

Society for the Protection of Unborn Children
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15 June 2007

Kate Lawrence
Clerk to the Joint Committee on the Draft Human Tissue and Embryos Bill
House of Lords
London
SW1A 0PW
per email: htedraftbill@parliament.uk
(Hard copy to follow)

Dear Miss Lawrence,

**Submission to the Join Committee on
the Draft Human Tissue and Embryos Bill**

Further to the call for evidence issued on 24 May, please see the enclosed submissions from the Society for the Protection of Unborn Children (SPUC) and the Southern Cross Bioethics Institute of Adelaide, Australia.

Yours,
Paul Tully
General Secretary

Submissions from SPUC on the Draft Human Tissue and Embryos Bill, June 2007:

The draft Bill overall

With particular reference to questions 1, 2 [(i)-(iv)] & 3:

1. The draft Bill will have significant impact upon the delivery of infertility treatment and therefore upon the children born and their biological, gestational and social parents. The draft Bill is unsatisfactory because it:
 - 1.1. Expands measures that entail the destruction of human life at its earliest and most vulnerable stage,
 - 1.2. Manifests an eugenic mentality which underlies some of the its key proposals.
 - 1.3. Manifests arbitrariness in its applied limits.
 - 1.4. Accelerates the waning respect for human life that is marking scientific endeavours in the modern biotechnological era.
 - 1.5. Fails to provide the leadership necessary for ethically sound goals to be pursued.
 - 1.6. Has been devised on the basis of a one-way ratchet on the use of human embryos in research involving their destruction, and only changes that will extend this use will be considered.

- 1.7. Ignores critical scientific and ethical questions in what appears to be an attempt to allay public unease by the promise of tight regulations.
- 1.8. By endorsing the destruction of human life at its most vulnerable stage, and seeking to extend the circumstances and ultimately the number of embryos so destroyed, is operating from a utilitarian ethic that is prepared to pursue potential goods such as health - that may never be realised – at the expense of the most fundamental good of human life itself.
- 1.9. Is a complex mix of acquiescence to scientific advances, commitment to various and at times conflicting ethics, inconsistent application of regulations and economically rationalist restructuring.

Experimental creation and use of embryos: Questions 7, 8, 9, 10:

2. On the research issues generally:
 - 2.1. Given the complexities inherent in the field, it is unlikely that society has in fact formed a considered opinion.
 - 2.2. Both the reproductive technology sector and elements of the research community have financial interests in promoting changes that are evident in *The Draft Bill*.

Research Involving Embryos

3. The changes proposed are only in one direction, that is, a more permissive one. How can this 'ratchet' approach allow for recent evidence of the early differentiation and specialisation of the embryo's cells?

Inter-species Embryos

4. The creation of an interspecies embryo that is essentially human solely for the purpose of destruction for speculative science is a clear affront to human dignity and represents no respect whatsoever for human life at its nascent stage.
 - 4.1. Furthermore, the intimate mixing of human and animal genetic material represents an additional affront to human dignity.
 - 4.2. Basic 'proof or principle' work in animal models has not yet been done with regard to these types of hybridisation experiments to show whether anything scientifically useful can be gained from them.
 - 4.3. It is therefore entirely inappropriate to even consider such experimentation with human genetic material.
 - 4.4. The long-standing paradigm in research involving human life is being breached in these proposals.
 - 4.5. Extensive access to embryonic stem cells over nearly 10 years has so far yielded limited scientifically valuable information.
 - 4.6. Conducting basic research to produce hybrids lays the groundwork for any maverick practitioner to transfer such an embryo to the body of a woman, regardless of the legal proscription.
 - 4.7. It is entirely unclear whether hybrid embryos will be useful in research.
 - 4.8. The creation and use in medical research of chimeras or hybrids should not take place.

Screening and Selection

5. The deliberate de-selection of disabled embryos is a statement about disabled human life, a eugenic one.
- 5.1. *The Draft Bill is* to be commended for maintaining a ban on sex selection for non-medical reasons, and in particular for extending the ban to the selection of gametes.
- 5.2. However, sex selection to be used for identifying embryos of a particular sex that may have a sex-linked disease or disorder will result in healthy embryos being discarded because they are of the 'wrong' sex and merely possibly affected.

Genetic Modification of Gametes and Embryos

6. Pressure will be applied to the government to permit what it now firmly says it will not permit, that is genetic alterations to embryos which will be transferred to the body of a woman.

Questions 11-16:

7. Alleviating Infertility:
 - 7.1. The emphasis on Assisted Reproductive Technology (ART) as the solution to infertility shifts the focus and resources away from developing treatments that actually treat infertility. That is, ones that restore fertility.
 - 7.2. ART pushes the boundaries of medical ethics in numerous ways and is inextricably linked with unacceptable activities including: human experimentation, intimate mixing of humans and animals reproductively, the unnecessary creation of experimental familial relationships, cloning, and eugenic practices.
 - 7.3. ART is also on the verge of participation in modifying *homo sapiens* by dabbling with heritable genetic modification.
 - 7.4. ART becomes less and less a solution to infertility and increasingly a means to pursue experimental research (social and scientific) at the expense of human embryos.

Welfare of the Child

8. The welfare of the child should be a guiding principle in the delivery of reproductive technology.
 - 8.1. The need for a father, a basic principle that is clearly in the best interest of the child, is rejected to satisfy ill-founded demands for the right to parenthood.
 - 8.2. The various legal fictions about who really are the parents of the child should be rejected as contrary to honesty, justice and the best interests of the child.
 - 8.3. A genuine commitment to the welfare of a child cannot ignore the fact that a child spends nine months developing prior to birth.
 - 8.4. The principle of welfare of the child is disregarded where embryonic human beings are deliberately created and destroyed in the name of speculative science.

Privacy and Confidentiality

9. Permission for the disclosure of identifying information for research purposes, contrary to “any duty of confidentiality owed in relation to the information”, breaches the most basic of ethical principles.

