CHAPTER 3

ETHICAL ISSUES

Introduction

3.1 The two main sets of ethical issues posed by the Bill before the Senate concern, first, the ethics of human cloning and, second, the ethics of destructive research on human embryos.

3.2 The Bill prohibits both reproductive and so-called therapeutic cloning, and makes it an offence to import a human embryo clone into Australia. The Bill provides for destructive research on human embryos under certain specified circumstances.

3.3 Evidence before the Committee suggests that there is near unanimous support for the prohibition on reproductive cloning, and very strong support for a prohibition or at least a moratorium on 'therapeutic' cloning.[1] This support is grounded in a strong consensus that such practices are 'ethically unacceptable'.[2]

3.4 That consensus in turn is based on both direct consequentialist considerations, such as the risk of creating abnormal or prematurely aged embryos or individuals, and on broader concerns such as the threat to concepts of identity and kinship, fear of eugenics, commodification of children and the implications for genetic diversity.[3]

3.5 There was almost no ethical disagreement expressed in evidence on the prohibition of human cloning. Concern was expressed about the legitimacy of the distinction drawn between reproductive and so-called 'therapeutic' cloning, and was discussed in the previous chapter.

3.6 There was, however, extensive debate about the ethical justifiability of the proposal that destructive research on human embryos be allowed to proceed. In what follows, the Committee outlines the main lines of ethical argument both for and against that research.

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1 The Australian Academy of Science, for example, supports 'therapeutic cloning as a possible way ahead for the production of appropriate stem cell lines if that turns out to be what is needed to produce them'. *Committee Hansard*, 19.9.02, p.124. However, it also stated that a 'moratorium for a few years on therapeutic cloning is a very reasonable road to take'. *Committee Hansard*, 19.9.02, p.116.

2 Hon. John Howard MP, Second Reading Speech, Research Involving Embryos and Prohibition of Human Cloning Bill 2002, House of Representatives, 27 June 2002.

3 See discussion of these issues in Department of the Parliamentary Library, Bills Digest No.17 2002-03*, Research Involving Embryos and Prohibition of Human Cloning Bill 2002*, Jennifer Norberry, Law and Bills Digest Group, 14 August 2002, pp.6-7.

3.7 It should be emphasised that the Committee's aim in this discussion is not to reach a definitive view on the ethical questions raised by the proposed research. It does, however, hope to contribute to a broadened or deepened understanding of the implications of the moral issues at stake.

3.8 To this end, the Committee attempts not simply to describe the different arguments put in evidence, but to analyse some of the implications of those arguments and to suggest what further questions may be raised by them.

Structure of argumentation

3.9 There are a range of arguments put for and against the ethical justifiability of permitting destructive research on human embryos. It will assist in clarifying the nature and status of these arguments, if some preliminary attention is given to their relationship with one another.

3.10 Imagine a proposal to perform destructive experimentation on an adult or child. Even if such experimentation promised great medical benefit, it would generate very little ethical debate. That is because for almost no one is it an open question as to whether it is morally acceptable to destroy an individual person for the sake of benefit to others.[4]

3.11 The heart of the ethical debate before the Committee is the question of whether or not the embryo enjoys the same moral status as an adult or child, and hence whether it is an open question that it may be morally acceptable to destroy a human embryo for the sake of benefit to others.

3.12 For those who think that the human embryo is morally equivalent to an adult or child, then acknowledging its moral status exhausts the question (in the negative) of whether it may be destroyed. Further reasons, either moral or scientific, may be adduced in support of the view that such experimentation is unacceptable, but these further reasons are not the decisive factors in the conclusion reached.

3.13 For those who think, however, that the human embryo under 14 days does not enjoy precisely the same moral status as an adult or child, then the nature of any further reasons for supporting or objecting to the practice becomes decisive.

Moral status of the human embryo

3.14 There are three broad ways in which the moral status of the human embryo may be considered. The Committee will consider how these views informed the

4 The Declaration of Helsinki, discussed in the previous chapter, states that 'In research on man [sic], the interest of science and society should never take precedence over considerations related to the wellbeing of the subject'. There are some consequentialist arguments in moral philosophy that would dispute that principle, but these do not have wide currency in the community.

evidence it received concerning the ethical justifiability of destructive research on human embryos.

3.15 The three views of the moral status of the embryo are that it possesses:

- no moral status;
- the same moral status as an adult human being;[5] or
- limited or different moral status compared with an adult human being.

No moral status

3.16 Very few argue that the human embryo has no moral status at all. Where it is argued, it often depends upon the idea that human moral status depends upon the properties of sentience or rationality.

3.17 For example, the Humanist Society of Victoria stated that:

> We do not regard early zygotes as humans: they lack the essential property of sentience, and in vivo, some 50% of these fertilised ova fail to implant and are discharged from the womb.[6]

3.18 This kind of argument was also made by Australian ethicist Peter Singer in evidence to the Senate Select Committee on Human Embryo Experimentation and more recently by Julian Savulescu, Professor of Applied Ethics, Oxford University, who has written:

> If we are fundamentally conscious minds, we do not begin to exist at least until the structures are present which could support consciousness. The Royal College of Obstetricians and Gynaecologist's Working Party produced a report on Fetal Awareness in 1997. It concluded that the structural development for ability to be conscious of pain is not present in the fetus before 26 weeks. Thus, the fetus does not achieve moral status before 26 weeks.[7]

3.19 As part of his argument that 'we' are fundamentally identified with our minds or that what really matters about us is consciousness, Professor Savulescu discusses the case of Tony Bland, a young man rendered permanently unconscious by the

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5 By the term 'adult human being', the Committee means to include human beings who are born as opposed to unborn. For the purposes of this usage, children and infants should be considered included in the term.

6 *Submission* 982, p.2 (Humanist Society of Victoria).

7 Julian Savulescu, 'The Ethics of Cloning and Embryonic Stem Cells as a Source of Tissue for Transplantation: Time to Take a Positive Approach to Law Reform in Australia', undated, p.8. See also *Submission* 899, in which the former Chair of the Senate Select Committee on Human Embryo Experimentation, the Reverend Professor Michael Tate, describes that Committee's rejection of the view presented by Professor Peter Singer. According to Professor Singer, 'a person could only be identified as such when consciousness and some capacity for moral discernment or decision making emerged'.

Hillsborough football disaster. Professor Savulescu notes that what justified the decision to withdraw artificial means of life-support from Tony Bland was that the fact of his permanent unconsciousness left him with 'no interest in remaining alive'.[8] By analogy, then, Professor Savulescu's argument is that an embryo which lacks consciousness likewise lacks any interest in remaining alive.

3.20 It is noteworthy, however, that although Professor Savulescu considers that Tony Bland's condition justifies the withdrawal of 'extraordinary' means to keep him alive, he does not propose that it licenses us to perform destructive experiments on him. In other words, a difficulty with this kind of argument is that it is seemingly too broad. It would mean, for example, that human beings who are comatose or severely mentally impaired would also lack moral status, and so would be available for destructive medical experimentation.

3.21 It seems then that absence of consciousness or sentience is not, by itself, sufficient to justify the withdrawal of *any* form of moral consideration for particular human beings.

