination children suspect, when growing up, that their social father may not be their genetic one before being told .

In conclusion it should be noted that all the studies undertaken so far on the psychological welfare of children born to a number of different types of assisted conception families are preliminary. Therefore, it would be irresponsible and improper to draw any solid conclusions from them until a few further decades of research results have been considered.

Concerns relating to the HFEA's ethical values

The SCHB was concerned about the HFEA's perceived ethical values in addressing the different welfare principles for the prospective children.

In paragraph 2.4. of the HFEA consultation document, the statement seems to imply that only a 'good chance of living happy and fulfilled life' is important for the prospective child born of assisted conception treatment. This is unfortunate since it is a very utilitarian way of considering human life and is devoid of any meaning. Some of the greatest persons in the history of humankind did not live 'happy and fulfilled lives' but no one could deny that they did not live meaningful lives.

When such utilitarian language is being used in a consultative document it is difficult for respondents to agree to any of the proposed responses.

Private versus Public Domains of Assisted Reproduction

In the normal process of human reproduction, persons will generally decide for themselves the context in which they choose to have a child. They will thus choose their partners, the specific point in time when they want a child etc. However, as soon as a person or couple is prevented from having a child in a 'private' manner because of natural limitations and seek assistance from the state to overcome these limitations, a discussion is then initiated concerning the conditions set by the public domain with respect to assisted reproduction.

For example, the House of Commons Science and Technology Committee indicated in its report entitled ***Human Reproductive Technologies and the Law*** that:

"it might be argued that the mere fact of third party involvement is enough to render the behaviour in question public rather than private."

But the committee then went on to conclude that any prior conditions concerning the creation of a child set by regulations in assisted reproduction are arguably leading to inconsistency and discrimination against certain groups or individuals based on the cause of their infertility rather than on any other ethical basis .

The report fails however, to understand that society has always had a moral role in the provision of regulations when help is sought from the public domain. Legislation is indeed generally drafted from ethical principles which are themselves always the reflection of moral beliefs. And in the context of human reproduction, society has accepted that the ethical creation of children should also be based on the welfare of the prospective children and not only to fulfil the wishes of parents.

Thus when society is asked (through its health care professionals) to assist a person or couple to create a child it then also has an inherent responsibility to make sure that the welfare of the child is taken into account through providing conditions which will protect the child from certain risks or harm.

This is similar to the legislation relating to adoption in the UK in which society has been given the responsibility of children and therefore seeks to provide the best outcome for these children in the consideration of their welfare.

In the ***Informal Summary of the House of Commons Science and Technology Committee Report*** it is also indicated that *"[r]eproductive freedoms must be balanced against the interests of society but alleged or potential harms to society or to patients need to be demonstrated with evidence before technological developments are prohibited"* it then goes on to state that *"the HFEA's use of evidence falls short of these ideals" and that the HFEA "has employed an excessive use of the precautionary principle"*.

But the MPs seem to have overlooked the proportionality principle when considering the precautionary principle. The proportionality principle indicates that, in any ethical analysis, the advantages should be examined against the risks (even when only limited evidence for these risks exist). In association with the precautionary principle this means that if any serious risks for the welfare of the future child exist resulting from a procedure in assisted procreation then this procedure should not take place.

In the House Commons report Professor John Harris from Manchester University indicates that *"[t]here are many arguments from many sides, which purport to give reasons for limiting access to reproductive technologies ... There is one reason to reject them all, and that is that they do not point to dangers or harms of sufficient seriousness or sufficient probability or proximity to justify the limitation on human freedom that they require."*

The SCHB, however, disagrees with this view and notes that there are indeed dangers or harms of sufficient seriousness or sufficient probability or proximity with respect to reproductive procedures which justify the limitation on human freedom. Thus it agrees with Professor Alastair Campbell who argues that when the state and the professions are involved in parenting decisions there is an obligation to avoid harm wherever possible . In other words as soon as the Public Domain is involved in the creation of the child, the state becomes responsible with the parents for the welfare of the prospective child. This is the important difference with respect to couples who conceive naturally in which case the state does not interfere.