Surrogacy

10. Permitting advertising and the payment of a range of fees represents a step towards commercialising surrogacy.
 - 10.1. The research that has been conducted, limited as it is, suggests that there exists potential and actual harm to all parties.
 - 10.2. Surrogacy fails to respect the dignity or primacy of the welfare of the child, contrary to the stated intentions of *The Review* and *The Draft Bill*.

Concluding points

11. It is seriously doubtful whether some of the proposed changes are necessary at all, and it is even more doubtful whether the community has had a real opportunity to adequately respond.
 - 11.1. In consideration of these matters, and the haste with which this process has been undertaken, it is likely that the public will develop an even greater sense of unease than it already has about ART and research using nascent human life.
 - 11.2. The medico-scientific community is at risk of tarnishing its image.

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The appended submission, was prepared by Southern Cross Bioethics Institute (SCBI), and is submitted on its behalf. SPUC acknowledges the assistance of SCBI in preparing the above submission to the Joint Committee, and notes that further significant points are made in SCBI’s submission. While in broad agreement on relevant principles, SPUC may disagree with some points and nuances of SCBI’s approach.

Submission from Southern Cross Bioethic Institute, Adelaide, Australia

Contact: Dr Greg Pike, gregpike@bioethics.org.au

Preface

The *Human Tissue and Embryos (Draft) Bill* – hereafter called *The Draft Bill* is based upon the Department of Health’s *Review of the Human Fertilisation and Embryology Act* – hereafter called *The Review*. The recommendations within *The Review* have been largely taken up and implemented in *The Draft Bill*.

The following is written primarily as a response to *The Review*, but with an understanding that the majority of the recommendations in *The Review* have now been implemented in *The Draft Bill*.

Therefore, whilst this document makes many references to *The Review* and few to specific sections of *The Draft Bill*, its substantive content on all of the relevant issues is directly applicable to *The Draft Bill*. Moreover, *The Review* is more explicit in providing the framework of reasoning that has given rise to *The Draft Bill*. So in many respects comments in relation to *The Review* provide a far more rounded picture of the many proposed changes to legislation that appear in *The Draft Bill*.

Background

In 2004, the Government announced plans to review the *Human Fertilisation and Embryology Act, 1990*. This was followed by a public consultation that ran from 16 August to 25 November 2005, during which time 535 submissions were received from a variety of interested parties.

In December 2006, Caroline Flint, the Minister of State for Public Health handed down a review based on the consultation¹. *The Review* was produced by *People, Science and Policy Limited*, and in the Department of Health’s words “comprises an independent summary of the arguments raised².”

The Review went much further than a summary and made important recommendations that the Government intended to be taken up by Parliament in revised legislation:

This paper sets out the detailed policy proposals that the Government will present to Parliament, which, if Parliament agrees, will form part of revised legislation. We intend that these proposed changes will first be considered in draft form, as a Bill published for pre-legislative scrutiny.³

The Review is an important document in that it makes recommendations with serious implications, that if taken up in revised legislation will have significant impact upon the delivery of infertility treatment and therefore upon the children born and their biological, gestational and social parents.

¹ The Review of the Human Fertilisation and Embryology Act can be accessed at <http://www.dh.gov.uk/assetRoot/04/14/13/15/04141315.pdf>

² http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4141311&chk=GJrzuq

³ *The Review*, vi

Even more importantly, *The Review* recommended expanding measures that entail the destruction of human life at its earliest and most vulnerable stage, measures that have now been taken up in *The Draft Bill*. And this has been done with apparent wilful blindness to the eugenic mentality underlying some of the key proposals and to the arbitrariness of its applied limits.

The Review and *The Draft Bill* therefore add to the waning respect for human life that is marking scientific endeavours in the modern biotechnological era. It is entirely possible for the medico-scientific enterprise to advance whilst upholding a deep respect for human life that was once its hallmark, yet both documents reveal a failure to provide the leadership necessary for ethically sound goals to be pursued.

Introduction

The Review and *The Draft Bill* come at a time when significant scientific advances are taking place. For example, more extensive genetic testing is now making it possible to screen embryos for increasing numbers of disorders as well as predispositions, late onset conditions and natural traits. Furthermore, with the isolation and culture of embryonic stem cells and the possibility of cloning technology being applied to humans, there is far greater and broader interest in access to human embryos for research purposes.

In its aims, *The Review* makes it clear that it is committed to scientific and medical advance flourishing, as well as to regulating the fields of reproductive technology and research utilizing early human life.⁴ It is these two commitments that influence the entire report and therefore the recommended changes.

Despite repeated reference to the “fundamental social, legal and ethical aspects” of reproductive technologies⁵, and that these “issues and questions go to the very heart of our existence as individuals, families and society”⁶, these aspects are considered in a limited way, or through a particular lens. For example, *The Review* makes it clear that in reviewing the HFE Act, only changes of a particular type are up for consideration. Hence, *The Review* takes the “basic components of the existing legal scheme as bedrock⁷.” This approach means, for example, that there can be no reversal to the use of human embryos in research involving their destruction, and only changes that will extend this use will be considered. As it turns out far more ethically problematic proposals are indeed recommended.

The Review and *The Draft Bill* appear to be driven by a technological imperative. It is “part of a review intended to ensure that the law remains fit for purpose in the early 21st century”⁸, implying that the scientific advances of this century should drive legal change, rather than scientific advances being considered in the light of the law. Furthermore, “the area of human reproductive technologies – as an inherently fast moving area of science and medicine – means that regulatory controls need to be responsive to technological

⁴ *The Review*, 2.2

⁵ *The Review*, v, 1.1, 2.9

⁶ *The Review*, 1.1

⁷ *The Review*, v

⁸ *Ibid.*

advances ...⁹”, which can be taken to mean a response that enables those scientific advances to proceed with legislative approval.