3.22 Using the same analogy, then, a number of submissions to the Committee drew a moral distinction between the withdrawal of 'life support' from frozen embryos and destructive experimentation upon them.[9]

3.23 They argued, in other words, that there was a serious moral difference between allowing the embryos to 'die' or 'succumb', and destroying them by extracting their stem cells. For that reason, they maintained that the fact that the 'excess' embryos at issue 'are going to die anyway' is irrelevant to the argument.

3.24 For example, the St Vincent's Hospital, Sydney, questioned the claim that given the embryos are destined for destruction it is not unreasonable to use them for research:

> Of course it is true that in each case the embryo will end up dead. But just as there is a significant difference between the death of a person who is deliberately killed and the death of someone who dies from natural causes, so there is a significant difference between an embryo's being deliberately dismembered and its dying naturally. The embryos to be experimented upon will most certainly die by dismemberment. Dismembering them, rather than allowing them to succumb unviolated, merely ' adds insult to injury'.[10]

3.25 Mr Raymond Campbell from the Queensland Bioethics Centre described the difference between three different actions in relation to the nature of the decision on how to treat the human embryo:

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8 Julian Savulescu, 'The Ethics of Cloning and Embryonic Stem Cells as a Source of Tissue for Transplantation', undated, p.7.

9 See, among many, *Submissions* 282, 672, 685, 870, and 1026.

10 *Submission* 1483, p.2 (St Vincent's Hospital Sydney).

> …no matter what you are going to do with the embryo you are going to remove it [from the freezer]. If you are going to implant it, you are going to remove it from the freezer, allow it to thaw and allow it to begin to develop and then implant it. If you are going to use it for embryonic stem cell research, you are going to remove it from the freezer, allow it to thaw and allow it to develop–because they are not at the stage of having the cells that they are wanted for as stem cells, so they are allowed to develop further–and then the stem cells are harvested, destroying the embryo. If you are going to allow it to succumb, it is the same action. You remove the embryo from the freezer, put it back in the environment and it will begin to develop again. Then it will reach a stage where it can no longer survive in that environment and it will die if it is not implanted. I would suggest that they are three very different kinds of actions.[11]

3.26 The Committee notes that use of the analogy between unconscious embryos and comatose human beings suggests the following line of thought. Different acts are morally charged in different ways. The withdrawal of artificial life support from a human entity is one kind of morally charged act; destructive experimentation of a human entity is another kind of morally charged act. It is possible that the absence of the properties of consciousness or sentience may function to justify the first act, but not the second.

3.27 Some of the points that arise for consideration from this discussion then seem to be as follows:

- the enjoyment of consciousness is not the sole criterion upon which moral consideration of other human beings seems to be warranted;
- an analogy may be drawn between human embryos and comatose human beings insofar as they lack consciousness; and
- there is a question as to whether there are other similarities or differences between human embryos and adult human beings which mean that this analogy, by itself, is insufficient to justify equality of consideration.

Same moral status as an adult human being

3.28 A large number of submissions to the inquiry expressed the view that the human embryo possesses the same moral status as an adult human being, and thus that destructive research involving embryos is unacceptable.[12]

3.29 There are two basic stages in the argument that supports this view. The first stage involves establishing the biological 'fact' that new human life commences at fertilisation. The second stage involves being able to bring this biologically related entity into full moral fellowship with 'us'.

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11 *Committee Hansard*, 26.9.02, p.223 (Mr Campbell).

12 See, for example, *Submissions* 156, 211, 361, 427, 667, 868, 892, 981, 1003, 1017, 1028, 1037, 1046.

Commencement of human life

3.30 There is in fact little disagreement that the embryo is a human life and that its life commences at fertilisation. The difficulties arise in specifying exactly in what sense it is to be considered 'a life', and hence what significance should be attached to it.

3.31 In its discussion of the biological facts of the matter, the Senate Select Committee on the Human Embryo Experimentation Bill 1985 stated that:

> Two universally accepted attributes are that the fertilised ovum has 'life' and that it is genetically human (ie. it is composed of genetic material entirely from the species *homo sapiens*). It is also generally agreed that it is an entity (a centrally organised unit which has a purposeful independent function as opposed to an organ or tissues). It also has developmental potential (whether that may progress to little more than cleavage, or to birth and on to subsequent adulthood).[13]

3.32 Various submissions to the inquiry appealed to recent work in embryology to support the claim that a recognisably distinct and individual human life commences the moment the sperm enters the egg. For example, the Southern Cross Bioethics Institute stated that:

> Microscopic evidence and chemical changes to the egg and sperm mark the entry as decisive. No other defining moment can be identified as the start…From fertilisation onwards the self-organising behaviour of the embryo is evident, and is quite unlike ordinary processes of cellular replication by which cells multiply. The union of pronuclei - DNA already premixed as it were by meiosis during the formation of egg and sperm - leads to a new and unique amalgamation with a new composition unlike any other.[14]

3.33 The Caroline Chisholm Centre for Health Ethics submitted that:

> The genetic individuality or identity of the adult is practically the same as that of the embryo, who possesses the actual potential to develop and grow into an adult, given a suitable uterine environment. The zygote and the resulting adult are the same living being. The zygote organises itself into a multicellular embryo, fetus, infant, child and adult without ceasing to be the one and same living human individual.[15]

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13 *Human Embryo Experimentation in Australia*, September 1986, pp.8-9.

14 *Submission* 892, p.2 (SCBI); see also *Submission* 876, (Catholic Archdiocese of Melbourne).

15 *Submission* 280, Attachment p.2 (Caroline Chisholm Centre for Health Ethics).

3.34 The arguments in these submissions seem to assume that, having established that the embryo is a distinct human entity from fertilisation, it follows immediately that this entity is 'owed a duty of unconditioned moral respect'.[16]

3.35 However, the Committee notes that these views concerning the commencement of human life at fertilisation were accepted even by scientists who support some form of destructive research on embryos.

3.36 For example, Professor John White, Spokesperson on Human Cloning, Australian Academy of Science, agreed that a 'human entity' comes into existence with fertilisation. When, however, he was asked to agree that therefore this embryo was a 'human being', Professor White responded as follows:

> I am not sure I understand that declension. I said 'entity' because the view that I and many other people would take is that, in embryology and in the development of the human person – and, indeed, even theologically, in the implantation of a soul – it might well be a gradual process.[17]

3.37 In explaining his preference for the term 'entity', Professor White noted that:

> There are many overtones to the word 'being' that I would build into it, and perhaps you would build different ones in…But I am quite happy to agree to 'entity'.[18]

3.38 In essence, Professor White's distinction points to the fact that, although it may be relatively uncontroversial to identify the embryo as biologically human, that identification does not necessarily settle the question of the sense in which the embryo shares our humanity and hence of the significance to be attributed to it.

Shared humanity?

3.39 Arguments were presented to the Committee both for and against the view that the embryo shares our humanity in the morally relevant sense.

3.40 The view that the early embryo is not yet fully our moral fellow is often supported with reference to biologically significant 'marker' events in embryonic development.

3.41 There are four factors, in particular, which are often cited as grounds for authorising experimentation on the embryo up until 14 days. They are:

- totipotency;
- twinning;
- natural embryo loss; and
- primitive streak.

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16 *Submission* 280, Attachment p.2 (Caroline Chisholm Centre for Health Ethics).

17 *Committee Hansard*, 19.9.02, p.128 (Professor White).