General

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

Scottish Council on Human Bioethics response:

The SCHB notes that the need of a child for a father mentioned in Section 13, paragraph 5 of the *Human Fertilisation and Embryology Act 1990* was generally replaced and 'watered-down' in the Code of Practice with the need for 'persons' or 'partners' which is not indicative of any specific male gender. This is unfortunate since the indications enacted by the representatives of the general public in the Westminster Parliament do not seem to have been respected by the HFEA Code of Practice.

As a result, the SCHB was concerned about the democratic manner in which the Code of Practice was being drafted. Indeed, Section 26 (3) of the Human fertilisation and Embryology Act 1990 indicates that:

Before preparing any draft, the Authority shall consult such persons as the Secretary of State may require it to consult and such other persons (if any) as it considers appropriate.

But who were these persons who were consulted? Was a broad public or stakeholder consultation undertaken before the preparation of the different editions of the Code of Practice? If this was not undertaken, then the Code of Practice cannot really reflect the democratic will of the people in the UK.

Enquiries to be made

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.

Scottish Council on Human Bioethics response:

Answer (e) is appropriate.
The SCHB is of the opinion that that clinics should be expected to enquire about risk factors provided by the patient, plus follow-up to the GP and other agencies, such as social services, routinely in order to satisfy themselves that there is no foreseeable medical or social risk to the child.
The Council is indeed of the opinion that most GPs are not qualified nor have the experience to gather the relevant information relating to the prospective child's welfare. The GP's opinion should therefore be complemented with the views of bodies such as the social services.

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?

a) Yes;
b) No.

Scottish Council on Human Bioethics response:

Answer (a) is appropriate.
The 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 since this may be relevant to the welfare of the prospective child.

Factors to be taken into account

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.

Scottish Council on Human Bioethics response:

The SCHB is of the opinion that answer (c) is appropriate whereby the existing guidance should be preserved though it had problems understanding the specific reference to quality of life in paragraph 3.3 of the report (is 'quality of life' the only meaningful measure of a person's life?).

Answer (c) would require clinics to take into account any risk of medical, physical or psychological harm, as well as a range of social factors which might affect a child's welfare. These social factors might include the age and health of the prospective parent(s), the stability of the family environment, the child's need for a father and the mother's ability to meet the child's needs.

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

a) Yes;
b) No.

Scottish Council on Human Bioethics response:

The SCHB is of the opinion that answer (a) is appropriate. Guidance from the HFEA, drafted in a democratic manner and based on the advice of stakeholders, should be given. If this does not happen, it would be difficult for any consistency to exist.

Welfare of the child assessments for particular treatments

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;

Scottish Council on Human Bioethics response:

The SCHB is of the opinion that (1) the creation embryos, (2) the adoption of embryos or (3) the adoption of children have similar ethical elements, namely that the welfare of prospective or existing children should be seen as a paramount.

The SCHB also agrees that the procedures relating to treatments with (1) donor eggs and sperm and (2) donated embryos should be separated since issues concerning the creation of human embryos differ from those relating to embryos that have already been created. It will, therefore, separate its response into the two different kinds of treatments:

A. Treatment with donor gametes:

The SCHB notes that parents who use donor insemination are often bringing a child into the world in order for him or her to relate to themselves while often ignoring the relationship the child may want to have with his or her genetic parents. Though the parents may concede to tell their child the truth when he or she is older, they would then have to understand that the child may wish to see and know his or her genetic parents and express a sort of 'love' which he or she may already experience. The child may also experience difficulties towards his or her genetic or social parents with the possibility of feeling a sense of rejection.

The SCHB is, therefore, of the opinion that until the following questions are answered satisfactorily concerning:

(1) the important bonds that exist between the biological parents and the child, and
(2) the unease the general population has concerning donor insemination,

then the possibility of using donated gametes in order to address infertility should not be promoted. Accordingly, the SCHB cannot reply to the other questions posed by the HFEA on this topic in its consultation without undermining its stance that such procedures should not proceed until further investigations are undertaken and the serious doubts concerning these procedures are addressed.

