

## **Response from the Church of England Mission and Public Affairs Council to the Call for Evidence from the Joint Committee on the Draft Human Tissue and Embryos Bill.**

### **3. How should Parliament and the regulatory body or bodies ensure an appropriate ethical framework to secure and maintain public confidence?**

The regulatory body currently has considerable powers in deciding what new technologies or uses of present technology should be licensed. To maintain public confidence in the HFEA/RATE's policy-making role, there should be independent ethical scrutiny of proposals to license new purposes of treatment or research, such as the extension of PGD to a disease not previously selected against.

An Ethics Committee, working closely with but not controlled by the HFEA/RATE, on which a broad range of views were represented could achieve this. This committee would make ethical judgments about the acceptability or otherwise of new uses of current techniques or new procedures, taking seriously the commitment to the special status of the embryo which remains at the heart of UK law.

The constitution of this Committee should include representatives of those who cannot serve on HFEA/RATE because of their clear opposition to embryo research. We feel that such viewpoints should not be marginalized or ignored, rather that their inclusion in such an independent Ethic Committee is entirely appropriate in a democratic society.

We feel such a Committee is now necessary because it has been possible for influential groups to claim to support this view of the embryo but then to proceed to make recommendations which imply that the embryo has no effective status which would ever count against procreative liberty arguments. A clear instance was the publication of the Science and Technology Committee's Report 'Human Reproductive Technologies and the Law', which was disowned by half the committee who objected to the lack of balance in the report and the 'extreme libertarian approach' it adopted, even though it purported to embrace the same view of the embryo's status as UK law.

### **4. (a) What are your views on the proposed transfer of the functions of the HFEA and HTA to a single new regulatory authority, RATE?**

We have two considerable concerns. First, that a single regulatory authority will not be able to deal effectively with the large amount of work it would receive. It would be unacceptable if there were lack of time for proper consideration of ethical aspects of new proposals. Indeed, rushing these matters will only result in the erosion of public confidence and a consequent reduction in support for medical and scientific developments. Secondly, it would be helpful to be reassured that, in bringing together the HFEA and the HTA, there would still be separate committees for the two areas. Otherwise the culture of RATE might be to think of embryos as just another form of human tissue.

### **Question 8 relating to hybrids/chimeras:**

**Do you support:**

- (i) the approach signalled by the Government in the White Paper,**
- (ii) the new approach announced by the Government (as outlined above); or**
- (iii) the approach recommended by the Commons Science and Technology Committee?**

We cannot support the approach recommended by the Science and Technology Committee (STC). This would allow the production of all possible kinds of hybrids and chimeras, including 'true' hybrids. Though the majority of such hybrids would be unlikely to be viable, the STC's approach would even allow the fertilisation of a human egg by non-human primate sperm or vice versa, with increased likelihood of viability. Such a suggestion betrays a serious disregard for ethics in favour of seeking scientific knowledge by all available means.

We are concerned that the STC should propose that the 14-day limit for the development of interspecies embryos should not be extended 'unless proved necessary'. Again we see an invitation to pressure from researchers to remove a carefully drawn boundary, which has been internationally agreed as the basis for assuring ethical use of embryos in vitro. Scientific 'necessity' does not outweigh ethics unless we are now saying that it no longer matters that something is right or wrong only that we are able to do the research we want to do without restriction.

We oppose the production of true hybrids. It is not entirely clear that it is really necessary for the law to allow the current exception of the 'hamster egg test' for the viability of human sperm. It appears that no licence has been issued for this since 2003 as ICSI has rendered this test unnecessary. Two submissions to the STC enquiry suggested that a similar test perhaps using mouse eggs is still needed in order to check the chromosomal normality of sperm in suspected cases of male infertility. More information is required in order to discern whether this is so or perhaps if other alternative methods of testing are available which would mean a blanket ban could be imposed on the formation of any true hybrids.

Before discussing the issue of cytoplasmic hybrids, it is necessary to explain our view of the status of the human embryo. Though we do not regard the preimplantation embryo as yet having the same status of a person made in the image of God, neither do we believe that the in vitro embryo is devoid of moral weight or consideration. This is because in the right circumstances (of successful implantation in the womb) such an embryo could indeed grow into a person made in the image of God. Too often there is assumed polarisation which admits only absolute views which either allow no protection at all or complete inviolability to the embryo. Because of the Christian mandate to seek healing, we believe that there are situations, addressing the serious medical need of others, in which it is permissible to use or select against in vitro embryos. This means we take a similar view to that already stated in UK law that the in vitro embryo has a special status which protects it from being used, selected against or destroyed for trivial purposes. However we do not believe that embryos should be produced by IVF purely for research, where there is no intention of their ever being implanted to fulfil their potential. Only 'spare' embryos left over from IVF treatment should be used in research. This means embryos are always created as an end in themselves and helps to safeguard their special status.