18 *Committee Hansard*, 19.9.02, p.128 (Professor White).

3.42 Briefly, up until the 16-32 cell stage the individual cells of the embryo each have the potential, if placed in the right environment, to develop into separate individuals.[19] This capacity is referred to as the 'totipotency' of the cells. Also during the first two weeks of pregnancy, twins can be formed either as a result of the successful implantation of two fertilised eggs or as a result of the splitting of the single embryo.[20]

3.43 'Natural embryo loss' refers to the fact that it is estimated that up to half of all naturally formed embryos 'fail before the full establishment of pregnancy'. The House of Representatives report on human cloning noted that:

> The reasons for these failures are obscure and almost impossible to study in the human, but are thought to be due to genetic abnormalities in the embryo (about 30%), inadequate synchrony or development of hormonal signals between the embryo and the mother (about 30%), with the remainder due to unexplained causes.[21]

3.44 Finally, the 'primitive streak' refers to the alignment of cells that is formed at about the fourteenth day and that will go on to become the central nervous system. According to Professor White, that is the point 'where a discernible, bilateral symmetry is apparent in the early embryo in the cluster of cells – the first sign of a nervous system and of right-handedness and left-handedness'.[22]

3.45 In general terms, the argument for the significance of these biological features of the early embryo for the attribution of moral status is that it is only by the fourteenth day that we can be sure that the embryo is an identifiable individual, and will not be divided or naturally discarded.

3.46 Various objections are raised against this line of argument. In particular, the problem identified is that, given the essentially developmental nature of embryonic life, the insertion of a concrete point at which we suddenly begin to take that life morally seriously seems arbitrary.

3.47 The proposal that embryo experimentation should be allowed up until the fourteenth day was made by the Warnock Committee in the United Kingdom in 1984. Professor White acknowledged that 'in some sense' this 'might be arbitrary' and remarked that 'nevertheless a date has been fixed and a pragmatic arrangement for the treatment of early embryos has been arrived at both in law and in practice'.[23]

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19 *Human cloning*, p.17. The report on stem cell research by the House of Lords in the United Kingdom states that embryonic cells are totipotent up until the 8 cell stage. See *Select Committee on Stem Cell Research Report*, February 2002, Chapter 4, http://www.publications.parliament.uk/pa/Id200102/Idselect/Idstem/83/8305.htm

20 *Human cloning*, p.14.

21 *Human cloning*, p.14.

22 *Committee Hansard*, 19.09.02, p.127 (Professor White).

23 *Committee Hansard*, 19.09.02, p.127 (Professor White).

3.48 Critics of the 'fourteen day' line, have in fact cited the Warnock Report itself for evidence of the arbitrary nature of the point determined. The Report states:

> 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.[24]

3.49 If the view that the early embryo is not yet fully our moral fellow is argued with reference to biologically significant 'marker' events, the view that it is fully 'one of us' is often supported with reference to the dangers inherent in the systematic exclusion of certain classes of human being from the human moral community.

3.50 For example, the Southern Cross Bioethics Institute argued that:

> down through history there have been circumstances when personhood was denied to certain groups of people, usually for the purpose of withholding their basic human rights. For example, the *Canadian Indian Act 1880* states that 'the term person means an individual other than an Indian'. Within 5 years this changed. The *Canada Franchise Act 1885* states that '[a person] is a male person, including an Indian and excluding a person of Mongolian or Chinese Race'.[25]

3.51 The Catholic Archdiocese of Melbourne argued that:

> If [embryos] *are* tiny human beings then the fact that they are tiny is no more morally relevant than that they are black or white, Australian or foreign, boy or girl, at the beginning of life or soon to die. They are members of the human family…Reducing members of our human family to mere commodities or lab animals will ultimately be corrupting for us all.[26]

3.52 In a similar vein, the South Australian Branch of Do No Harm stated:

> An embryo is a member of the human family equal in status to any other…Experimentation on embryos is no different to experimenting upon any human being. The size or age of the human being does not alter their status as part of the human family nor does it determine (or diminish) their rights to protection under the law.[27]

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24 Senate Select Committee on Human Embryo Experimentation Bill 1985, *Human Embryo Experimentation in Australia*, September1986, p.28; see also *Submission* 892 (SCBI).

25 *Submission* 892, p.6 (SCBI).

26 *Submission* 876, p.5 (Catholic Archdiocese of Melbourne).

27 *Submission* 211, p.2 (Do No Harm, SA).

3.53 Dr Nicholas Tonti-Filippini developed a brief ontological argument on the nature of the human embryo:

> From the moment that the first cell is formed, a human embryo is an individual organism oriented to development to human adulthood, normally requiring only nutrition and a favourable environment for that development to occur, and whose inherited nature is formed by the human genome which carries the inherent radical capacity for rationality that is distinctive of human beings.[28]

3.54 An argument for the moral status of the embryo based on human rights conventions was also developed by Ms Rita Joseph. She argued in her submission that to pass this Bill would be to contravene international human rights law, saying that:

> This proposed bill will run directly counter to Australia's firm and repeated commitments to provide legislative protection for maternity and for all children before birth. This bill, if brought into law, will fail to comply with a whole raft of fundamental UN States' obligations under international human rights instruments to which Australia has committed and subsequently should honour.[29]

3.55 Dr Katrina Hallen also provided a long list of international human rights instruments which she claimed supported the right of human embryos to not be subjected to destructive research, including the Nuremburg Code, the International Covenant on Civil and Political Rights, the Universal Declaration on Human Rights and the Declaration of Helsinki.[30]

3.56 In considering the different kinds of argument for thinking that the early embryo shares fully in our humanity, and hence is deserving of the same moral protection as any other human being, the Committee notes the following points:

- the focus on biological markers is an attempt to isolate an 'objective' point at which a morally relevant difference in the embryo's development can be recognised;
- the application of 'anti-discrimination' and 'rights' arguments in favour of the embryo is an attempt to alter the perspective on the debate, such that the embryo can be 'seen' as vulnerable, as others historically have been, to our lack of recognition. The use of the language of 'family membership' or 'kinship' is significant here. From the perspective of these arguments, the identification of biological markers after conception is not so much the *identification* of 'objective' features but is an *expression* of a refusal of recognition or of kinship with the early embryo.

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28 *Submission* 86, Additional information 26.9.02 (Dr Tonti-Filippini).

29 *Submission* 1053, p.4 (Ms Joseph).

30 *Submission* 1301 (Dr Hallen); see also *Submission* 156 (Dr Orr).

3.57 It may be argued that behind this debate is a more fundamental question. That question involves the issue of what it is involved in, or what content can be given to claim that the early human embryo shares fully in the moral status we assign to adult human beings.

3.58 This issue may be further illuminated by considering the view of those who assign to the embryo some moral status, but one which is limited in comparison with the status assigned to an adult human being.

Limited moral status

3.59 The ascription of moral status is both constituted by and recognised through the responses or practices which attend particular relationships or which mark particular events.

3.60 For example, the ascription of full moral status to human beings is marked by, among other things, the prohibition on murder, the institutions of justice and by rituals of mourning and reconciliation. It is marked also by the fact that we are able to take seriously the notion of responding to another with respect or love, and of responding with remorse to the wrongs we do them.

