

Non-Traditional Research Outputs

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Research Background

This research paper developed from a two part invited lecture series for the York Institute for Health Research (YIHR) *Spotlight On Health Research Seminar Series*. It includes two articles with separate commentary by experts in other disciplines. The first article revisits earlier research (published in *Sydney Law Review*) examining amendments to the *Prohibition of Human Cloning [for Reproduction] Act (2002)* and the *Research Involving Human Embryos Act (2002)*. The second article brings together two areas separately considered elsewhere; regulatory regimes around the use of PGD to choose an embryo with an abnormality and the use of body modification technologies for non-therapeutic or enhancing purposes.

Research Contribution

The first paper explores the legal regulation of biotechnologies that make it possible to create varying embryonic forms including clones and hybrids. It raises questions about the meaning of legal "personhood" and the role of women in the gestation of prohibited embryos. The second paper explores the role for law in regulating the use of genetic and cosmetic modification technologies where it is to achieve outcomes that do not conform to traditional ideals of normalcy.

Research Significance

This research interrogates the values we apply when regulating to limit or prohibit production of certain kinds of humans. The legal and ethical dilemmas posed by this regulatory task are novel and require a new degree of scrutiny that explores the underlying assumptions and motivations behind the law. This research begins an important international and cross-disciplinary discussion about the appropriate role for law in this context. The report appears both online and in CD form and has been distributed through the Canadian YIHR network. Further development of the ideas appears in Australia as part of Chapter 5 in B Bennett, T Carney and I Karpin (eds) *The Brave New World of Health* (Federation Press, Sydney 2008).

Preface

This volume features the work of Professor Isabel Karpin, presented at YIHR's Spotlight on Health Research seminar series "Issues in Genetic Research" on January 18th and 22nd, 2007. Dr. Karpin is a Senior Lecturer at the University of Sydney and specializes in feminist legal theory, health law, law and culture, and constitutional law. Her contribution to legal research and scholarship is in the area of law that can be described generally as the regulation of assisted reproductive technologies, biotechnology and genetics as well as the legal responses to new developments in these technologies and the challenges they pose to our understandings of normality, disability, individuality, and the family.

Her doctoral work entitled *'Embodying Justice: Legal Responses to the Transgressive Body'*, examined the regulation of marginalized bodies, with a particular focus on the pregnant body.

In her paper *'The Uncanny Embryos'*, she discusses the implications of new assisted reproduction technologies that make possible the creation of previously unheard-of embryonic forms, and raises questions of their legal and normative status with regard to their potential to achieve "personhood". She argues that this status is contingent upon a woman's willingness to gestate the embryo in question, and that current Australian legislation effectively negates the fundamental role of the female body in the process of "person-making".

In a response to this paper, Professor Duff Waring, a philosopher with York University's School of Arts and Letters, discusses Dr. Karpin's view of the female act of gestation as a determinative step in the trajectory toward personhood. He challenges his audience to think creatively about the values we ought to affirm when we decide upon the conceptions of the person and the human family with which we ought to go forward. Dr. Waring then considers the social and ethical ideas that feminist regulatory perspectives should aim to promote through legal frameworks that affect "transgressive others."

In *'Better Than Normal'*, Dr. Karpin explores the use of genetic and cosmetic technologies in defiance of programmed ideals of normalcy to select for so-called states of abnormality or disability in a process she terms "negative enhancement". She draws attention to the differential manner in which corporeal and genetic modifications that transgress standards of normalcy are perceived before the law, with individual decision-making regarding genetic modification seen as more in need of state governance or prohibition.

Finally, Professor Geoffrey Reaume of York's School of Health Policy & Management puts the discussion into a historical context with an overview and analysis of the history of disability including his own area of academic interest, madness. He discusses ongoing discriminatory practices that originate from a historically engrained eugenic agenda, and highlights ways in which these long-standing ideals are being challenged by people with disabilities, expanding upon Dr. Karpin's discussion of disability as fluid, evolving and highly dependent on social and environmental contexts, as well as on technology.

Issues in Genetic Research is the second of a series of Monographs published by the York Institute for Health Research to highlight the work of innovative health researchers with the goal of stimulating further discussion, collaboration and research.