There is, therefore, a sense that ethical considerations should respond to technological advance rather than technological advances being considered in the light of long-standing, carefully developed and normative ethical frameworks.

The Review also reveals a commitment to the development of a regulatory structure to deal with this area. It notes that the Government’s principal aims include:

to promote public confidence in the development and use of human reproductive technologies through effective regulatory controls applicable to them, and;

to secure that regulatory controls accord with better regulation principles and encourage best regulatory practice.¹⁰

Whilst these two aims are entirely valid and laudable, and regulation is generally agreed to be necessary, the emphasis in the report upon regulation as a means of ensuring public confidence or allaying public concern is reminiscent of the manner in which the Warnock committee dealt with the issue of embryo research.

The Warnock Committee¹¹ decided that research on human embryos should be allowed up until 14 days. The committee made the following statement:

While, as we have seen, the timing of the different stages of development is critical, once the process has begun there is no particular part of the developmental process that is more important than another; all are part of a continuous process, and unless each stage takes place normally, at the correct time, and in the correct sequence, further development will cease. Thus biologically there is no one single identifiable stage in the development of the embryo beyond which the in vitro embryo should not be kept alive. *However we agreed that this was an area in which some precise decision must be taken, in order to allay public anxiety.*¹²[Emphasis added]

In their critique of Warnock, Clarke and Linzey note:

... this is a clear case of extrinsic criteria being used to solve a problem which requires the determination of firm and unequivocal intrinsic criteria.¹³

The point is, just as the Warnock committee chose to assign inferior status to the biological reality of human development and its philosophical and ethical ramifications, and instead focused on allaying public anxiety, *The Review* and *The Draft Bill* likewise ignore critical scientific and ethical questions in what appears to be an attempt to allay public unease by the promise of tight regulations.

⁹ *The Review*, 2.5

¹⁰ *The Review*, 2.2

¹¹ Baroness Mary Warnock was invited by Her Majesty’s Government in July 1982 to chair a Committee of Inquiry into the ‘social, ethical and legal implications of recent, and potential developments in the field of human assisted reproduction’. The report of that committee is called the *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, Cmnd. 9314, London, 1984.

¹² Warnock, M (Chairman) *Report of the Committee of Inquiry into Human Fertilisation and Embryology*. (London: HMSO Department of Health and Social Security) Cmnd. 9314, 1984, 65.

¹³ Clarke, P.A.B. and A. Linzey, *Research on Embryos: Politics, Theology and Law*. Lester Crook, London, 1988, p. 26.

The promise of tight regulations acts as a foil to what are really quite permissive proposals. Moreover, it is easy to promote a tough regulatory approach about some issues, for example the “firmly established ban on reproductive cloning”¹⁴, given that people are almost universally opposed to it anyway.

It is difficult to reconcile the emphasis on tight regulation that is inherent within *The Review* and *The Draft Bill*, with the shifting basis upon which judgments appear to be made. It is as if the accent on tight regulation that comes after a contentious practice has been sanctioned, is intended to pacify the troubled collective conscience that accompanies a decision to do something that is ethically troublesome. Or alternatively, tight regulation gives the appearance of control for practices for which controls have in reality been eased.

The Review in particular voices a particular perspective about ethics and public policy. It states:

Society’s collective and considered opinion is the ultimate arbiter of the controls to be applied to the development and use of human reproductive technologies.¹⁵

While at face value this seems democratically reasonable, it contains the implicit assumption that society has had a real opportunity to form a considered opinion, and if it has, that the consultative process gives an accurate reflection of “society’s collective and considered opinion”. Given the complexities inherent in the field, it is unlikely that society has in fact formed a considered opinion. In which case, only sectors of the community with particular interests will provide a view, and of those, some will have interests that amount to conflicts of interest. For example, both the reproductive technology sector and elements of the research community have financial interests in promoting certain of the activities that are the subject of *The Review* and hence changes that are evident in *The Draft Bill*. As is true with any potential conflict of interest, these must not only be clearly and openly articulated, they must also be taken into account.

However, the more basic concern here is the implication that ethics must give way to public perception or opinion, or worse that ethics is *simply* a matter of public opinion.

Even if there appears to be a commitment to the ethic that “society’s collective and considered opinion is the ultimate arbiter of the controls to be applied ...”, on at least two occasions, *The Review* is willing to go against that opinion, and this is now reflected in *The Draft Bill*.

First,

Respondents were generally less convinced of the need to make changes to the scope of permissible embryo research.¹⁶

Despite this, *The Review* and now *The Draft Bill* make recommendations to considerably widen the scope of embryo research.

And second,

Responses to the Government’s consultation from individual members of the public generally favoured retention of a reference to the child’s need for a father, as part of the consideration of the welfare of the child. Many thought

¹⁴ *The Review*, v.

¹⁵ *The Review*, 1.12

¹⁶ *The Review*, 1.11

that the legislation should be revised to refer to a need for both a mother and a father.¹⁷

Despite this, the Government proposes removal of reference to the child's need for a father.¹⁸

In the foreword of *The Review*, reference is made to the common good.

The overarching aim is to pursue the common good through a system broadly acceptable to society.¹⁹

The notion of the common good has a rich history in ethics and typically includes upholding human dignity and creating the conditions necessary for human fulfilment. However, one can only assume that its use here without any explanation is a motherhood statement, that, given *The Review's* recommendations and the contents of *The Draft Bill*, should be taken to mean a utilitarian 'good' that is potentially to be realised at the expense of a range of other goods.

By endorsing the destruction of human life at its most vulnerable stage, and seeking to extend the circumstances and ultimately the number of embryos so destroyed, *The Draft Bill* is operating from a utilitarian ethic that is prepared to pursue potential goods such as health - that may never be realised - at the expense of the most fundamental good of human life itself.