3.61 The fact that it is difficult for some to take seriously certain forms of response to early embryos may arguably itself reveal that their moral status is more limited or is at least different from 'ours'. For example, embryos allowed to 'succumb' are not given funerals; donating parents are not considered to be abandoning their children; and there seem to be limits on the extent to which 'parents' mourn their unused embryos or to which scientists might intelligibly feel remorse for their treatment of them. These responses all seem to point to the difficulty for some of taking seriously the notion that embryos enjoy just the same moral status as 'we' do.

3.62 These considerations are not, of course, decisive. For some, the inability seriously to imagine these kinds of responses may be indicators of the failure of imagination or sensibility rather than of the 'status' of the embryo.

3.63 Nevertheless, these considerations seem to point to the possibility of there being a 'third way' between the denial of any moral status to the early embryo and the ascription of the same status as possessed by adult human beings.

3.64 According to this 'third way', the unborn belong in *a* sense to the human family and are deserving of *forms* of moral consideration. But this leaves open the question of just what forms that consideration must take.

3.65 The Committee notes that the Bill itself, and some of those who support it, implicitly adopt this third way.

3.66 Clearly some moral status is accorded to embryos. This shows itself in features such as the limitation on the age of the embryos to be used, the prohibition on the creation of embryos specifically for research, and the specification that the research to be undertaken must be serious and must not entail the unnecessary

destruction of embryos. Recognition of the moral status of embryos has taken the form of a policy of 'harm minimisation'.

3.67 Nevertheless the limitation of the moral status accorded to human embryos is revealed by the very existence of the Bill, which presupposes that the interests of adult human beings in the potential benefits of the research take precedence over any interests possessed by the embryos.

3.68 The Committee noted earlier in its discussion, that for those who think that the human embryo is morally equivalent to an adult or child, there can be no moral justification for allowing it to be destroyed for the benefit of others.

3.69 For those who think, however, that the human embryo under 14 days does not enjoy precisely the same moral status as an adult or child, then the nature of any further reasons for supporting or objecting to the practice becomes decisive.

3.70 In the remainder of the chapter, the Committee will outline the nature of the 'further reasons' given in evidence, both for and against destructive experimentation on human embryos. The nature of these reasons may be divided into two main categories, namely utilitarian or consequentialist, and other arguments.

Utilitarian arguments

3.71 The utilitarian argument in favour of engaging in stem cell research focused on the potential therapeutic benefits that might arise from it. These benefits, it is said, would accrue not only to the thousands of individuals suffering from a host of diseases and disabilities, but through them to their families and the whole community.

3.72 The benefits would be measured in terms of increased health and well-being, or 'quality of life', as well as in terms of cost savings to the community's health and welfare budgets.

3.73 Ms Sheila Royles, Spokesperson, Coalition for Advancement of Medical Research Australia (CAMRA) told the Committee that CAMRA believed that 'embryonic stem cell research holds one of the greatest hopes for finding a cure for hundreds and thousands of Australians with diseases and disabilities. We believe that these people should have the opportunity for a better quality of life and to not literally be protected to death by legislation'.[31]

3.74 Ms Royles outlined the scale of the potential benefit of research in the following terms:

> In terms of the key stats for some of these patient groups, one person dies of motor neurone disease every day - that is a larger number than AIDS - and the life expectancy is on average three to four years. One person is confined to a wheelchair every day in Australia, and there are 100,000 children and

31 *Committee Hansard*, 17.9.02, p.71 (Ms Royles).

> adults with juvenile diabetes in Australia who have to inject themselves two or three times a day just to stay alive. The cost to the community of looking after these people is many billions of dollars.[32]

3.75 James Shepherd, the 13-year old youth ambassador for the Juvenile Diabetes Research Foundation, spoke to the Committee of the personal cost of living with juvenile diabetes. Mr Shepherd said that he had lived with juvenile diabetes since he was five years old and that 'it has been quite traumatic for myself and my family':

> In the course of my life I have had approaching 7,000 needles and approximately 16,000 finger pricks, but that is just an external factor because it is more than anything mentally difficult to cope with diabetes. For example, there is always the looming prospect on the horizon of complications which can derive from diabetes, such as blindness, kidney problems and the increased chance of death due to heart disease, to name a few.[33]

3.76 James Shepherd went on to say that his diabetes 'affects everything I do. There is no break; there is no holiday'. He informed the Committee that:

> There are approximately 100,000 juvenile diabetics in Australia, and there are more being diagnosed each year. I think all of us deserve a chance for a cure. As Sheila said, the cure could lie in adult stem cells or embryonic stem cells or it could lie in one of the many other types of research, but I think that every possibility for a cure should be fully explored before it is banned completely. It is a hard thing to live with, and I think we have every right to a cure and any way that cure could be achieved should be fully tested before that window is closed.[34]

3.77 Mr Kevin Langdon, President, Motor Neurone Disease Association of NSW, made similar points on behalf of those suffering from motor neurone disease. He said:

> Imagine a disease which little by little robs you of the use of your arms, your legs, and even your voice. Imagine seeing the muscles in your body slowly waste away while your senses and intellect remain perfectly in order. The ability to feel emotion – love, anger, joy and bitterness – remains intact, but one has no way of expressing them.[35]

3.78 The disease, Mr Langdon said, profoundly affects not only the individual patient, but every member of the family. Dr Paul Brock, who also suffers from motor neurone disease, informed the Committee that:

> from the moment I am lifted out of bed in the morning until the bedclothes are pulled up over me every night, in order to live I am *literally* dependent

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32 *Committee Hansard*, 17.9.02, p.71 (Ms Royles).

33 *Committee Hansard*, 17.9.02, p.71 (James Shepherd).

34 *Committee Hansard*, 17.9.02, p.71 (James Shepherd).

35 *Committee Hansard*, 17.9.02, p.71 (Mr Langdon).

> on my wife, my two daughters aged 7 and 11, my team of carers, and a variety of devices. The physical, emotional, stressful and financial costs to me and my family cannot be expressed in words. I can no longer walk; nor hug my wife and daughters. I cannot eat without assistance. Nor use the toilet or have a shower unaided. An author of over 100 books, monographs, chapters, scholarly articles, and poems – I can now barely sign my name.[36]

3.79 The Committee also heard evidence from the Australasian Spinal Research Trust, represented by Mr Robert Turner, Honorary Chief Executive Officer, and Ms Johanna Knott, Director. Ms Knott expressed the view that, given the promise offered by research into embryonic stem cells, it would be unethical not to allow it to proceed. She said:

> Many hundreds of thousands of Australians suffer from serious or currently incurable diseases or conditions. In fact, one in eight suffers from neurological disorders alone. Twenty thousand plus people in Australia have severe spinal cord injuries, and that rate grows by one per day. Our government is supposed to do the greatest good for the greatest number of people, and I believe we have a moral responsibility to help others. But time is crucial. If scientists are forced to attempt to make adult stem cells behave like embryonic stem cells you could waste five years or more, and many people just do not have that time.[37]

3.80 In a similar vein, Dr Brock claimed that '[t]here is an ethical and moral imperative…to encourage scientifically rigorous and ethically responsible embryonic stem cell research in its virtuous pursuit of human healing'.[38] He objected to the common use, by opponents of embryonic stem cell research, of the assertion that 'the ends do not justify the means'. Dr Brock maintained that:

> what is central to the ethical and moral debate is the need to distinguish between *some* ends and *some* means. While there are some 'ends' that can *never* justify the 'means', there are some 'ends' that can *only* justify the 'means'. For example, when the Nazis tortured concentration camp inmates by injecting dangerous drugs for 'experimental' purposes and by removing body parts – this was evil. But when an anaesthetist administers dangerous drugs as part of an operation to remove a healthy kidney of a donor to heal a life by transplantation – this is good.[39]

3.81 James Shepherd, finally, exhorted Committee members to consider the arguments presented from the perspective that they themselves are potential sufferers of currently incurable conditions. He said:

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36 *Submission* 843, p.1 (Dr Brock).