York Institute for Health Research

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The Uncanny Embryos: Revisited after the passing of the Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Bill (2006)

Isabel Karpin¹

Introduction

Genetic manipulation technologies have given rise to the possibility of all kinds of new embryonic forms: embryos designed with inheritable mutations (sometimes called enhancements, sometimes therapies); embryos with a chimerical combination of cells, hybrid embryos, embryo clones and more.² The possibility of these multiple embryonic forms when combined with the burgeoning and successful field of assisted reproduction suggests the spectre of multiple human forms such as chimerical humans, hybrid humans, enhanced humans, and cloned humans. What does it mean to be a human person in a world where these transformations at the embryonic level are possible? Does it change anything? Does it change everything? The answer to this question cannot be known without first interrogating how it is that we have come to see human embryos as something *akin* to persons. This requires a leap of the imagination that depends either on the disappearance of women as essential to the process of *person-making* or the assumption that where there are embryos, there are women who will gestate them. Through these two modes, technologically produced embryos – that is, embryos made with the assistance of technology – are imbued by some with the full potential of personhood even though they have yet to find a uterine home. I will return to the uterine home shortly.

Up until November 2006 in Australia, the legal response to the transformative possibilities of genetic manipulation technologies in relation to cloned and hybrid embryos, amongst others, was simply to prohibit and criminalize their creation.³ In November and December of 2006, however, the landscape changed. New legislation was debated and passed and therapeutic cloning or

¹ This article builds on my article Karpin I “The Uncanny Embryos: Legal Limits to the Human and Reproduction without Women” (2006) 28(4) *Sydney Law Review* 599-623 I have added a new component to the text dealing with recent amendments and updated and revised other parts. My thanks to *Sydney Law Review* for allowing me to reproduce sections of the paper here.

² For definitions of each of these forms see s8 of The *Prohibition of Human Cloning Act (Cth) 2002*

³ Prior to its amendment, Part Two of the *Prohibition of Human Cloning Act 2002 (Cth)* contained far reaching prohibitions. Most of those prohibitions remain, however significant amendments allowing the creation of cloned embryos for research purposes have now been passed. This will be discussed in detail below. Further, s15 of the Act continues to preclude inheritable genetic modification; however somatic cell modification of an embryo of the kind that might be called gene therapy is not precluded. Genetic alterations to a single embryo are less controversial than alterations that are inheritable. There is some concern within the scientific community that such alterations could accidentally result in heritable changes. See John M. Kaplan and Ina Roy, Accidental germ-line modification through somatic cell gene therapies: some ethical considerations, *The American Journal of Bioethics* 1 (2003), 1–6, who argue that the risk of accidental germ-line modification is not significant enough to preclude further somatic therapies. Note s15 prohibits only intentional inheritable alterations.

somatic cell nuclear transfer was given the green light. The amending legislation was a response to recommendations made by the Lockhart Committee Review which had been set up to review the *Prohibition of Human Cloning Act 2002* (PHC) and the *Research Involving Human Embryos Act 2002* (RIHE).⁴ The Lockhart Committee recommended significant changes, most notably a relaxation of the prohibition of human cloning to allow for somatic cell nuclear transfer to be used to create embryos for research purposes only. Debates over the proposed amendments lasted two days in the Senate and two days in the House of Representatives. The Bill was finally passed with a slim majority of 34 to 32 in the Senate and 62 to 42 in the House of Representatives. The Bill formally titled the *Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Bill 2006* (Cth) but known as the Patterson Bill, came into effect on June 12, 2007.⁵

Importantly, none of the changes to the legislation allow the creation of currently prohibited embryos for reproductive purposes. Yet much of the debate around the enactment of the amending legislation referred to the embryos to be created under the new provisions as if they were both potential human beings and already human beings. This was partly due to the fact that the Lockhart Committee Review had made a distinction between embryos that were fated for research and therefore, they argued, had no human potential, and embryos intended for reproduction and therefore having an altogether different trajectory towards personhood. The Lockhart Committee review puts it like this: “if the embryo created by SCNT is not intended to be implanted, it does not represent a potential new individual in the way that the product of fertilisation does”.⁶ Earlier the Committee states that:

[it] agreed that human embryo clones are human embryos and that, given the right environment for development, could develop into a human being. Furthermore, if such an embryo were implanted into the body of a woman to achieve a pregnancy, this entity would certainly have the same status as any other human embryo, and were this pregnancy to result in a live birth, that child would enjoy the same rights and protection as any other child. However, a human embryo clone created to extract stem cells is not