A utilitarian ethic pervades both *The Review* and *The Draft Bill*, making it very difficult to believe that current positions held on 'ethical' grounds will hold for long. This is evident on several occasions. For example, the door is left open regarding artificial gametes²⁰, genetic modification of embryos²¹, and the creation of human/animal hybrids and chimeras²². On utilitarian grounds, even the firmly expressed ban on reproductive cloning could be subject to reversal if and when either the process becomes more efficient or cases emerge where the birth of a cloned child could be 'rationalised'.

In summary, *The Review* is a complex mix of acquiescence to scientific advances, commitment to various and at times conflicting ethics, inconsistent application of regulations and economically rationalist restructuring. It is evident that most, if not all, of this is now contained within *The Draft Bill*. Despite this, there are some good proposals in *The Review* and *The Draft Bill* that are ethically sound.

Reproductive Technology

Alleviating Infertility

There is no doubt that infertility is a problem in the community and perhaps increasingly so. However, it is important to note that Assisted Reproductive Technology (ART) is not so much a treatment for infertility as an alternate means by which new human life can be

¹⁷ *The Review*, 2.25

¹⁸ *The Review*, 2.26

¹⁹ *The Review*, v

²⁰ *The Review*, 2.16

²¹ *The Review*, 2.52

²² *The Review*, 2.85

created. Couples who enter ART leave the programme either with a child or without one²³, but in either case, typically in the same state of infertility as when they entered ART.

This is an important distinction because unlike other health treatments where health is restored by the treatment, ART does not achieve that, but rather provides an alternate means of achieving pregnancy.

The reason this distinction is important is because the emphasis on ART as the solution to infertility shifts the focus and resources away from developing treatments that actually treat infertility. That is, ones that restore fertility.

The failure to genuinely address this distinction has contributed to what ART now is, that is a technological enterprise that deals with gametes, embryos, mothers, fathers and others in a mechanistic and often commodified way.

It is now the type of enterprise that pushes the boundaries of medical ethics in numerous ways and is inextricably linked with unacceptable human experimentation, intimate mixing of humans and animals reproductively, the creation of experimental familial relationships, cloning, and eugenic practices. It is also on the verge of participation in modifying *homo sapiens* by dabbling with heritable genetic modification.

It is way beyond the medical treatment of infertility.

The suggestion made in *The Review* on at least three occasions²⁴ that ART is about ‘alleviating infertility’ is not only inaccurate but also portrays an illusion about what ART has really become. *The Draft Bill* takes up this illusion and perpetuates.

Embryo and Gamete Definitions

Both *The Review* and *The Draft Bill* are to be commended for resisting attempts to redefine the term embryo, even though there is a certain circularity in *The Draft Bill’s* definition, viz., “embryo means a live human embryo”²⁵. Maintaining a definition that is typically used in embryology is an authentic approach that reflects reality. Furthermore, given that new means – like parthenogenesis and cloning have become available for creating embryos, retaining a broad definition offers the opportunity for protection of embryos, albeit a very limited one given the strong sentiment that, despite lip service being given to the “special status” of embryos²⁶, they are fair targets for destruction.

The fact that eggs in the process of fertilisation will continue to be included under the embryo definition is welcome, especially given the use of eggs to create embryos by alternate means and that regulation will extend to the initiation of any such processes.

The meaning of the terms gamete, sperm and eggs are relatively well established in the scientific literature. It would be in keeping with the use of a definition of embryo to likewise adopt a definition of the term gamete. To encompass new developments like artificial gametes, the following definition could be used.

²³ Success rates in ART, whilst problematic because of inconsistency in the way they are determined, are nevertheless such that a couple are far more likely to leave an ART programme without a child than with one.

²⁴ *The Review*, 1.6, 2.15, 2.64

²⁵ *The Draft Bill*, s14(2)

²⁶ *The Review*, v, 1.7, 2.9

A gamete is a human sperm or egg and includes any cell that has resulted from a process of meiosis.

Furthermore, given that the term “precursor cell” is occasionally used to describe a cell that can give rise to a gamete, a definition of precursor cell could be used and, for the purposes of regulation, come under the definition of gamete.

A precursor cell is any cell that has the potential to develop into a human egg or sperm.

The ban on the use of artificial gametes²⁷ is an important recognition of the safety issues, but by leaving the door open the Government has made it clear that it considers the ethical issues to be irrelevant, despite stating that it has consulted on “safety and ethical grounds” and agrees with the responses received²⁸. It leaves the door open by considering altering the law “if safety concerns were allayed in the future”²⁹. This is yet another example of lip-service to ethics with no real commitment to an examination of the serious ethical issues that would be associated with the use of artificial gametes.

Welfare of the Child

The Review notes that most respondents in the public consultation were generally in favour of retaining the idea that the welfare of the child should be a guiding principle in the delivery of reproductive technology³⁰. This is entirely appropriate, given that children, by virtue of their vulnerability, should occupy a special place. This notion is grounded in human rights instruments such as *The Universal Declaration of Human Rights, 1948*³¹, and the *Convention on the Rights of the Child*.

It comes as somewhat of a relief that the “Government believes that the presence of a “welfare of the child” section in the law remains valuable and proposes 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 affected³².”

This is especially the case given that *The Review* notes at least two attempts to undermine this provision; first, from the HFEA itself in its guidance to clinics to focus only on the “likelihood of serious harm”³³, and second, from the *House of Commons Science and Technology Committee* in its proposal to abolish reference to the welfare of the child altogether³⁴. The *Committee* argued that this should be the case given that “persons able to conceive naturally, or persons receiving non-licensable fertility treatments, do not face similar checks”³⁵. This is a poor argument because it ignores what are in fact desirable standards for the whole community. The reality is that to place checks upon those who can

²⁷ *The Review*, 2.16

²⁸ *The Review*, 2.15

²⁹ *The Review*, 2.16

³⁰ *The Review*, 1.11

³¹ Article 25(2)

³² With regard to the welfare of “any other child who may be affected”, see the section on surrogacy where the endorsement of surrogacy fails to recognize the potential for significant harm to existing children of a surrogate caused by handing their sibling over to another couple. Retaining regard for the welfare of “any other child who may be affected” by ART treatment should be used to inform any decision about permission to undertake surrogacy arrangements.