37 *Committee Hansard*, 17.9.02, p.73 (Ms Knott).

38 *Submission* 843, p.2 (Dr Brock).

39 *Submission* 843, p.2 (Dr Brock).

> it is not often that people without diseases relate to us. The media commonly refer to us as 'these people who deserve a transplant', and stuff like that…Subconsciously people distance themselves. They think, 'That's them. I couldn't have that', whereas it is possible for anyone here to walk into hospital and walk out knowing that they have one of the diseases represented here. So the point should be made that we are just normal people who are unfortunate enough to catch these diseases; we are not a completely separate race of individuals.[40]

3.82 All of these witnesses clearly recognised that possible positive outcomes were in the future, rather than tomorrow. As Ms Knott said, 'I do not expect a cure tomorrow or even next year, and I do not intend to overstate the promise of research, but how can you overstate hope?'[41]

3.83 There were virtually no utilitarian arguments presented against engaging in stem cell research. One such argument was made by Dr Nicholas Tonti-Filippini who expressed concern that products from such research may eventually be used in developing bio-warfare technologies. He noted that 'pharmo-kinetic' research is currently being undertaken to identify 'genomic risk factors for pharmaceutical products'. However,

> This type of knowledge may well provide race specific information about the effects of bio-pharmacological agents and hence a bio-warfare use of the technology…The advantage of embryonic stem cell culture in this respect is their proliferative nature - their rapid replication and growth. It may well be that infectious or carcinogenic agents could be developed that were specific to particular genotypes based on research on stem cell differentiation studies.[42]

3.84 A number of other submissions to the inquiry raised matters that may be categorised broadly as concerns about the 'slippery slope'. Although this style of argumentation may be considered utilitarian, or at least consequentialist, the Committee will treat them separately in the next section.

Other arguments

3.85 A variety of other arguments were presented to the Committee, both for and against allowing destructive research on human embryos to proceed under the conditions specified by the Bill. In what follows, the Committee outlines these views and any rebuttals of them that appeared in evidence.

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40 *Committee Hansard*, 17.9.02, p.81 (James Shepherd).

41 *Committee Hansard* 17.9.02,p.73 (Ms Knott).

42 *Submission* 86, p.6 (Dr Tonti-Filippini).

Slippery slope

3.86 One concern expressed under this heading relates to the feasibility of limiting the embryos eligible for use to those deemed 'excess' from IVF programmes. The Anglican Diocese of Sydney stated that:

> If…we decide to establish an industry which is dependent on human embryos for laboratory material, we are establishing human embryos as a resource the demand for which may well continue. Requests for more human embryos, be they frozen excess ART embryos created after 5 April or fresh ones created specifically for research, will come before Parliament. The establishment of embryonic stem cell research in local biotech industries will invariably lead to requests for embryos which will meet current Good Manufacturing Practice (cGMP) safety requirements if therapeutic product development is to occur. These cGMP requirements are different from standards required in IVF programmes and are more stringent. Frozen excess ART embryos will never be adequate as a source.[43]

3.87 A second concern relates to the relationship between allowing destructive experimentation on embryos and future pressure to allow cloning. Although cloning is explicitly disallowed by the present Bill, evidence expressed concern that destructive experimentation is nevertheless the first step down that road. This concern is given weight by the fact that there has apparently been a gradual slippage away from parameters that surround the acceptable treatment of embryos since the IVF programme began.

3.88 For example, Dr Peter McCullagh commented that it 'seems rather perverse, in the light of the advocacy for use of the *resource* which embryos are now considered to represent, that advocacy for permission to develop embryo freezing techniques in 1982 was framed in terms of its benefit *to the embryo*'.[44]

3.89 Dr Joe Santamaria, a consultant physician and bioethicist, said that it is naïve to think that the present prohibition of cloning, on the grounds of its 'repugnance' to the community, will last. He said:

> If you pass the current legislation for the use of human embryos for experimental purposes (whether they are surplus or not), you have stripped all human embryos, however conceived, of any moral status. Once the law is activated, the procedures become normative and the community's innate repugnance is eroded.[45]

3.90 Similar points were made in the submission of Right to Life Australia Inc. A speech given by Ms Margaret Tighe, President, Right to Life Australia, at Monash University on 8 May 2002, noted:

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43 *Submission* 672, p.3 (Anglican Diocese of Sydney).

44 *Submission* 480, p.6 (Dr McCullagh).

45 *Submission* 1011, p.5 (Dr Santamaria).

> It has been interesting to observe the slow but steady advances of the lucrative reproductive technology industry since the birth of Melbourne's first IVF baby in 1980. The progress of that burgeoning industry has been an exercise in 'softly, softly, catchee monkey'! In these early days, it was all motherhood and apple pie. No experiments on human embryos said the scientists. No freezing and stockpiling of embryos. No selection and discarding of embryos to name but a few excesses. Yet one by one, these promises have been broken…[46]

3.91 Ms Tighe opined that:

> That is why, as surely as night follows day cloning of human embryos will be the next stage (only so called therapeutic cloning mind you) followed subsequently with seductive arguments and media campaigns designed to usher in reproductive cloning. It can always be justified by the hard case…And with a slick PR campaign to influence the gullible public into thinking it's cruel to oppose these measures because of the supposed good they might do, we will eventually see a cloned baby on TV.[47]

Conceptual loss

3.92 A number of submissions referred, in different ways, to the idea that permitting certain practices will lead, through their alteration of our concepts about human life and its significance, to the loss of certain possibilities or values.

3.93 For example, some submissions expressed concern that the failure to respect the 'human dignity' of the early embryo would lead to the erosion of fundamental respect for other human beings, particularly the most vulnerable. Dr Amanda Lamont asked:

> If today we decide to ignore the dignity of a baby in a test tube, what is there to protect the dignity of those deemed 'less fully functional' by our society tomorrow? *We* are the elderly generations of tomorrow, and those of us involved in this debate will be personally reaping the effects in our old age. Do we want to be allowed to die with dignity when our time comes, or would it be acceptable for our bodies to be used for experimentation while we are still half-alive, like the frozen embryos…?[48]

3.94 The Hon Graham Kierath argued that:

> Once we have made the irrevocable and frightening step to accept exploitation of, and experimentation on, human beings, there can then be no objection in principle to going further and further…Are we a society which protects the most vulnerable – the poor, the sick and the unborn, from the predations of those who are more powerful, more vocal or even dishonest?

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46 *Submission* 1003, Attachment p.2 (Right to Life Australia Inc).

47 *Submission* 1003, Attachment p.2 (Right to Life Australia Inc).

48 *Submission* 1010, p.2 (Dr Lamont).