⁴ Lockhart Committee, *Legislation Review: Prohibition of Human Cloning Act 2002 and Research Involving Human Embryos Act 2002*, Legislation Review Committee Reports (2005) (hereafter Lockhart Committee Review)

⁵ The Bill also changes the title of the *Prohibition of Human Cloning Act 2002* to the *Prohibition of Human Cloning for Reproduction Act 2002*. Hereafter, the original *Prohibition of Human Cloning Act* will be abbreviated as the PHC Act and the amended Act will be abbreviated as the PHCR Act. The *Research Involving Human Embryo Act* will be abbreviated as the RIHE Act for both the original Act and the amendment Act but it will be made clear which version is being referred to.

⁶ Lockhart Committee Review p 171 above n4. See also the Lockhart Committee’s reference to the National Health and Medical Research Council (NHMRC) Discussion Paper: Human Embryo – A Biological Definition (NHMRC December 2005) where it was suggested “that potential for implantation and future development to a live birth could provide a useful criteria for considering whether such an entity should be included in the definition of a human embryo or not.” However that potential was noted to be determined by the appearance of the primitive streak at p173.

intended to be implanted, but is created as a cellular extension of the original subject. The Committee therefore agreed with the many respondents who thought that the moral significance of cloned embryos that are not implanted is linked more closely to their potential for research developments, including the development of treatments for serious medical conditions, than to their potential as a human life.⁷

This excerpt highlights a central, significant and much neglected fact – the potential for any embryo to become someone is contingent upon female embodiment and a willingness to gestate and create the person in question. While this seems clear enough, the distinction that the Lockhart Committee makes between artificially created sperm and egg embryos and artificially created SCNT embryos as seemingly already set upon different trajectories by virtue of their mode of creation is problematic. That trajectory has in fact been carefully constructed through legislative prohibition against the creation of sperm and egg embryos for research purposes. As I argue later, this artificial distinction is only necessary because “personhood” is being prefigured before gestation in the case of these embryos. Instead, I argue, neither SCNT nor sperm and egg embryos represent new individuals or even potential individuals until someone agrees to gestate them.

In another interesting twist, it is worth noting that prior to the amendments passed in December, the only kind of embryo upon which research could be undertaken was an excess assisted reproductive technology (ART) sperm and egg embryo. While the legislation did not (and does not) therefore, allow the “creation” of sperm and egg embryos for research, the double effect of legislation that allows the creation of embryos for ART and the use of surplus for research is, some might argue, to allow the creation of sperm and egg embryos for research.

Before considering the general changes to the legislation, it is important to note then that the amending legislation has also increased the pool of potential sperm and egg embryos available for research purposes. This has been achieved by the inclusion of a complement of sections. First, the addition of a definition of embryos that are unsuitable for implantation has been inserted into in section 7(1) of the RIHE. Section 7(1) states:

unsuitable for implantation, in relation to a human embryo, means a human embryo that

(a) is diagnosed by preimplantation genetic diagnosis as unsuitable for implantation,

⁷ Lockhart Committee Review p 170 *ibid*

in accordance with the *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (2004)*, issued by the CEO of the NHMRC; or

- (b) is determined to be unsuitable for implantation in the body of a woman, in accordance with objective criteria specified in guidelines issued by the CEO of the NHMRC under the *National Health and Medical Research Council Act 1992* and prescribed by the regulations for the purposes of this paragraph.

The National Health and Medical Research Council (NHMRC) has issued revised Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice which state in section 17 that the “PHCR and the RIHE Acts permit research on excess ART embryos, including those that are unsuitable for implantation.”⁸ In section 17.15 the guidelines refer researchers to the objective criteria available from the NHMRC. These objective criteria which are still in draft form state that “unsuitable for implantation in relation to a human embryo means a human embryo that: (a) has been identified by preimplantation genetic diagnosis as carrying a serious genetic condition or (b) is defined as unsuitable for implantation according to objective criteria below.” The criteria that are set out in the guide include certain levels of fragmentation and degeneration, failure to divide and compact and similar factors.

The determination as to suitability of all embryos, even those not undergoing PGD is done by the observations of a scientist looking at the embryos through a microscope. Some embryos are created that do not develop, fragment or die at a very early stage. Because they are too fragile to be frozen, such embryos are generally discarded and are termed as "unsuitable for implantation".

