Human Embryos – the Subject of Research

A Submission from Auckland Medical Aid Trust on the use of Gametes and Human Embryos in Reproductive Research

Introduction

This document is a submission from the Auckland Medical Aid Trust about the use of Gametes and Human Embryos in Reproductive Research. The submission is made as part of consultation being undertaken by the Advisory Committee on Assisted Reproductive Technology (ACART), who will be providing the Minister of Health with an advisory report later this year.

The Auckland Medical Aid Trust is a charitable trust established in 1974 to deal with matters concerning human reproduction. There are currently three Trustees, with the day-to-day affairs managed by an Executive Officer. The Trust has, since inception, operated an Abortion Clinic in Auckland to complement public hospital service provision; it has given charitable grants to various individuals and organizations for research and other purposes; it has sponsored the publication of books within the scope of its objects; it has sponsored the formation of another charitable trust to assist those whose lives have been affected by adoption; and most recently, it has established a doctoral scholarship at the University of Auckland to sponsor research into issues in the field of human reproduction.

The consultation process

By way of opening, it is scandalous that an inquiry into such an important field as research on human embryos be conducted in such a short time frame, and shuffled into a period of the year frequently and traditionally reserved for family life and holidays. The discussion document and the call for submissions were released ten days before Christmas[1], by which time most organisations and voluntary groups have finished for the year. Realistically, and coinciding with 'back to school', the beginning of February as a start date for consideration of these issues leaves about a month before submissions are due. Such a hurried process, and its allocation to a time of year that does little to facilitate consultation, arouses suspicion that this submission process is merely a formality that will have little bearing on pre-conceived government initiatives.

It is also worth noting that the current submission exercise is being conducted within the political realm of government[2], with little fanfare in the form of public advertising. Given the necessarily political and economic function of government and its strongly expressed opinions about the value of biotechnology to the future economy of New Zealand[3], certain reservations might be held about the political neutrality of such an exercise. This reservation underscores our increasing reliance on science as the way we understand life, and in particular, the way the scientific paradigm falls squarely within the realm of economic interest.

Limiting the discourse

While the discussion paper acknowledges that the topic of research using gametes and embryos raises "complex and potentially divisive ethical and social questions" (par.

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[1] The invitation and discussion document, *bio033 (Submissions invited on using Human Embryos for Research 15.12.06)ver01.doc)* was received by email distribution from Suzanne O'Rourke, late Friday afternoon on 15 December 2006.

[2] While the process is not subject to direct government intervention, the appointment of the various supervisory bodies and the legislation process that establishes and monitors their sphere of activity is very much part of national government.

[3] See, for example, *New Zealand Biotechnology Strategy* (Ministry of Research, Science and Technology, 2003).

107), an inadequate and inappropriate attempt is made to frame up possible responses within a preconceived model, public opinion being squeezed into a position between two opposing poles of an imaginary continuum. The discussion document constructs a binary opposition between, on the one hand, those who oppose research on human embryos because of the moral status of the embryo (par. 108); and on the other hand, those who see such research as defensible because the embryo has no moral status (par. 109). By lining up other possible responses in a straight line between these two opposing poles, the argument is that, "consequently, the ethical justification of research projects using human embryonic stem cells will depend on the potential benefits of the research and the quality of the scientific questions being asked" (par. 110). However, it is not evident that the tightly-framed continuum, in which the population is organised between two opposing poles, encapsulates the range of possible responses – certainly not before submissions are received. While such pre-structuring does a lot to frame up the responses in particular language and possibly makes for a more efficient collation of survey results, such preconceptions work against the spirit of consultation that ACART is looking for in fulfilling its government brief to canvas public opinion on this topic.

A similar technique is used in presenting typical religious traditions of thought (par. 111-117), where we are told that different religious traditions have "quite different perspectives …" and that there will also be "differences within religious traditions" (par. 111). We are then presented with a fixed account of several religious views (par. 112-115), linking differences to the significance of the primitive streak (par. 116-117) in a 'stages of development' model that binds potential respondents inside another linear model. However, this submission is aware (and pleased) that not all thinking occurs in such linear fashion. Again, the preconception militates against the consultation process and is disrespectful to its participants.