³³ *The Review*, 2.21

³⁴ *The Review*, 2.22

³⁵ *The Review*, 2.22

conceive naturally is impossible, even though the community does in many other ways uphold the standard that the welfare of the child is paramount by acting in numerous ways to protect children. To remove such a provision from ART would be to abrogate responsibility and further reinforce the fact that ART is becoming more of a technological and commercial enterprise than a health one.

Of greater concern is that the government has decided, contrary to the input from the majority of members of the public, that reference to the need for a father be removed from the Act³⁶. However, the argument it uses is very weak. The Government attempts to justify removal of the need for a father by weighing the harm that could arise to the child “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”³⁷. What this means is that a basic principle that is clearly in the best interest of the child is thrown out to satisfy the wishes of some women who are physiologically capable of conceiving but who choose not to. This is yet another example of the way that ART is being used to service not the health needs of individuals, but increasingly their social desires.

A genuine commitment to the welfare of a child cannot ignore the fact that a child spends nine months developing *in utero*. To hold as paramount the welfare of the child is a half-baked concept if it does not include the unborn child. Therefore, it must be acknowledged that the government’s commitment to retaining the principle that the welfare of the child must be paramount is a particularly limited one that excludes the unborn child. Moreover the principle is disregarded where embryonic human beings are deliberately created and destroyed in the name of speculative science.

Furthermore, the government’s commitment to the welfare of the child must be questioned given its commitment to experimentation with the lives of children born of ART by endorsing a “greater range of persons to be recognized as parents following assisted reproduction”.³⁸ Whilst it is only partly clear what this really means in practice, there can be little doubt that it will include various legal fictions about who really are the parents of the child. Given the experience with the problems for many children who have been conceived using donor sperm, a high degree of caution would have been expected regarding further experimentation with parenthood provisions. Unfortunately, this appears not to be the case.

Screening and Selection

The screening of embryos in ART via pre-implantation genetic diagnosis (PGD), is carried out with a view to a selection being made. Therefore, regardless of the grounds for the selection, merely conducting PGD is about choosing some embryos over others and therefore deliberately discarding those deemed ‘unsuitable’. This entails a deliberate choice about one individual embryonic human being as ‘better’ than another. This type of judgement is generally believed to be unacceptable where born human beings are concerned, and therefore its application in PGD reveals a double standard. Moreover, in settings where this type of mentality has existed, it has been recognised for what it is, that is, a eugenic one.

³⁶ *The Review*, 2.26

³⁷ *The Review*, 2.26

³⁸ *The Review*, 2.69

It would not be surprising that those with a disability, would see the application of selection criteria, whether applied via PGD to embryos in ART or via selective termination of disabled foetuses, as a statement about the value of the lives of humans with disabilities.

The deliberate de-selection of disabled embryos is a statement about disabled human life.

While it is true, as *The Review* notes, that “less technical forms of selection ... have been undertaken for many years”, like choosing the “physical characteristics of a gamete donor”³⁹, it is quite misleading to suggest that PGD is simply more technical. In reality, PGD is fundamentally different because it involves the deliberate destruction of embryos. While it is not surprising to see such a gloss in a report that fully endorses and expands upon processes that involve destroying embryonic human beings, one might have hoped for a more honest recognition about what was actually being done.

Even the fact that approval is implied for selecting the “physical characteristics of a gamete donor”⁴⁰, is eugenic. How this idea is any different to what was proposed by the eugenic societies of early last century, or to some current egg and sperm supplier’s promotion of their athletic, intelligent and beautiful donors⁴¹, would need explanation, to say the least.

That a eugenic mentality is furthered by *The Review* is evidenced by the fact that the deliberate screening in of a disease or disorder will be prohibited.⁴² Whilst it would be extremely rare for couples to deliberately choose a disabled embryo for transfer rather than a healthy one, will the restriction be used to exert pressure upon a couple who only have disabled embryos for implantation, and in respecting the right to life of those embryos, want to have them transferred to enable them a chance at life? The tenor of *The Review* suggests that disabled embryos should never be transferred even if so desired by a couple.

It should be noted that no qualification is offered about the extent of the “disease or disorder”, which could be quite minor. For example, would a predisposition to early onset Alzheimer’s disease be sufficient grounds to discard an embryo so affected?

The Review and *The Draft Bill* are to be commended for maintaining a ban on sex selection for non-medical reasons, and in particular for extending the ban to the selection of gametes.

However, permission is retained for sex selection to be used for identifying embryos of a particular sex that may have a sex-linked disease or disorder⁴³. Such selection will result in healthy embryos being discarded because they are of the ‘wrong’ sex and merely possibly affected. In this sense an inadequate distinction is made between sex selection for family balancing and sex selection as a part of a eugenic intent to discard genetically or otherwise disabled embryos.

³⁹ *The Review*, 2.39

⁴⁰ *The Review*, 2.39

⁴¹ See for example <http://www.ronsangels.com>

⁴² *The Review*, 2.43

⁴³ *The Review*, 2.45

Genetic Modification of Gametes and Embryos

In retaining a ban on genetic alterations to a gamete or an embryo for transfer, *The Review* and *The Draft Bill* are following a strong ethical position that is widely held in the bioethics community⁴⁴.

However, the strength of this ban is considerably weakened by the proposed change that would permit research involving genetic alterations to embryos. By allowing such research, all the groundwork will be done which may eventually provide genetic alterations that some people will want to see in their children. Hence, pressure will then be applied to the government to permit what it now firmly says it will not permit, that is genetic alterations to embryos which will be transferred to the body of a woman.