These new guidelines work in combination with section 24(8) of the RIHE Act which allows modification of the consent provisions where the embryos are unsuitable for implantation. Prior to the amendments, part of the requirements for the use of donated surplus embryos was a 14 day cooling-off period having the effect of making so-called “fresh embryos” completely unavailable. The note to the new section 24(8) of the RIHE Act suggests that such modification to the consent provisions may consist of an alteration to the cooling-off period, for instance.⁹

While this may seem uncontroversial for those of us who are not concerned by the use of these early stage embryos for research, some disability studies scholars and bioethicists have raised concerns about these changes. Firstly, there is concern that the effect of the changes is to allow

⁸ NHMRC *Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice* (p. 69)

⁹ The note to section 24(8) of the RIHE states: “For example, the guidelines could apply to a particular licence in a modified form, to alter the cooling-off period required in relation to the use of excess ART embryos that are unsuitable for implantation.”

doctors to determine embryos diagnosed as having a genetic defect and therefore a potential disability as pre-emptively unsuitable rather than leaving such decisions to the potential parent to be made contextually. Secondly, there are concerns that these changes may lead scientists to lean on the side of unsuitability where there is uncertainty about the application of the objective criteria. Nisker and Mykitiuk argue for instance that these changes “raises the possibility that standards for what is considered a ‘suitable’ or ‘unaffected’ embryo may become narrower in the interests of ensuring a supply of fresh embryos for research.”¹⁰

Returning then to the point made by the Lockhart committee that the status of SCNT embryos is more closely linked to their “potential for research developments, including the development of treatments for serious medical conditions, than to their potential as a human life”¹¹; while this is clearly the intent and context in which SCNT embryos are created, there is nevertheless nothing intrinsic to the embryo itself that makes it destined for research rather than reproduction. One significant difference, however, is that in the case of SCNT embryos there is no evidence that they can, as yet, be successfully implanted or carried to term.

Nevertheless, one of the primary arguments made in favour of the new amendments allowing SCNT embryos for research purposes was that the prohibition against creating sperm and egg embryos for research purposes would remain intact and, with respect to so-called “healthy” embryos or embryos “suitable for implantation,” it does.

Opposition to the bill from a number of quarters picked up on this inconsistency, but rather than reading it as the Lockhart committee suggested, namely that the value of an embryo is determined by whether it is intended for implantation, many who argued against the bill saw the distinction between the two kinds of embryos as inequitable. They argued for both to be valued equally as potential human beings. The alternate argument that neither has value until a woman agrees to gestate it into a human being was never considered. Senator Bartlett came closest to this position when he said:

the counterintuitive result of my position would be that it would be better if sperm-egg embryos were able to be created specifically for research as well so there was no potential for a different value to be attached to different classes of embryos. I continually have in my mind the view that all people are created equal, even though I realise that embryos are created in different ways. But if they are both perceived to be embryos then the perception that they may have different worth is a perception that I think could have significant problems if applied in different contexts. I do not think it is a problem if

¹⁰ R. Mykitiuk and J. Nisker, "Embryo 'Health': Biomedical and Social Determinants" (2007, forthcoming)

¹¹ *Supra* n7

applied within the context of this legislation, but if it is applied in other contexts I think it is a problem, potentially. That is why the principle that all people are created equal is one that most, if not all, of us adhere to.¹²

By contrast the Hon. Anthony Abbott, Minister for Health and Ageing, speaking in the House of Representatives debate responded to the distinction as follows:

The proponents of this bill claim that there is a difference between embryos created for research and embryos created for reproduction. There is a difference all right: one is created for life and the other is created for death—one is an end in itself and the other is part of what is intended to become a burgeoning human spare parts industry.¹³

Abbott's suggestion that one is created for life and the other for death is particularly interesting because it illustrates the idea I am proposing of the phantasmal embryo. I argue that laws regulating reproductive technology and research science produce what I call, the phantasmal embryo. This embryo occupies the legal imaginary with the force of a vivid premonition of the child-to-be. It is an embryo disconnected from the female body as if already born. In this way it becomes possible for Abbott to describe these embryos as created for death though in fact they have not yet lived because he is relying upon their premonitional status as giving them life, preemptively.