Even worse, the reins are drawn in more tightly on the possibly diverse (and as yet unknown) responses from various individuals and communities engaged in the current consultation process. We are told that responses (as yet not received) to questions about embryo research depend primarily on how views about "the moral status of the embryo; that is, the extent to which the embryo should be recognised as a human being (person), with all the rights and protections associated with personhood." This level of clarity either presumes the answers are known before the questions are asked, or worse, attempts to shape the responses to fit a particular construction. This submission, for example, is not as concerned with the moral status of the embryo, as it is with the relative and unequal power status of the different communities that attempt to control the discourse – including various assemblages of academics, scientists, health 'consumers'[4], governments, economic investors and public interest groups such as ourselves. To control the discourse is to have particular moral views accepted as 'right' or 'commonsense' with some semblance of consensus, albeit in a social sphere characterised more by variety and difference than commonly held views.

The term 'modernity' is often used to refer to the philosophical search for absolutes, universals and foundations in theory, extending through empirical observations, through the human sciences, and in this case, into the quest for some certainty about what we should do as a society about the moral dilemma about research on human embryos. Modernity is about conflict-*resolution*, "about admitting of no contradictions except conflicts amenable to, and awaiting resolution" (Baumann, 1993, p. 8).

The postmodern, on the other hand, admits to *aporia* – the existence of contradictions that cannot be overcome, conflicts that cannot be resolved. Zygmunt Baumann's postmodern approach to ethics suggests that as a society we are unlikely to reach any universal moral certainty over issues such as research on human embryos. This is not to advocate a relativism in which anything goes or a helplessness in which there is nothing we can do about moral problems. Rather, prescribed ethical codes and the moral practices they support can be seen as parochial politics posing as universal law.

[4] The Health and Disability Commissioner's Code of Health and Disability Services Consumers' Rights Regulation (1996) defines people seeking health treatment as 'consumers', locating health firmly with an economic mode of production and consumption.

Baumann takes issue with legislators trying to develop an all-comprehensive, unitary ethics, a cohesive code of moral rules for public acceptance

> It is the *disbelief* in such a possibility that is postmodern… The foolproof – universal and unshakably founded – ethical code will never be found… a non-aporetic, non-ambivalent morality, and ethics that is universal and 'objectively founded;, is a practical impossibility; perhaps also and *oxymoron*, a contradiction in terms" (Baumann, 1993, p. 10).

In spite of the reservations expressed above, the public process is a useful one and the discussion document helpful in providing background information to consider some of the issues targeted by the consultation. It would be difficult at a national level to establish an appropriate balance between making such a document clear and simple, and on the other hand providing sufficient level of detail. One notable lack of specifics is the nature of the 100,000 frozen embryos in New Zealand and Australia (par. 60). It is not clear what stages of development are represented in this 'embryo bank', and what proportion of these might be viable. Given the document's emphasis on the various stages of development in defining moral considerations, this is important knowledge in considering whether and how already-existing embryos might be used for research.

Considerations of 'normal'

In considering therapeutic aspects of genetic technology, it seems easy to agree that we should want to cure or alleviate illness, disease or disability; or that we should want to improve health and well-being. Before undertaking such cures, some assessment is obviously made about what is normal, what is desired, and what is an acceptable range of deviation. For exampled, the discussion document notes that "embryo quality may be improved" (par. 74), "defects in mitochondrial DNA" (*ibid*.), and the "normal growth of an embryo … constrained by defects (par. 75). Research on human embryos is thus treated as a quality management issue, with quality-controlled production processes to ensure normal development.