> If so, then there is no way that experimentation, or the use of stem cells from, embryos, ie. tiny human beings, should even be contemplated.[49]

Commodification of life

3.95 Other evidence expressed concern about the potential of certain practices to cheapen our very sense of the significance of life. Submissions spoke in terms of the *commodification* or *instrumentalisation* of life.[50]

3.96 The Australian Catholic Bishops Conference criticised the capacity of IVF clinics to manipulate the numbers of 'excess' embryos produced and wrote:

> To so manipulate the production of human life is an affront to human dignity and fosters a view of life which is more akin to the embryo as 'property', able to be bought and sold as a commodity, than as a member of the human family…In short, the dominant paradigm promoted by the destructive, but commercially profitable, use of the 'frozen generation' is that of 'production – manufacture – commodification – commercialisation of life'.[51]

3.97 For some, the impact of this 'commodification' of the early embryo's life is already illustrated by the fact that parents are able to donate their 'excess' embryos for research. The National Civic Council (WA) argued that:

> The Bill is drafted on the assumption that human embryos are in a relationship to those for whom, or from whose gametes they were created, that is more akin to the relationship of owner to property than of parent to offspring.[52]

3.98 However, the Council said: 'Parents are not permitted under common law to make decisions for their children that are patently contrary to the life and welfare of their children'.[53]

3.99 The Reverend Professor Michael Tate, who chaired the Senate Select Committee on Human Embryo Experimentation in 1985, submitted that:

> The market model is such a dominant feature of our current world culture that sometimes it is difficult to appreciate that property is not the all determining concept governing relationships in human society…We certainly concurred…that the market model was quite inadequate in the case of this subject.

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49 *Submission* 1016, p.2 (Hon G Kierath, MP).

50 See, for example, *Submissions* 156, 359, 876.

51 *Submission* 981, p.2 (Australian Catholic Bishops Conference).

52 *Submission* 282, p.5 (National Civic Council (WA)).

53 *Submission* 282, p.5 (National Civic Council (WA)).

> The embryo is not 'property belonging to' gamete donors or either one of them. The 'property rights' of the provider of egg or sperm are exhausted on fertilization. At that point, guardianship arises, and would ordinarily be exercised by the intended social parents…[54]

3.100 The Committee received some evidence from the organisation, ACCESS Australia's National Infertility Network, however, which argued against the view that the willingness of parents to donate their embryos for research signifies a lack of respect or a crude commodification of life. ACCESS submitted:

> Those of us who have created embryos have grappled with the ethical and social implications of what to do with them because we must. They are ultimately our responsibility. Then we live with the decisions we make about them. We care about the fate of the embryos that were created to be our children, to see that their existence has had some meaning. We do not believe that to use them for research would be disrespectful, quite the contrary. For many couples, the opportunity to donate their embryos for ART research gives them some added meaning, as they contribute to scientific knowledge that will lead to improvements in ART practice and ease human suffering. No one else values or respects these embryos more.[55]

3.101 The submission emphasises that 'we value life and we value children, which is why we have been prepared to go through extensive investigations and treatment to try to create a family'.[56]

Community sentiment

3.102 The Committee notes further that concern about the conceptual or societal effect of allowing destructive research on early embryos does not appear to be reflected in general community sentiment.

3.103 The report of the Select Committee on Stem Cell Research in the United Kingdom noted that 'the question of research on human embryos has to be considered within the context of the law in the United Kingdom and the social attitudes it reflects'.[57] That context, the Committee noted, includes legislation permitting abortion in a relatively wide range of circumstances and an IVF practice which involves the discarding of a substantial number of surplus embryos. The Committee suggested that: 'It would be difficult to justify an absolute prohibition on the destruction of early embryos while permitting abortion in a relatively wide range of circumstances post-

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54 *Submission* 899, p.3 (Professor Tate).

55 *Submission* 1047, p.3 (ACCESS).

56 *Submission* 1047, p.3 (ACCESS).

57 House of Lords, Select Committee on Stem Cell Research Report, Chapter 4, p.5, http://www.publications.parliament.uk/pa/Id200102/Idselect/Idstem/83/8305.htm (16 September 2002).

implantation – indeed well after the emergence of the primitive streak and into the foetal stage of development'.[58]

3.104 In the Australian context, the Committee notes also that 72 per cent of Australians surveyed have indicated their approval of research using excess IVF embryos for the development of therapies, assuming the informed consent of donors.[59] Further, according to ACCESS, approximately 60 per cent of couples involved in ART treatment will choose to donate the embryos they no longer need for research.[60]

3.105 Dr Megan Best questioned the significance of these levels of community support, however, saying that:

> I cannot help but feel that the promotion of this bill by many proponents has been misleading and I wonder if destructive research on human embryos would be as widely accepted by the community if it were known that the purposes for which they will be used may turn out to be not life-saving but economical. (I am thinking of some pharmaceutical applications here).[61]

Holistic conception of the human condition

3.106 A final objection raised on conceptual grounds to the research concerns the damage done by refusing to integrate the experience of disease and disability into a holistic conception of the human condition.

3.107 Mr Erik Leipoldt informed the Committee that he has lived as a quadriplegic for almost 25 years. He wrote:

> People have an innate fear of disability, imperfection and mental and physical decay. We want to escape this human condition. But to really escape it would be to outgrow it by developing a more wholesome concept of it in our own minds. Wanting to control everything only leads to more unhappiness. Learning a balance between what can be realistically controlled and what is best learned to be lived with leads to a happier life…This means that we cannot expect embryonic stem cell cures to address the real causes of our suffering. We can start by acknowledging vulnerability and dependence as parts of the human condition, rather than overemphasise physical perfection and independence and apply them in our private lives and policies.[62]

3.108 Mr Liepoldt also argued that disability is being portrayed as a 'tragic condition' and used by those promoting embryonic stem cell research in 'an

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58 House of Lords, Select Committee on Stem Cell Research Report, Chapter 4, p.5.

59 Roy Morgan International conducted surveys in June and November 2001, showing that 72% and 70% of Australians approve the research. *Submission* 895 (CAMRA).

60 *Submission* 1047, p.4 (ACCESS).

61 *Submission* 419, p.2 (Dr Best).

62 *Submission* 301, p.1 (Mr Leipoldt).

irresponsible and opportunistic fashion' to set back the cause of ensuring that people with disabilities are 'accepted as equally valued members of society'.[63]

3.109 These 'tactics', according to Mr Liepoldt have implications for society's conceptions of 'normality' or 'a good life', and neglect the fact that the 'collective values and attitudes that our society applies to people with disabilities' are 'responsible for transforming much of the impairment to a disability experience'.[64] For these reasons, Mr Leipoldt said that he found it offensive to be used 'as a lobbying tool for the biotech industry'.[65]

3.110 Other evidence echoed these concerns, and drew the further conclusion that many people with disabilities or diseases are being manipulated into supporting embryonic stem cell research by scientists whose real interests lie elsewhere.