We consider that there are some differences in the case of CNR. Here a somatic

human cell (or its nucleus) is placed in an enucleated egg cell so that it is dedifferentiated or reprogrammed back to its condition of totipotency in the embryo. This embryo has not been formed by the usual method of sexual reproduction as in IVF, but by asexual reproduction or cloning. We strongly oppose the implantation of cloned embryos, and such 'reproductive cloning' is rightly prohibited in law.

Whereas, in the case of IVF embryos, it is right that there should be a possibility that they could be implanted and grow into a person, the opposite pertains for CNR embryos which, by their nature as clones, should not be implanted. We do not believe people should be born from asexual reproduction- further, producing a clone would exhibit unwarranted control over and instrumentalisation of another person and provide serious problems of identity and lineage. Also, though it is technically possible that, like IVF embryos, implanted cloned embryos might grow into a healthy baby, there are likely to be major imprinting difficulties which preclude such an outcome and lead to grossly impaired development with concomitant suffering to both mother and child. Clearly there is never any intention to bring a child to birth when a human skin cell is reprogrammed to enable the production of embryonic stem cells which might be used therapeutically to help a sufferer from a disease like Alzheimer's or Parkinson's. It is these differences between IVF and CNR which lead us to accept the carefully regulated production of CNR embryos for research into alleviating disease using the embryonic stem cells obtained.

The case of the proposed cytoplasmic hybrids adds the further complications about the appropriateness of mixing human material and animal gametes and the blurring of the identity of the resulting embryo. We do not think the debate about the percentage humanness of an embryo produced by placing a human nucleus into an enucleated animal egg has been helpful. The argument has been made that such an embryo is 'less than 100%' human in its DNA and therefore cannot have more protection than that afforded to a CNR embryo made entirely with human DNA and currently sanctioned in law. Such approaches are disingenuous because their logic would lead to saying that a true hybrid, arising from human sperm fertilising a non-human primate egg, contains only 50% human DNA and is therefore even less protectable and more acceptable than a cytoplasmic hybrid. Clearly the scientists applying for these licences did feel that the embryonic stem cells they hope to isolate would be sufficiently close to normal human embryonic stems as to be worth producing and researching upon.

The formation of a CNR embryo using human and animal material can elicit feelings of repugnance, especially at the thought of bringing into being someone who is genetically 'not fully human'. This 'yuk' factor is neither a final arbiter of acceptability nor necessarily the artefact of unscientific and uneducated thought. Rather it reminds us to pause and consider carefully where the appropriate boundaries should lie and to seek wisdom to do so. From a Christian perspective, the scriptural distinction of 'kinds' of creatures, taken together with the uniqueness of humans as those made in God's image and prohibitions about bestiality mean that the most stringent restrictions should be in force to prevent such a hybrid being brought to birth.

In the responses to the STC enquiry, serious doubts have been raised, by both supporters and opponents of forming cytoplasmic hybrids, about whether this research is feasible and any productive results can be obtained from it. The statement that it is impossible to know whether this research is useful until we do it is true. Yet it does not demonstrate that the research should be carried out and such an argument could be used to legitimise almost anything. The prospect of great advances in transplant medicine

through stem cell therapy, together with the lucrative development of these therapies is the goal of this proposed research. While we fully support the discovery of means of alleviating presently untreatable diseases, we are concerned that unrealistic expectations may cause distress and disappointment to sufferers. The impression should not be given that the only route towards stem cell therapies is through the use of cytoplasmic hybrids. Rather, work on the isolation and differentiation of adult stem cells should be encouraged. Furthermore, the elucidation of the mechanism by which a differentiated cell is dedifferentiated when placed in an enucleated egg cell should lead to our being able to produce embryonic stem cells from already differentiated cells thus circumventing the formation of CNR embryos for this purpose.

We recognise that many Christians who accept the creation of embryonic stem cells by CNR using only human material feel deeply uncomfortable about creating cytoplasmic hybrids even for research up to 14 days. Given the dubious efficacy of this research and its controversial nature, we feel that some assurance should be given to those who are concerned about this development. Our support for this work going ahead as proposed in the draft bill therefore has two added provisos.

First, that there is not an unending commitment to using embryos in this way but rather a limitation on the issuing of licences for such research to a period of say five years. If it is shown in this period that little progress can be made using cytoplasmic hybrids, it would signal a genuine commitment to upholding the status of the embryo as defined in law if such licences were then no longer allowed to be issued.

Secondly, we would like to see the Government state an intention that if research into the dedifferentiation of differentiated cells is successful, licences will not be issued for using embryos to obtain embryonic stem cells once these can be derived from differentiated cells.