The norm, however, is not a transcendental standard or neutral in its operation. Rather, it establishes and discriminates against the abnormal. Foucault (2003) sees this discrimination as a kind of racism, whose function is not so much the prejudice or defence of one *group* against *another*, as society's internal defence against its abnormal individuals. Foucault posits deviations in conduct as a potential symptom of illness when the conduct deviates from "the rules of order or conformity defined on the basis of administrative regularity, familial obligations, or political and social normativity" (Foucault, 2003: 159).

If a similar judgment is made about genetic or embryological deviations, human genetic material and future human beings may be subject to redesign, with decisions about therapy and enhancement also based on administrative regularity, familial obligations, or political and social normativity. This is clearly a case of treating others as means rather than ends, in the achievement of a more orderly and manageable society or a more predictable and less disturbing heredity through the redesign of its troublesome subjects. As medicine and research 'advance', there is a corresponding shift in what is considered 'normal' health and an increasing expectation that it can be achieved. As 'abnormalities' are identified and reduced, there is a corresponding reduction of variegation within the human species, promoting instead a kind of homogenisation of the population, with unknown future consequences. Given the current limitations on using genetic technology for reproductive purposes, such consequences are for the time being, limited to therapeutic application.

Debating the limits of 'normal' is hugely significant in the current consultation process, but is not provided for in the discussion document's questions. Limiting the scope of matters to be considered and compressing the time frame for consultation are the kind of shortcuts that should not be taken, as it leaves scientists and researchers potentially exposed to full responsibility for research that has such far-reaching effects.

The notion of 'lack' as a stimulus

The discussion document notes that, "researchers do not yet know what chemical signals are used to direct embryonic stem cells to differentiate into specialised cell types in the human body" (par. 46); and further, "fundamental research is required to

realise many of the therapeutic possibilities of embryo research" (par. 67). The implication is that research should continue because we have insufficient knowledge, (i.e., research as the antidote to insufficient knowledge). This is couched in terms of a 'need' for further research, in which science is its own self-justification, and technology the vehicle for its achievement. Non-existence of a technology is presented as a 'lack' or 'inadequacy', for which corrective steps must be taken. In other words, the thought about *what we don't know* becomes an imperative to find out, to have to act. Yet according to the discussion document, scientific knowledge is of limited use in deciding what *should be done*. This, we are told, needs to be "informed by society's ethical, spiritual and cultural perspectives on gamete and embryo research" (par. 104), and it would seem that much work (and consultation) is yet to be done before heading off on the technological track. A perceived 'lack' is not necessarily an imperative to act – the fact that there are unknowns in the design and functioning of human nature and reproduction is not necessarily a mandate to have to find out and to interfere in that process.

Keeping it technical

Paragraphs 82 and 83 of the discussion document deal with modifying the germ line, a technique that affects future generations. There is mention of "significant concerns" about the long-term effects of such modification, although no specifics are investigated. Similarly, although the document notes that the topic of research using gametes and embryos raises "complex and potentially divisive ethical and social questions" (par. 107), emphasis is on the difficulty of such 'achievements' because of the "complexity of the genes" and the "influence of the environment". In other words, the objections to the process are presented in terms of insufficient technical knowledge about the process, rather than as a result of philosophical considerations. We are told, for example, that the "technique represents several technical challenges" (par. 74). Limiting the focus to technical aspects ignores suspicions that people have about their increasingly subservient role in relation to technology, to science and to economic considerations. Couching the topic in terms of complexity plugs into our desire to know, acting as a spur to further action, an impetus for more knowledge, and the development of more technology, in the hope the next development will make us better.