Moreover, despite the fact that submissions during the consultation period were “generally less convinced of the need to make changes to the scope of permissible embryo research”⁴⁵, by permitting these critical changes allowing genetic alterations to human embryos in research programmes, *The Review* is proposing something contrary to the wishes of the public.

Privacy and Confidentiality

Reference in *The Review* to the revision of confidentiality restrictions⁴⁶ is difficult to interpret given that insufficient information is provided to determine what it would actually mean in practice. However, concern over loss of confidentiality is now evident in section 33C of *The Draft Bill*. The primacy given to medical research in general that is apparent in both *The Review* and *The Draft Bill* is now disturbingly sharpened in s33C. Permission for the disclosure of identifying information for research purposes, contrary to “any duty of confidentiality owed in relation to the information”⁴⁷, breaches the most basic of ethical principles. Moreover, the fact that there are many people potentially affected by information that could arise in the context of reproductive technology treatment, particularly where genetic information is concerned, is all the more troublesome.

Surrogacy

The Review states that the government intends “to clarify the extent to which not-for-profit organisations may undertake activities for the facilitation of surrogacy arrangements.”⁴⁸, and *The Draft Bill* picks this up by permitting advertising and the payment of a range of fees. As such the proposal represents a step towards commercialising surrogacy. However, this comes without sufficient basic research into surrogacy arrangements. The research that has been conducted, limited as it is, suggests that there exists potential and actual harm to all parties.

Surrogacy *per se* is problematic for the following reasons:

1. It is difficult if not impossible for a potential surrogate mother to give genuine informed consent. This is because of the possibility of emotional coercion, especially when the surrogate is a relative of the commissioning couple. Furthermore, there are psychological

⁴⁴ See for example David B. Resnik, Genetic Engineering, Human, In: *Encyclopedia of Bioethics*, 3rd Ed., Ed by Stephen G. Post, MacMillan, New York, 2004, pp 959-966.

⁴⁵ *The Review*, 1,11

⁴⁶ *The Review*, 2.56

⁴⁷ See explanatory notes to *The Draft Bill*, at 146.

⁴⁸ *The Review*, 2.64

and physiological health risks that the surrogate cannot be fully aware of prior to entering into a surrogacy arrangement. As Willmott notes, “Any consent given by a potential surrogate mother cannot be regarded as a real consent, the mother being motivated by factors other than her own or any future child's best interests.”⁴⁹ Furthermore, as Dodd and Jones state, “No two women experience pregnancy in quite the same way and the same woman can experience different pregnancies differently... Thus, how can a woman give fully informed consent to part with a child she will have felt growing and developing inside her, that she will have given form to through her body, before she knows the feelings these experiences will have produced?”⁵⁰

2. Surrogacy ruptures the maternal/infant bond, which affects both the mother and the child biologically and psychologically. It diminishes the importance of the role of gestation in establishing these bonds, which are critical for the proper development of the child and the welfare of both mother and child. Cognitive psychology on early childhood development, that is, social/inter-subjective bonds and attachments, reinforces the reality of important psychological bonds being formed from birth onwards^{51,52,53}. Given that in many surrogacy arrangements the surrogate parts with the child some time after birth, this is deeply problematic.

3. A surrogacy arrangement will often involve ART, which carries potential health risks to both the child and the surrogate. A surrogate will be undergoing ovarian hyperstimulation, which is not low risk.

4. In a surrogacy arrangement the welfare of the child is subordinated to fulfilling the desires of an infertile couple to have a child. This involves objectification of the child. Additionally, studies reveal that the motivation behind the alleged altruism of surrogates is sometimes questionable. 26% of potential surrogates had previously had an abortion and 9% had placed a child up for adoption⁵⁴, raising questions about whether surrogacy is an appropriate way of dealing with prior loss. There is also the probability that the child will suffer from “genealogical bewilderment”⁵⁵ by attempting to reconcile the unique circumstances of their family structure, which could lead to long-term psychological and behavioural problems. At this stage the empirical evidence about the long-term effects on

⁴⁹ Willmott (2002) Surrogacy: Ill Conceived Rights. *Journal of Law and Medicine*, 10:198-220.

⁵⁰ Dodd & Jones (1989) Surrogacy and Autonomy, *Bioethics News* 8:1-6

⁵¹ Meltzoff, AN & A Gopnik (1993). The role of imitation in understanding persons and developing theories of mind. In S. Baron-Cohen & H. Tager-Flusberg (Eds.). *Understanding other minds: Perspectives from autism*. Oxford: Oxford University Press.

⁵² Gopnik, A & AN Meltzoff (1998). Infant cognition. In *The Encyclopaedia of Philosophy*. Routledge

⁵³ Hobson, R. Peter, (2002) *The cradle of thought*, MacMillan.

⁵⁴ Parker (1983) Motivation of Surrogate Mothers: Initial Findings. *American Journal of Psychiatry*. 140:117-119. In Ciccarelli and Beckman (2005) Navigating Rough Waters: An Overview of Psychological Aspects of Surrogacy. *Journal of Social Issues*. 61(1):30

⁵⁵ Genealogical bewilderment is a relatively new phenomenon and few studies have been undertaken in the area - there is ample evidence for genealogical bewilderment in adoption, which shares similarities with surrogacy. Many studies have shown the long-term effects of adoption on those involved. David Kirschner, a clinical child psychologist, has coined the term “Adopted Child Syndrome”. He notes, “In case after case, I have observed what I have come to call the Adopted Child Syndrome, which may include pathological lying, stealing, truancy, manipulation, shallowness of attachment, provocation of parents and other authorities, threatened or actual running away, promiscuity, learning problems, fire-setting, and increasingly serious antisocial behavior, often leading to court custody. It may include an extremely negative or grandiose self-image, low frustration tolerance, and an absence of normal guilt or anxiety.” (Kirschner (1990) The Adopted Child Syndrome: What Therapists Should Know, *Psychotherapy in Private Practice*, 8(3), Hayworth Press.)

the child are inconclusive but with significant grounds for the likelihood of harmful consequences. Hence legislating that encourages surrogacy, as *The Draft Bill* does, amounts to an experiment with the child's life and with all those involved.