Regarding the proposals for other forms of hybrids and chimeras, we are aware that some, if not all, these forms are already being researched upon. We do not think they are of as great concern as those forms, like true or cytoplasmic hybrids, which have an inherent ambiguity about their status as human or animal from their beginning.

### **Question 8 relating to research licences.**

**How should Parliament approach legislating for those purposes for which licences for research may be granted in the future (arising out of future research) but that are not yet determined? Should such judgements be left to the regulatory body or bodies to determine?**

The current debate about cytoplasmic hybrids is pertinent to this question as a case in point. The decision about whether to issue licences to produce cytoplasmic hybrids will in all likelihood be taken not by Parliament but by the HFEA at their September meeting, following its public consultation exercise on this issue but in advance of the present draft bill becoming law. We regret this because we feel it is Parliament and not the HFEA who should make the decision about whether such novel research is acceptable. Judgements about completely new areas of research should not in future be made by the HFEA/RATE but by Parliament.

In the event that it is decided that HFEA/RATE should make these judgements instead of Parliament, then an independent Ethics Committee should be consulted by the

HFEA/RATE and the support of this committee be obtained before the licence could be granted. Areas of novel research such as the present proposal to licence cytoplasmic hybrids or the permission to form CNR embryos in 2001 should also be subject to full public consultation.

**9. How should Parliament or the regulatory body or bodies take public views and public engagement into account?**

We realise that it is difficult to gauge public opinion on complex issues over which many are not prepared to engage or express an informed view. Nevertheless this suggests not abandonment of seeking public response but more sophisticated means of eliciting it. We believe that the current HFEA consultation about hybrids and chimeras is exemplary of a new level of consultation. It should yield a truer picture than any that have gone before, including as it does focus groups, a written consultation, a public consultation evening and an opinion poll, and taking place over the realistic and reasonable timescale of 3 months.

**10. What are your views on the provisions in paragraph 3 of Schedule 2 setting out the conditions under which (a) embryos can be tested and (b) sex selection practices can be carried out?**

(a) While we support the carefully regulated use of tissue typing on a case-by-case basis, we are concerned that the HFEA's initial assertion that this would only be done as 'a last resort' procedure is diminished by the proposed wording in 1ZA (4) of the draft bill (page 59). Here the Authority is only bound to 'have regard to' any alternative sources of tissue which are or may become available to treat the sibling. This is far less stringent than allowing tissue typing as a last resort. We therefore ask that the wording here should require the Authority to ensure that all other avenues of providing sources of tissue have been exhausted first.

In addition, a protocol for limiting future demands on the donor child has been suggested in an American context by Wolf et al. in 'Using preimplantation genetic diagnosis to create a stem cell donor: issues, guidelines and limits', *Journal of Law, medicine and ethics*, 31 (2003), 327-9 and it should be explored here also to protect the future interests of the donor child.

(b) We are very pleased that the ban on 'social' sex selection is being made explicit in law.

**12. What are your views on the proposal in the draft Bill to remove from the existing conditions of treatment the requirement to take account of "the need of that child for a father" before treatment services can be provided?**

We believe it is wrong to remove the requirement to take account of "the need of

that child for a father” from the Bill as it sends an entirely erroneous signal about the significance of fathers especially at a time when many children and families are suffering because of lack of attention and care from absent fathers.

In paras. 2.25 and 2.26 of the White Paper, the Government suggests it is removing ‘the need of a child for a father’ clause so as not to appear to discriminate against same sex couples (or single mothers) who want to have a child using IVF. The Government is bowing to the argument that as single people and gay couples can legally adopt, so the same permission must therefore be given if they wish to ‘commission’ a child using IVF. This is a *non sequitur* because the situations are markedly different. In adoption, the hospitality of a home is being offered to an already existing child who has had the misfortune through circumstance or necessity to lose or be removed from contact with its parents. Bringing the care of an adoptive home to a needy child is a wholly different circumstance to deciding in advance to use IVF technology to bring into the world a child who will, ‘by design’, never have a father (or mother, in the case gay men commissioning a child by IVF surrogacy). It sends the signal that everyone has a right to a child and this ‘right’ over-rides consideration of that child’s welfare.

If discrimination is the issue here, we feel the greater discrimination is in ensuring that a child will never have any chance of knowing a father, rather than in saying that gay couples have an automatic right to have a child. We consider that the child’s right not to be deliberately deprived of having a father is greater than any right of a gay couple to commission a child by IVF. The prior protection in law should be afforded to those with the greater vulnerability – the children yet to be born.