Managing human quality

The discussion document portrays the human organism as human resource within the language of production management: "manipulating the egg cytoplasm… to improve embryo quality" (par. 76); "deficiencies in the egg cytoplasm… [and]… the correct metabolic requirements for a developing embryo" (par.74), Further research, we are told could "potentially improve this technique" (*ibid*.) Such language meshes easily with the function of 'human resources' in late Western consumer capitalism to facilitate mass production of items such as Henry Ford's Model T, and more lately items such as computers and cell phones. While technical aspects of such production have been improved by quality management, decades of development have left us with social problems like (real and virtual) traffic jams, pollution, accidents, and increasing piles of old junk to litter the planet. At least with the increasing piles of junk from existing manufacture, environmental implications are reasonably predictable (even if not very savoury). By contrast, the possible impact of by-products and detritus from embryo research cannot be foreseen in its intersection with human bio-futures and inadequate knowledge thereof. Efficient, well-managed, accelerating research technology is not necessarily a direction we should move in, especially not until the population (rather than a small group of 'experts') has had a reasonable chance to consider what is involved. And especially not amidst an intensification of consumerism driven by economic imperatives.

Pace of development

According to the discussion document, "some researchers consider there may be significant advantages to creating embryos for research through IVF" (par. 63). By implication, the advantage seems to relate to the speedy production and ready supply of particular kinds of embryos (just in time management model, where parts are delivered just as they are needed for factory production). This puts the technology and the rate of development into the hands of the researchers, providing a means of

accelerating the rate of new technological and scientific knowledge beyond that which the public can assimilate. These fields are already ahead of our ability to interpret the implications in terms of their broader dimensions, and present the potential for unknown problems ahead if not located within the broader social environment, and linked in some way with prevailing cultural and social norms. Such pace leaves the knowledge and its direction in the hands of scientists and governments, a model that history has taught us is rather short on ethical consideration[5].

Changes in gene biotechnology have led the New Zealand Law Foundation to commission a special project to bring legal thinking up to date with rapid change in the field of biotechnology. Foundation Chairman, James Johnston, argues that the pace of change often denies communities the opportunity to debate and research the consequences of science. It is crucial, he says, that the debate is well informed and wide enough to include "scientific, medical, ethical, cultural, economic and philosophical perspectives" (*Human Genome Research Project*, 2006, p. iii). These considerations are referred to in the discussion document and need to be accorded their proper place.

One of the ways in which research can be accelerated is by removing the burden of proof from researchers that their research will do no harm. In discussing cell biopsies, the document says, "There is as yet no evidence to suggest that the cell biopsy adversely affects the health of the resulting child." Presumably, this is taken as justification for the technique and for its continuation until somebody *else* proves some harm. Onus is thus removed from researchers for the outcomes of their activities, in favour of pushing the boundaries of research until something is seen to be harmful. Given the unequal balance of funding and technological competence in the direction or promoting rather than preventing research, shifting the onus like this leaves the field heavily weighted in favour of those wanting to push the knowledge barriers over those wanting to prevent harm. This submission accepts that such proof may not be possible until at least some research is undertaken.

The *Human Genome Research Project* (2006) suggests there is a reasonable consensus that human embryos deserve some protection; in other words, the burden of proof belongs to those who want to diminish or withdraw protection (p194). We are comfortable with the onus being on the researcher for any resulting harm, with a duty of care of similar order to that expected (but often not exercised) by property developers in relation to the Resource Management Act.

The discussion document mentions an "appropriate degree of caution" (par. 88) in developing stem cell therapies. It is not clear, though, what an 'appropriate degree' is. A possible consideration is the 'precautionary principle' – a generic mechanism for reducing, if not eliminating, risks to public health and/or the environment, particularly in the development of new technologies. Although there is no definitive expression of the principle, its various formulations advise that we take measures to avoid harm to the environment and public health even if we are not sure about that harm. One typical formulation, appropriate to the field of biotechnology is:

> If there is reason to believe that a technology or activity may result in harm and there is scientific uncertainty regarding the nature and extent of that harm, then measures to anticipate and prevent harm are necessary and justifiable (Raffensperger & Barrett, 2001: 811).

The Royal Commission Report on Genetic Modification (2001) considered the precautionary principle at length but remained unconvinced that a single principle could be applied across the board to the use of genetic modification in New Zealand. Decisions on the use of the technology, the report noted, must rest on a range of factors, including the risks and acceptability to the public of the proposed use. The (probably intentional) vagueness of such assurances does not inspire confidence. An 'appropriate degree of caution' is equally vague and does little to attend to widespread

[5] Considered here are the atrocities committed under the name of science in, among other places, Nazi Germany last century.

concern about radical technology that impacts on the future health and even the nature of humankind.