In fact, as we know the premonitional life of the embryo is contingent upon a woman agreeing to gestate it and carry it to term. However, in Abbott's rhetorical turn that which makes the human, namely female gestation, is disappeared.

Existing outside the gestating body of the woman, the technologically produced embryo that is the subject of these debates disturbs these parliamentarians because it is uncanny in the Freudian sense of the *unheimlich*, or unhomely.¹⁴ This extra-uterine embryo is no longer at home in the female body. Disconnected from the bodies from which it originated or any body that might welcome it in, this embryo both pre-empts its possible gestation via female embodiment **and** questions the need of it. In the Freudian conceptualisation of the uncanny, the uncanny develops from the transformation of something that once seemed homely into something decidedly not so.¹⁵ Freud's idea of the uncanny is useful in attempting to map the unnerving impact that these

¹² Commonwealth, *Parliamentary Debates*, Senate, 7 November 2006, (Andrew Bartlett) at 81 ,

¹³ Commonwealth, *Parliamentary Debates*, House of Representatives, 6 December 2006, (Hon Anthony Abbott, Minister for Health and Ageing) at 13.

¹⁴ Sigmund Freud, 'The Uncanny' in *The Standard Edition of the Complete Psychological Works of Sigmund Freud* (1953).

¹⁵ Anthony Vidler, *The Architectural Uncanny: Essays in the Modern Unhomely* (1994) at 6

embryos have upon the legal imagination – at once utterly familiar, the routine stuff of life and yet frighteningly other. The technologically produced embryo¹⁶ existing outside the female body is at its most uncanny when it doubles for the child. Apparently the same and yet it is not even a person. Its uncanniness lies in the familiarity it offers while it simultaneously evokes the horror of the alien presence.

This is particularly so when the possibility of creating hybrid embryos is debated. Hybrid embryos amplify the uncanny nature of the technologically produced embryo.

This becomes evident in the discussion by Senator Bartlett in the Parliamentary debates relating to the amendments of proposed amendments to allow limited creation of hybrid embryos for research purposes. Apart from cloned embryos, the new legislation also allows for the creation of hybrids for research purposes via the fertilisation of an animal egg by human sperm. A proposed subsection allowing the “creation of hybrid embryos by introducing the nucleus of a human cell into an animal egg” was however deleted by an amendment from Senator Bartlett before the bill was passed through the Senate.¹⁷ One of the key reasons that these kinds of hybrid embryonic forms have been prohibited to date is because they give rise to questions about how we define the human. There is no definition of ‘human’ in the current legislation. Concerns about the creation of hybrid embryos that still prevailed when the bill was passed through the Senate suggest that even those who now support the creation of embryonic stem cells still view the embryo as having a human-like status sufficient to make mixing it with animal eggs repugnant. While Senator Bartlett, who proposed the amendment, argued that the basis for rejecting this clause was an inadequate consideration of the rights of animals, he did say:

The other point I want to emphasise is that, whilst I do not at all agree with the distorted view that somehow this legislation would allow half-horse or half-animal creatures or rabbit men bouncing around the neighbourhood or whatever, this legislation does at least remove the potential for that distortion and even for that misunderstanding.¹⁸

Rather than allowing the extra-uterine uncanny embryo and all its repressed evocations to occupy the central focus, I argue that in new legislative responses to reproductive genetic technologies, an alternate phantasmal premonition should be foregrounded -- that of the *not-yet-pregnant, pregnant woman*. By emphasising the pregnant woman who is not-yet-pregnant I want to evoke

¹⁶ Technologically produced embryo refers to any embryo that is made outside the womb with the intervention of technology whether or not they have been manipulated genetically or mixed with cells from non-humans.

¹⁷ Proposed subsection 20(1)(g) of the RIHE Act in the Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Bill 2006 (Cth) (hereafter the Patterson Bill).

¹⁸ *Supra* n12 at 78

the underlying assumption that where there are embryos there are also women who will become pregnant with them and are therefore already premonitionally pregnant. By doing this the provisionality of these technologically created embryos is highlighted. Gestation for some of these so-called embryos is, in fact, not a real trajectory and in such cases, I argue, they cannot continue to occupy the same symbolical range as the embryo that is destined for gestation. The embryo is only connected with its potential for personhood by female embodiment. Those who wish to make the argument that all embryos have equivalent value do so only by rendering the female body irrelevant. In order to do this a complex process of disappearing has to take place. If we return the female body to visibility then the basis of the discussion is fundamentally changed.