B. Treatment with donor embryos:

In this case, the SCHB is of the view that answer (c) is appropriate. In other words when patients are considering the adoption of an embryo, a more thorough welfare of the child assessment should be made and patients should receive additional information and preparation for becoming the parents of an adopted embryo.

The SCHB is of the view that embryo adoption should be considered in the same light as the adoption of children born after birth. In other words, children born through embryo adoption should have the same right to know their genetic parents as children adopted after birth.

With respect to frozen embryos, the Council is of the opinion that, if a child has been brought up knowing the truth about his or her adopted origins, he or she may find it beneficial to be enlightened about the fact that he or she was rescued from the frozen state. As well as wanting to meet his or her biological siblings the person may also need to be counselled because of the effect of being a survivor compared to many of the other embryos who perished when defrosted.

7. If you opted for either 6 b) or c), what kind of assessment and/or preparation for donor conception patients is desirable?

Scottish Council on Human Bioethics response:

The SCHB agrees that the same kind of assessment and/or preparation for persons considering the adoption of embryos should take place as persons considering the adoption of children who have been born.

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.

Scottish Council on Human Bioethics response:

When patients are undergoing unlicensed treatments, the SCHB is of the opinion that the welfare of the child assessment should be proportional to the specific treatment and the risks involved with regard to the prospective child.

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

Scottish Council on Human Bioethics response:

Should children born through artificial conception have less protection than adopted children?

The SCHB notes that in the *Human Fertilisation and Embryology Act 1990*, the child's welfare should only be taken into 'account' before treatment is offered with the principle of the child's welfare being rejected as the paramount consideration by MPs and Peers during the passage of the Act through Parliament.
This contrast with the *Adoption and Children Act 2002*, in which the welfare of the child is considered to be the *'paramount consideration of the court or adoption agency'* when making decisions about the care of a child. In this case, describing welfare as paramount means that all other considerations are of secondary importance to the best interests of the child concerned .

The HFEA consultation document suggests that the difference in welfare considerations between the two acts relates to the difference between the status of the prospective child in assisted conception, on the one hand, and its status in areas of practice relating to actual children already born for adoption, on the other.
For example, it states that in assisted conception the treating clinician must balance the wishes of the prospective parents against the interests of a child who does not yet exist. In other words, the clinician must assess the harm that the child is likely to face if it is born to those patients, based upon what the family circumstances might be once the family is created .

But the SCHB takes issue with this analysis and questions the rationality of this argument without having seen any evidence to support this opinion. The relevant question, in this regard, is why do persons want children in the first place. Do they want a child primarily for themselves or do they also want a child for the child's sake?

If parents want children primarily for themselves and seek to obtain these children in order to address personal needs or wishes, then it is indeed difficult to see how any welfare of the child could take priority. Instead the autonomy and the wishes of the persons wanting to have a child would be the main decision factor and the interests of the child will always come second.

If, on the other hand, a child is seen as the product of a loving relationship between persons in which the love expands onto the potential child, then the circumstances would be quite different. Indeed, because a loving relationship is also about putting the other person first and making them a priority, then the welfare of the child to be created should be paramount to the prospective parents. In this case, the prospective children would be considered in a similar way to those children being considered for adoption, i.e. their welfare would be paramount and come first.

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[1] As Professor McLean pointed out in her evidence to the Justice and Home Affairs Committee during the passage of the

Scottish Act, it will amount to no more than an assumption that a proxy decision maker will act in good faith. Official Report - Scottish Parliament JHAC 17 November 1999.

[2] Re F 1990 2 AC 1

[3] Col 395 17 November.

[4] Justice Cttee transcript 17.11.99 at para 400.

[5] Making the Right Moves published by the Scottish Executive 1999 http//:www.scotland.gov.uk/rightmoves/docs