Protection of the research subjects

The discussion paper refers to *The Declaration of Helsinki*, which restricts medical research on human subjects to research where 'the importance of the objective outweighs the inherent risks and burdens to the subject' (par. 137). The paper then questions whether the provisions of this Declaration apply equally to embryos. Embryo research is inherently different, we are told, in that any research "results in the destruction of the specific embryo under investigation, thereby preventing benefit to that particular embryo" (par. 138). The logic seems to be that as long as the embryo is destined for destruction, it does not need to be considered as a subject worthy of ethical consideration. In other words, as long as the subjects are to be destroyed, they don't need protection. This seems absurd, and would suggest that there was nothing wrong with the Nazi treatment of the Jews in the second World War because they were destined for death camps. The likely destination of the embryos *cannot* be the criteria for how they are considered ethically.

Similarly, this submission does not agree with the idea that research to provide better knowledge about fertility or about embryos as a whole, is blanket justification for the destruction of individual embryos (par. 141). This point is made, even though the area of fertility has traditionally been an area in which embryos may have been destroyed during research. If this has happened in the past, that does not provide any ethical justification for its continuation – political and empirical perhaps, but not ethical. The utilitarian principle of the few being sacrificed for the many is wrong.

The discussion paper notes a view that the creation of embryos for research may be inconsistent with the principle of respect for human dignity, because it instrumentalises human life and treats embryos as commodities (par. 129). Such a view is based on a *moral* consideration of what *ought* to be. To counter that view, the discussion document offers us a consideration of the existing use of embryos within New Zealand, i.e., an *empirical* consideration of what *is* currently the case. The paper then argues that because "only limited respect is currently given to the early embryo" (par. 130), the creation of embryos for research purposes may not diminish the respect bestowed upon embryos. This is a philosophical error, raised by David Hume (1927), Scottish philosopher and historian, who noted that many writers make claims about what ought to be (*prescriptive* statements) on the basis of statements about what is (*descriptive* statements). To engage with the question of what *ought* to be, is to enter the domain of ethics and morals, not the world of empirical science or practical observation. And, as the discussion document rightly points out, in a pluralistic society such as New Zealand, people will draw their values from different sources. This submission contends that it is debatable whether disparate views *can* be (or even *should* be) reconciled into a single ethical view.

Economic imperatives

The discussion document informs us that the HART Act bans "the giving and receiving of payment or valuable consideration for the supply of human embryos and gametes" (par. 147). This legislative provision is said to "express values and beliefs about the commodification of early forms of human life" (*ibid*).

This submission supports the intention of the legislation and agrees that payment should not be allowed for the supply of human tissue. Further, (this may require international agreements to be put in place), payment and profiteering should not be possible from the design and redesign of human tissue in any form, including "cell lines and discoveries made using those cell lines" (par. 195). Currently, the situation in the UK prevents donors from having an interest in the future use of their cells, whereas scientists and corporations investing in patents may benefit enormously. In terms of commodification, this high-level trading seems as wrong as the sale of tissue at the donor level.

Much of the development in embryonic research technology is in the hands of private companies, who may well put profit ahead of principle in the multibillion-dollar biotech industry. We believe it is important to minimise the possibility of profiteering not only at

the level of entrepreneurial tissue donors, but also at the level of corporate investment in international patents, unless of course the intention is to enframe biological science primarily as a feature of the economy rather than of medicine. Such enframing leads to a different status for various kinds of knowledge. On the one hand, are knowledge realms like computer science and biotechnology that are useful and productive for the economy, characterised by their managerial efficiency and measurable outcomes. On the other hand, are the 'soft' options like arts, literature, philosophy and the humanities that are of benefit to a rich social life and people living as community.