Of those without an organisational affiliation who responded to this question in the Government’s consultation, over 80% were in favour of inserting ‘the need of a child for a father and a mother’ into the Act. We agree, but want to emphasize that affirming consideration of the need of a child for a father and a mother is not equating alternative parenting or unconventional families with irresponsible or abusive parenting. Rather it is putting the welfare of the child first and looking to what are likely to be the best interests of a child who has yet to be born. The Christian response is to seek to support all families in bringing up a child in a loving and secure home life, and to acknowledge the extra help needed, for instance, when circumstances like death of a partner or desertion mean that a single parent carries the onerous burden of lone parent.

In para. 2.26 of the White Paper, the Government says that it ‘is not convinced that the retention of this provision could be justified in terms of evidence of harm, particularly when weighed against the potential harms arising from the consequences of encouraging some women who wish to conceive to make private arrangements for insemination rather than use licensed treatment services’. We wonder why the Government has changed its ethical stance to base it on ‘evidence of harm’ when it rightly rebuked the STC for taking just such an approach because such evidence is not always forthcoming in advance, saying instead that ‘the potential harms that should be taken into account may not necessarily be susceptible to demonstration and evidence in advance. For example, in our view the application of a precautionary approach requires that consideration of harms to society or to patients must include the consideration of potential harms to future offspring’.

An argument based on ‘evidence of harm’ is very weak because of the paucity of actual evidence here – as pointed out by Bishop Michael Nazir-Ali in his evidence to the STC and admitted by the Government in its consultation. Therefore, because the evidence available is equivocal and not decisive, it is far better then to take the

precautionary approach of not putting a child into a situation where it may be harmed because its identity is designed from the start to be that of a person who never had a social or biological father. This is qualitatively different from children whose fathers have died or deserted, or whose father is social rather than biological because of sperm donation. They are not children deliberately brought into the world without any chance of having a father to either be present in their lives or to refer to. This is a situation which could seriously impair a child's ability to resolve its identity.

The STC say the need of a child for a father clause is 'unjustifiably offensive' to many. This is a disingenuous argument because to remove this stipulation and imply that having a father is not important to the child can be argued to be unjustifiably offensive to a hugely greater number of people.

In recent years the Government has stated that they believe that it is better for a child to have both a father and a mother, that 'the single most important factor is the welfare of the child' and that 'the welfare of children cannot always be adequately protected by concern for the interests of the adults involved'. We are concerned that the Government now appears to have abandoned these views in deciding to remove the 'need of a child for a father' clause and in shifting the emphasis from the welfare of the child to the desires and supposed rights of adults to be able to have a child using IVF. We urge the Government to retain the need of a child for a father clause.

### **13. What are your views on the approach to the welfare of the child provisions in clause 21?**

We believe that the only way to address the drift towards personal procreative autonomy becoming the only ethical consideration is to stipulate in law that the welfare of the child to be born after IVF is paramount, in the same way as this is already dictated in the Adoption and Children Act 2002.

### **19. Are there any other provisions in the draft Bill, or provisions you would like to see in the draft Bill, on which you would like to give your views?**

(i) We are astonished that the Government is sanctioning the first steps anywhere in the world towards germ-line alteration of human beings (Draft Bill, para. 79, p.102). Removing the existing prohibition on altering the genetic make-up of a cell of an embryo is a dangerous and unwarranted change. There is not even any pressure from scientists to make such a move and we are at a loss to know why the Government would countenance such an action and assure it of our strong opposition. The Gene Therapy Advisory Committee (GTAC) looks very carefully at proposals to ensure there is no possibility of novel genetic material getting into the germline. The proposed provision sends out a very different, and contradictory, message which could undermine public confidence.

Neither is it any reassurance that genetic modification of embryos will currently only be allowed for research purposes. If results were to demonstrate a facility in gene therapy, it would no doubt be argued that the investment in research should not be wasted but now applied in treatments. There is no way short of unacceptable experimentation on human beings over a long period of ensuring that such germ-line alteration is safe. Moreover, there is no good reason to expend the research time and effort on genetic

modification of embryos because PGD offers a presently accessible, more straightforward way of ensuring that embryos which would suffer serious disease are not implanted.

(ii) We note that the Draft Bill adds the use of embryos for the purpose of training persons in the testing of embryos (Schedule 2, 1 (ca), page 207). While we recognise the importance of careful manipulation of embryos, which requires training, we request that the Act should stipulate that embryos used for training purposes are not created for that purpose but that only those which are surplus to IVF requirements are used.

(iii) We have suggested the establishment of an Ethics Committee independent of the HFEA/RATE comprising people with a wide variety of views. This is because we are concerned at the drift away from any consideration of the moral status of the embryo and towards a personal autonomy or 'procreative liberty' agenda. This takes an almost exclusively utilitarian approach, seeking only to establish whether a procedure requested by parents or clinicians is safe rather than ethically justified.

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