3.111 Dr Peter McCullagh, for example, spoke of the 'exploitation of highly vulnerable people living with disabilities',[66] while Dr David van Gend asserted that it was 'a bad thing' to say to the parents of a child who is paralysed that '[e]mbryo stem cells are your hope'. He said 'it is a false hope. You cannot do that to paralysed people nor to MS patients or Parkinson patients. You do not do that'.[67]

3.112 The Committee received evidence from other people with a disability or illness who objected to the destruction of human embryos. For example, the Disability Action Group said that:

> We…strongly object to the cynical exploitation of our disabilities by people who wish to carry out destructive research on human embryos. Arguments for such research, which we believe to be mostly unconscionable, must be made without gratuitously using us as human leverage…
>
> Furthermore, recent confirmation of the fact that "excess" embryos may be used as genetic material for drug testing puts people with disabilities in the invidious position of benefiting from others' destruction.[68]

3.113 Dr Christopher Newell, a bioethicist and academic who also has a disability, acknowledged his debt to medical science but also the harm that is proposed to the embryo:

> …I am a person with disability who, like so many, is alive today because of the developments of medical science.

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63 *Submission* 301, p.1 (Mr Leipoldt).

64 *Submission* 301, p.1 (Mr Leipoldt).

65 *Submission* 301, (Transcript of his talk on Radio National, 'Perspective', 5 September 2002).

66 *Submission* 480, p.8 (Dr McCullagh). See also, *Submission* 876.

67 *Committee Hansard*, 24.9.02, p.182 (Dr van Gend).

68 *Submission* 1598, p.4 (Disability Action Group); see also *Submissions* 1081, 1084, 1293.

> Medical science offers many potential benefits into the future but it is clear that there must be limits. One of the basic ethical principles directly derived from the Hippocratic tradition, affirmed in a variety of non-consequentialist philosophical and religious codes, is "first of all do no harm". It is clear that the proposal to use embryonic stem cells will provide a harm…[69]

3.114 The group Diabetics for Ethical Treatment objected to the stance of some patient advocacy groups:

> Some patient advocate groups which support destructive research involving human embryos are putting themselves forward as representing all patients with degenerative diseases, including diabetics. We categorically reject the right of these groups to speak for us…
>
> We firmly believe that an attack on the dignity and well-being of any group of human beings is an attack on human dignity itself. It is a profound insult to people with disabilities and illnesses, including diabetics, to presume that we are willing to accept therapies developed at the cost of other human lives.[70]

3.115 The Committee also received evidence, however, from people living with illness or disability which strongly disputed the claim that they had been manipulated or exploited into supporting embryonic stem cell research.

3.116 Mr Robert Turner, Honorary Chief Executive Officer, Australasian Spinal Research Trust, and the father of a quadriplegic son, indeed suggested that such claims were themselves patronising:

> Certainly, …one of the things they fight against is being talked down to like that as though they have not got the ability to discriminate between what is exploitation and what is not. When I take him out in a wheelchair…people talk to me instead of talking to him simply because he is in a wheelchair. This is symptomatic of that: 'They don't know what they're doing; poor fools. Somebody has their hand up their back manipulating them'. Nothing could be further from the truth.[71]

3.117 Ms Johanna Knott told the Committee that she was responsible for founding the Australasian Spinal Research Trust and that 'no-one could say I was manipulated into doing that'.[72] She said that:

> [F]or 10 years I have not been able to eat, wash, go to the bathroom or get dressed without someone else's help. Some people may be able to get used to living like that, but I am not one of those people. I have a keen interest in

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69 *Submission* 898, p.1 (Dr Newell).

70 *Submission* 1293, p.5 (Diabetics for Ethical Treatment).

71 *Committee Hansard*, 17.9.02, p.85 (Mr Turner).

72 *Committee Hansard*, 17.9.02, p.85 (Ms Knott).

> research, and I am deeply disturbed by any attempts to block scientific progress.[73]

3.118 She also advised the Committee that: 'The reality is that we do follow very closely, and we have done for a number of years, what research has gone on around the world, and I think we do have a good sense of what is credible and what is not'.[74]

Distribution of resources

3.119 Some submissions expressed the opinion that the money set aside for embryonic stem cell research could more profitably be spent on other research or services, and thus that the question of the ethical distribution of resources needs to be considered.

3.120 For example, Dr Christopher Newell stated that:

> If the Australian parliament really wanted to address the situation of Australians with disabilities those tear-streaked speeches would also be focusing on the significant unmet need for those of us with disability and our families. Likewise it would be focussing on putting its resources into community support and primary health care interventions which would also have a role in preventing and ameliorating disability. Sadly many of the interventions which would ameliorate the situation of people with a disability in Australia and overseas are not sexy or hi-tech.[75]

3.121 The Australian Family Association (Bayswater/Boronia Branch) expressed the view that the promise of results from research into embryonic stem cells is highly speculative, and that money should be provided only to more 'proven' research or services. The Association wrote:

> If adult stem cell research is where the genuine hope lies, then why are precious public funds being diverted away from it? With many programs ranging from abused women to drug addiction to Aboriginal health crying out for money, why would the Government be allocating our money to such a questionable line of research?[76]

3.122 Similarly, the Catholic Archdiocese of Melbourne questioned the validity of funding embryonic stem cell research at the expense of 'the ethically uncontentious but scientifically more promising avenues' of adult stem cell research.[77]

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73 *Committee Hansard*, 17.9.02, p.73 (Ms Knott).

74 *Committee Hansard*, 17.9.02, p.74 (Ms Knott).

75 *Submission* 898, p.7 (Dr Newell). See also *Submission* 1025 (Endeavour Forum).

76 *Submission* 983 (Australian Family Association (Baywater/Boronia Branch)).

77 *Submission* 876, p.2 (Catholic Archdiocese of Melbourne). See also *Submission* 981.

3.123 Often, questions about the allocation of funds were expressed in tandem with suspicion about the motives and commercial incentives driving the biotechnology industry in its support for embryonic stem cell research.[78]

3.124 The Committee received no evidence which analysed the actual distribution of research funds between different research priorities.

Autonomy argument

3.125 Some evidence argued that potential donors have the right to choose whether their embryos are used in research or not, and that the Government should not legislate to prevent them being allowed to make that choice.[79]

3.126 The Juvenile Diabetes Research Foundation stated its view that, assuming the appropriate ethical and scientific guidelines are in place, 'it should be the moral choice of those individuals that drive the donation of excess embryos into medical research'.[80]

3.127 Professor David de Kretser AO, Director, Monash Institute of Reproduction and Development, suggested that:

> For the opponents of this legislation we would propose the examination of the premise, already accepted by our society, namely that the parents of a child on a life support system that is about to be withdrawn are accorded the right to decide whether the organs of that child can be donated for transplantation. Surely the parents of an embryo, whose life support system is about to be withdrawn have an equal right to donate the cells of that embryo, potential transplants of the future, to generate embryonic stem cells.[81]

3.128 Ms Sandra Dill, Executive Director, ACCESS, Australia's National Infertility Network Ltd, exhorted the Committee to:

> acknowledge infertile couples – who have sought from the beginning to act in their embryos' best interests – by allowing them to make decisions according to their conscience. Fertile people in our community enjoy the right to act in their children's best interests; importantly, you will treat infertile people with the same respect by ensuring us corresponding rights to make decisions about embryos that once had the potential to be our children.[82]

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78 See, for example, *Submissions* 301, 359, 480, 876, 983.

79 ACCESS quoted former US Surgeon General, C. Everett Koop, who was personally opposed to abortion, but who argued that personal moral beliefs should not automatically be enacted into laws enforced by the State. *Submission* 1047.