5. Surrogacy objectifies and exploits women. Surrogacy essentially amounts to a woman offering her body and her gestational child – effectively becoming an incubator for another couple. In a study by Van Zyl and Van Nierkerk⁵⁶ the typical responses given by surrogate mothers, with regard to how they felt about their relationship with the foetus, were as follows, “I don't think of the baby as mine. I donated an egg I wasn't going to be using”; “The baby isn't mine. I am only carrying the baby”; and “I am strictly a hotel”.

6. Reimbursement to cover medical expenses is not easy to define and has the potential to act as inducement or coercion. The result of this is likely to be the exploitation of surrogate mothers and in particular those who belong to a lower socio-economic group.

7. The complexity of the permissible surrogacy arrangements means that there is a range of genetic relationships possible.⁵⁷ The possible permutations and the ramifications that they have been given limited consideration.

8. Many surrogacy arrangements involve a surrogate who already has children. These children will see their mother carrying a child who they will perceive to be *their* sibling, regardless of how much direction they might be given to the contrary. They will then observe their mother give away their brother or sister.

In summary, surrogacy fails to respect the dignity or primacy of the welfare of the child, contrary to the stated intentions of *The Review* and *The Draft Bill*.

⁵⁶ Van Zyl and Van Nierkerk (2000) Interpretations, Perspectives and Intentions in Surrogate Motherhood. *Journal of Medical Ethics*, 26:404-409.

⁵⁷ There are many possible combinations of relationships in surrogacy arrangements, depending upon who supplies the sperm, egg, or womb. Where donated sperm and egg are used, the commissioning couple would have no genetic relationship with the child. It could therefore be argued that this outcome is more like adoption, making the request for surrogacy unnecessary. Where the surrogate is a close relative, perhaps the commissioning woman's mother or sister, the potential for relational confusion increases. In cases where the surrogate provides the egg, her genetic link to the child would be expected to make relinquishment all the more difficult. In circumstances where the commissioning male's mother agrees to be a surrogate, and the commissioning male's sperm is used, the child would be the genetic child of the commissioning male and his mother, what might be called 'gestational incest'. The psychological impact upon a child born in these circumstances could be catastrophic. In the opposite case, where the commissioning male's sperm is used to inseminate the commissioning female's mother, whilst there would be no 'gestational incest', the psychological impact upon the child as well as all involved could nevertheless be deeply problematic. In these circumstances, the child would be the genetic child of the commissioning male's mother-in-law, who would presumably be present throughout the child's upbringing.

Status and Legal Parenthood

It is evident that the primary reason for the proposed changes to “enable a greater range of persons to be recognised as parents following assisted reproduction”⁵⁸ is so that same-sex couples can access ART. This strengthens the reality that ART is far more than the treatment of infertility. In the context of same-sex couples, ART is in the business of treating ‘psychological infertility’ by providing a child to a same-sex couple, when no actual infertility exists. Any illusion that ART is solely for treating infertility should be abandoned.

Research Involving Embryos

The Review and *The Draft Bill* propose several changes to legislation covering research involving embryos. And the changes proposed are only in one direction, that is, a more permissive one.⁵⁹

It is regrettable that *The Review* begins the section on research involving embryos with a circular argument in what appears to be a justification of sorts for embryo research *per se*. It states, “The permissibility of research involving human embryos reflects the fact that advances in assisted reproduction – such as the development of in vitro fertilisation itself – could not have taken place without such research.”⁶⁰ In reality, the permissibility reflects no such thing. The permissibility has been a matter of public debate about the ethics of embryo research. While it is true that ART has become what it is partly because of embryo research, whether it is permissible is another matter. The fact the pioneers of ART carried out their experiments with nascent human life in the absence of public debate reflects on their ethical perspective and behaviour, and in no way suggests of itself that embryo research is permissible.

The Review and *The Draft Bill* propose to widen the scope of research involving human embryos by adding to the list of purposes for which they may be used (destroyed). To be included are:

1. research into serious injuries⁶¹ or serious medical conditions⁶²
2. permission to “replace the nucleus of a cell of an embryo”⁶³
3. “training in treatment and research techniques”⁶⁴
4. the possible use of embryos directly in therapy⁶⁵

The first of these is not surprising given the fact that licensable activities already include the investigation of serious diseases. However, any suggestion that the use of embryos is restricted to research that applies only to serious matters in human health can be quickly dispensed with. The list of currently licensable activities already includes “developing more effective techniques of contraception” and “increasing knowledge about the

⁵⁸ *The Review*, 2.69

⁵⁹ *The Review*, 2.72

⁶⁰ *The Review*, 2.71

⁶¹ *The Review*, 2.74

⁶² *The Draft Bill*, s3A(2)(a)

⁶³ *The Review*, 2.77

⁶⁴ *The Review*, 2.78

⁶⁵ *The Review*, 2.79 & 2.80

development of embryos”. In light of these - and the proposal for embryos to be used for “training in treatment and research techniques” - reference by the government to the “special status outside the body” of the human embryo is shown for what it is, that is, a platitude.

One of the more interesting recent developments in stem cell science suggests that the use of embryos, whether produced by fertilisation, cloning or other means, to extract embryonic stem cells may not be unnecessary.

Shinya Yamanaka of Kyoto University has produced pluripotent stem cells from mature mouse skin cells that possess the characteristics of embryonic stem cells.⁶⁶ The results have been confirmed by two other teams, at the Whitehead Institute for Biomedical Research in Cambridge, Massachusetts and the Harvard Stem Cell Institute.⁶⁷ Work is currently underway to repeat the finding using human cells.