This submission does not want to prevent scientific research or the development of technologies that will significantly benefit a wide range of people, but it is important to achieve a balance. A promising model is developing within the computer-software development community. Sidestepping the profit-making intentions of the widespread licensing and proprietary arrangements for software sales and distribution, a number of developers are now promoting 'open source' knowledge in the public domain. Inventions and discoveries are publicised for the common good without any need for private ownership. The model seems to work well and may be applicable as a way to consider the problem of private ownership of various arrangements of the human genetic code.

Conclusion

Given the limited nature of the consultation process criticised in this submission, and the constraining nature of the questions being asked, this submission has been rather full and prefers not to answer the questions in the boxed structure provided. Much of the above can be taken as answers to ACART in their search for public opinion. Further, the limited time we have had to consider and discuss the questions about embryos has left a rather brief list of summary statements.

1. The consultation model used in this process has been insufficient to inspire confidence in its findings. Future consultation needs to be more wide-ranging, extended in time, and open-ended in nature.

2. Auckland Medical Aid Trust sees little need to restrict the *purposes* of research, and subject to wider ethical considerations and the other opinions expressed herein, is happy to support research for basic science, fertility treatment, hereditary disease, and general medicine.

3. What seems like a very important aspect of embryo research is the possibility – from the development of therapeutic cloning – of providing tissue or stem cells for therapeutic use (par. 65). The notion of 'viability' is introduced as an already-existing criterion (within the NECAHR *Interim Guidelines*) for embryos to be used in research (par. 56), and it seems sensible to progress this aspect of research into therapeutic developments, particularly where the patient provides the donor nucleus so that any subsequently transplanted tissue would be genetically identical to the patient's own tissue. The resulting tissue is not a viable embryo, but could be considered an 'extension' of the donor. The discussion documents notes that "person-specific therapies using SCNT embryos will almost not be developed for a number of years" (par. 65), although it appears easily justifiable as a research purpose. This position is supported by recommendations from the Australian *Lockhart Report* which go as far as to allow the "transfer of human somatic cell nuclei into animal eggs…for the creation and use of human embryo clones for research, training and clinical application" (par. 187).

4. The discussion document notes an ethical difference between *creating* embryos specifically for research purposes and the use of *surplus* embryos (par. 128). In creating embryos for research, the destruction of those embryos is premeditated, so no argument arises over the planned use. This is an important point and one worth exploring further, since the kind of research permitted can be pre-regulated.

5. This intentional production of embryonic material for research is even less problematic if we are talking about embryos that are 'non-viable', i.e., do not have the potential to form a human being. This leads far more peacefully to therapeutic use of stem cells than the public alarm raised in discussion about the destruction of

already existing embryos or the production of whole viable embryos which are used for science and then later destroyed.

6. The use of already-existing (surplus IVF) embryos is not so clearly defined, in that they were fertilised for a different purpose. If legislation were to change to allow the use of these surplus embryos for research, it would seem right that both parents of the embryo would need to give express permission for such use to be made. This submission supports the notion that surplus IVF embryos could be a suitable source for embryos for research, provided that both parents agree. It also supports the use of non-viable embryos and donated gametes on the basis of permission being obtained.
7. This submission does not yet support the production of embryos specifically for research or the development of hybrid embryos, and considers that a moratorium should be introduced on such aspects until proper public consultation has taken place.
8. There should be a ban, or at least a moratorium, on import and export of embryonic material. Reasons for this include the potential exploitation of targeted groups of people, difficulties with quality control outside NZ quality regimes, and the potential for commodity trading.
9. Commercial gain should be minimised or prevented in the development of research and/or knowledge about human embryos. Commercial gain includes profiteering, private ownership, monetary incentives, patents, corporate investing, and commercial rights on knowledge about human organism.
10. Similarly, commercial gain should be prevented from the development of human tissue related to this process.
11. Patents should not be allowed on human organisms, since that would treat biology as mechanical 'invention' rather than natural discovery.

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