80 *Submission* 896, p.2 (Juvenile Diabetes Research Foundation).

81 *Submission* 1041, p.6 (Professor Kretser).

82 *Committee Hansard*, 26.9.02, p.191 (Ms Dill).

3.129 Against this line of argument, however, Dr David van Gend from Do No Harm, argued that if widespread embryo research is allowed to go ahead, Australians will have difficulty exercising their right to conscientiously object or opt out of involvement. In this sense, the autonomy of those opposed to the research would be at risk.[83]

3.130 Dr Tonti-Filippini also expressed concern at the extent to which the autonomy of donors is protected in the Bill. He commented that donors would not know what would happen to their embryos or the stem cells derived from them, and said:

> there is no reporting back to the people who gave them in the first place. I just find the respect for autonomy–let alone respect for embryos and stem cells–to be appalling and a complete oversight in the structure of this.[84]

Scientific, economic and technological impact

3.131 A number of witnesses warned of the likely negative impact on Australian science and technology of the failure to pass legislation permitting embryonic stem cell research. That impact will, it is said, be caused by the fact that Australian researchers will be forced to continue their research in countries such as Singapore and the UK and by the loss of international research funding.[85]

3.132 For example, BresaGen, a publicly listed Australian company 'acknowledged as one of the three world leaders in the therapeutic application of Human ESC [embryonic stem cell] technology', wrote:

> We believe this legislation is critically important in maintaining Australia's current high scientific position in both ES cell research and assisted reproductive technology (ART). The change is important for the advancement of therapeutic opportunities for patient care and disease treatment, and for the progress of the Australian Biotechnology Industry.
>
> The passage of this legislation is essential in BresaGen retaining a significant presence in this country. BresaGen has overseas nodes, and failure of this legislation to pass will certainly force BresaGen to consider its Australian presence.[86]

3.133 Professor David de Kretser warned that the failure of the legislation would severely compromise the scientific prospects of stem cell research in Australia as well as emerging biotechnology industries. He noted that future research would require that stem cell lines be sourced from overseas, probably from commercial companies, and that these sources 'will almost certainly wish to retain some rights to any intellectual property generated by the research'. The consequence will be a substantial loss of

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83 *Committee Hansard*, 24.9.02, p.175 (Dr van Gend).

84 *Committee Hansard*, 24.09.02, p.165 (Dr Tonti-Filippini).

85 *Submission* 895, p.1 (CAMRA).

86 *Submission* 1030, p.2 (BresaGen Ltd).

control over the commercialisation of research done in Australia, which 'is not in Australia's long-term economic interests'.[87]

3.134 Professor Silburn, however, talked of his concern about the commercialisation of research 'as a scientist who is very committed to keeping public research in the public domain. I am not interested in commercialisation or patents. That is not the issue of what true science is about'.[88]

3.135 ES Cell International Pte Ltd noted that a 'political environment supportive of stem cell research is one reason why ESI has invested so considerably in Australia, and will be a significant factor in relation to our future investment decisions'.[89] Professor Alan Trounson, Deputy Director, Monash Institute of Reproduction and Development, and CEO Designate, National Stem Cell Centre, informed the Committee that the award of Commonwealth funding to the National Stem Cell Centre has enabled the recruitment of internationally recognised scientists to Australia. It is also the major reason 'for retaining one of Australia's most eminent adult stem cell researchers' who 'declined a very attractive offer to move to the USA in August 2002'.[90]

3.136 Professor Trounson also noted that:

> Presumably, if the bill is not passed, we will have to buy embryonic stem cells – if we are going to continue the research - from overseas. All the current embryonic stem cells are subject to some commercial restrictions and nearly all of them require that you return the intellectual property to that company. All of those companies are now majority owned overseas.[91]

3.137 Finally, Professor Bob Williamson, Director, Murdoch Childrens Research Institute and Professor of Medical Genetics, University of Melbourne, noted that the proposed legislation is already more restrictive than those regulating researchers in the UK, all non-NIH research in the United States, and Singapore. He said:

> I hope that we will be sufficiently in step with other OECD countries so that legislation does not disadvantage Australian attempts to create sustainable jobs and new therapies, and cause some of our research to move abroad.
>
> I also hope we will not be in the ethically dubious position of having to import the results of research that we ban in this country, to offer therapy to our children.[92]

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87 *Submission* 1041, p.5 (Professor de Kretser).

88 *Committee Hansard*, 17.9.02, p.52 (Professor Silburn).

89 *Submission* 1039 p.2 (ES Cell International Pte Ltd).

90 *Submission* 1043 (Professor Trounson).

91 *Committee Hansard*, 24.9.02, p.153 (Professor Trounson).

92 *Submission* 1002, p.3 (Professor Williamson).

3.138 Some witnesses expressed concern, however, that the economic interests of those involved directly in the research may be distorting the arguments in favour of stem cell research. Dr Brian Pollard claimed that comments from those with a stake in the embryo research industry should be considered against a range of pressures and motivating factors:

> It would be foolish…not to recognise that other motivating factors are also undeniably present, though they may never be made public, such as scientific intellectual satisfaction, scientific kudos from respected colleagues locally and internationally, advancement in status or employment and the potential for vast monetary gain.[93]

National legislation

3.139 Evidence to the Committee suggested that the passage of national legislation permitting research involving human embryos under specified circumstances might be the lesser of two evils. This is because, in the absence of a comprehensive national framework, the States would be free to enact their own legislation that could be less restrictive than the legislation before the Commonwealth Parliament.

3.140 The Queensland Government stated that the Council of Australian Governments had driven the pursuit of a nationally consistent framework in this area, because the kind of 'dual system of regulation such as that which exists in the United States' is not in Australia's interests. It considered that such a system sends inconsistent messages to the community, scientists and investors, and 'creates loopholes and safe havens for practices which are considered either universally abhorrent, unsafe or unacceptable'.[94]

3.141 Professor Martin Pera warned that, defeat of the legislation would both restrict the ability of Australian scientists 'to remain at the forefront of embryonic stem cell research', and 'return us to an unsatisfactory position in which contradictory piecemeal regulations govern embryo research in the various states and territories'.[95]

3.142 Four of the biotechnology companies involved in embryonic stem cell research in Australia are members of AusBiotech Ltd, a company which describes itself as 'at the edge of acadaemia and industry'.[96] The Executive Director of AusBiotech, Dr Anthony Coulepis, told the Committee that:

> All four companies have said quite clearly to us that they believe they are at the cutting edge. If this legislation does not go through, they are first of all going to turn to their states - which is why we believe that the senators who are concerned about this legislation would be less concerned if there were

93 *Submission* 685, p.3 (Dr Pollard).

94 *Submission* 1500, p.1 (Qld Government).

95 *Committee Hansard*, 24.9.02, p.135 (Professor Pera).

96 *Committee Hansard*, 19.9.02, p.120 (Dr Coulepis).

national legislation which then controls what we do in the country, as opposed to allowing the country to go its own way. One of the cautions we are getting from our stakeholders is that national legislation will give us that degree of unity to be able to say how we can control this better. So the companies are saying, 'If this does not go through, we will first turn to our states. If we cannot get any relief from our states, we are going to go offshore'.[97]

97 *Committee Hansard*, 19.9.02, pp.121-122 (Dr Coulepis).