Therefore, expanded access to human embryos for the derivation of embryonic stem cells may now be unnecessary.

Inter-species Embryos

The Draft Bill permits, under license, the creation of a variety of inter-species embryos and their destruction in research programmes. Some of these embryos might be considered essentially human whereas others would be essentially animal and others approximately half-animal, half-human.

The creation of such an interspecies embryo that is essentially human solely for the purpose of destruction for speculative science is a clear affront to human dignity and represents no respect whatsoever for human life at its nascent stage.

Furthermore, the intimate mixing of human and animal genetic material represents an additional affront to human dignity.

On ethical grounds the technology is also problematic because it is contrary to the wishes of the public. There is a natural aversion in the community to the creation of embryos from human and animal biological material. In its recent consultation, the Department of Health noted that the “overall tenor of responses to the consultation was opposed to the creation of hybrids and chimeras”.⁶⁸

The Draft Bill states that no hybrid should be permitted to develop beyond 14 days⁶⁹. However, this is arbitrary and hence open to change.

Basic ‘proof or principle’ work in animal models has not yet been done with regard to these types of hybridisation experiments to show whether anything scientifically useful can be gained from them. It is therefore entirely inappropriate to even consider such experimentation with human genetic material. The long-standing paradigm in research involving human life is being breached in these proposals.

⁶⁶ Okita, K., Ichisaka, T. & Yamanaka, S. Nature doi:10.1038/nature05934 (2007).

⁶⁷ Wernig, M. *et al.* Nature doi:10.1038/nature05944 (2007) and Maherali, N. *et al.* Cell Stem Cell doi:10.1016/j.stem.2007.05.014 (2007).

⁶⁸ *Government proposals for the regulation of hybrid and chimera embryos*, House of Commons Science and Technology Committee, Fifth Report of Session 2006-07, p 56

⁶⁹ *The Draft Bill*, s4A(3).

The use of hybrids has primarily been proposed for the derivation of embryonic stem cells from disease-specific hybrids. However, good alternative sources of disease-specific adult stem cells from nasal mucosa already exist.⁷⁰ Furthermore, extensive access to embryonic stem cells over nearly 10 years has so far yielded limited scientifically valuable information.

Conducting basic research to produce hybrids lays the groundwork for any maverick practitioner to transfer such an embryo to the body of a woman, regardless of the legal proscription. Since scientists and reproductive technology practitioners have already transferred cloned human embryos to women's bodies⁷¹, transferring and attempting to bring to term an essentially human hybrid embryo must be considered eventually likely.

Since this technology is seen by many as a stepping-stone to the eventual development of cell-based therapies using human eggs⁷², all of the ethical difficulties that pertain to sourcing human eggs will resurface.

On practical grounds this technology is problematic because:

- It is entirely unclear whether hybrid embryos will be useful in research. Any cloning procedure results in considerable genetic damage⁷³, and this would presumably be worse earlier in development. It is likely that even greater damage will occur with hybrids.
- No embryonic stem cell lines have been produced from cloned human embryos where human eggs have been used, and the only research where embryonic stem cells have been produced from hybrid embryos has been questioned as to validity and has not been repeated.⁷⁴
- Inasmuch as hybrid embryos are likely to represent a poor model of early human development, the use of hybrid embryos for toxicity and drug testing will be of limited value.

In consideration of these ethical and practical grounds, the creation and use in medical research of chimeras or hybrids should not take place.

RATE

In one sense it is understandable that the government would want to rationalise its resources by merging the HFEA and the ITA and form the new Regulatory Authority for Tissue and Embryos (RATE). However, the two areas are very different, and the proposed

⁷⁰ See evidence presented by Professor Alan Mackay-Sim, Griffiths University, Queensland, "I can tell you now that we have over 50 cell lines from people with disease, and they are much easier to make than somatic cell nuclear transfer therapeutically cloned cells, which cannot be made currently in humans", Inquiry into the Legislative responses to Recommendations of the Lockhart Review, Committee Hansard, 23 October 2006, page CA84, accessed 7 May 2007, see

http://www.aph.gov.au/senate/Committee/clac_ctte/leg_response_lockhart_review/report/d05.htm

⁷¹ Helen Pilcher, Zavos clone claims cause journal to axe paper, *BioEdOnline*, Sept 2004, accessed 7 May 2007, see <http://www.bioedonline.org/news/news.cfm?art=1146>

⁷² This is proposed in *Government proposals for the regulation of hybrid and chimera embryos*, House of Commons Science and Technology Committee, Fifth Report of Session 2006-07, p 34

⁷³ Wells, D. N., Animal cloning: problems and prospects. *Rev Sci Tech*, 24(1): 251-264, 2005.

⁷⁴ This work was conducted in 2001 by Dr Sheng in China. See *Government proposals for the regulation of hybrid and chimera embryos*, House of Commons Science and Technology Committee, Fifth Report of Session 2006-07, p 31

change sends a clear message that the government considers the field of human reproductive technology to be one that requires no special treatment. Moreover, the change carries a strong implication that gametes and embryos are really no different to other tissues of the human body. However, this is a view that neither the public has nor the government seems to want to promulgate.

Summary

The Draft Bill covers an enormous range of ethical issues, each with its own set of complexities and consequences. It is seriously doubtful whether some of the proposed changes are necessary at all, and it is even more doubtful whether the community has had a real opportunity to adequately respond. In consideration of these matters, and the haste with which this process has been undertaken, it is likely that the public will develop an even greater sense of unease than it already has about ART and research using nascent human life.

The government can ill afford such a perception. But perhaps more importantly, as the community begins to come to terms with biotechnology and what it may be able to offer, the medico-scientific community is at risk of tarnishing its image. To the extent that that has already happened, the damage has been done, but there is still every opportunity for it to pursue genuinely ethical pathways to discovery and the delivery of therapies.

SCBI