Bartlett, for instance, acknowledged that by removing the section allowing animal eggs to be used as hosts for SCNT rather than human eggs, he was creating a situation where more pressure would be applied to women to donate their eggs, but he was satisfied that enough safe guards were in place to make sure it was voluntary. The larger point that it is not appropriate to put women at greater risk (and it is always risky and invasive to retrieve eggs) when animal eggs are a viable alternative, does not get made. Instead the animal rights argument trumps the rights of human women.

In the parliamentary debates around the amendments that were passed in December 2006, one member of Parliament, speaking in opposition to the Bill, surprisingly voiced his concerns in terms that could be argued did, in fact, take the perspective of the not-yet-pregnant pregnant woman when he suggested that it might be wrong to deny a woman the right to gestate a human embryo clone made from her donated ovum should she wish to do that. He said:

We have the argument here that there is an absolute ban on reproductive cloning and that, once these embryos are created, it is illegal for them to be implanted in the womb and brought to term. If a woman has donated her ova and we have what people regard as either a human life or a potential human life, I do not know what argument will be used to tell the woman who is the mother—or potential mother, depending on where you sit in the debate—that, ‘Even if you want to have that embryo implanted, we’re not going to let you.’ Logically, I am not sure at what point she ceases to be the mother. I am not sure at what point she loses those rights. It is unlikely that that request is going to be made, but I am not sure, and I am yet to hear, what the logical argument is that says she has no right to make that request. Under this bill she does have no right, and I am not quite sure how that next line gets drawn when this step is taken.¹⁹

¹⁹ Commonwealth, *Parliamentary Debates*, House of Representatives, 6 December 2006 (Anthony Burke) at 16

This perspective (one so uncommonly voiced) raises a whole series of further questions that are yet to be considered precisely because this perspective is submerged. For instance, Burke assumes that the egg determines future parentage whereas many might have thought that in the case of somatic cell nuclear transfer, the nuclear DNA would determine parentage. On this latter view, the egg is really just a casing for the DNA provided by the original biological entity. In this case, then, the parent would be the person of whom the child was a clone. Secondly, it raises the question of how to manage the relinquishment of future claims over such genetic material. For instance, if the embryo was to be illegally implanted in the uterus of a woman several questions arise. Who would the resultant child be related to and to whom would it belong? If the “illegal” pregnancy were to be discovered before the birth of the child, should the woman be forced to undergo an abortion?

Here I want to suggest that it is not the discourse of science alone, or even primarily, that gives rise to these new possibilities. Instead, it is through the enactment of this kind of legislation that (legislative) life is given to entities that are yet to be made. In so doing, the law gives reality to the fantasy of the very beings that it in some instances seeks to deny. Law through both regulation and prohibition carries us forward in the imaginary leap that is necessary to take us from the embryonic being to the *post-human* being.

The move from embryonic cell mass to potential human being is given articulation through the legislative work that is undertaken to map out the boundaries and protect the limits of the embryo. However, it is only through the dematerialisation of women that the embryo is able to materialise into something valuable.

The disappearance of the female body in the context of scientific and legislative discussions about the embryo operates in a way that is similar to (in fact probably derived from) the development of the “public fetus” in the 1980s and 1990s, but it has two striking differences. First, the embryo does not have the same visual presence as that of the “public fetus” in that it is not visually amenable to anthropomorphisation through ultrasound or microscope technology. Secondly, the technologically produced embryo literally exists outside (and prior to) the female body. This is to be contrasted with the fetus which is separated from the woman who gestates it only visually with the aid of ultrasound technology. Here we might recall Barbara Katz Rothman’s famous description of the fetus: “the fetus in utero has become a metaphor for ‘man’ in space, floating free, attached only by the umbilical cord to the spaceship. But where is the mother in the metaphor? She has become empty space.”²⁰ The fetus then although very much contained within

²⁰ Barbara Katz Rothman *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood* (1986) p114. See also Rosalind Pollack Petchesky “Fetal Images: The Power of Visual Culture in the Politics of Reproduction 13 *Feminist Studies* 263 (1987) ,and Valerie Hartouni “Containing Women: Reproductive

in the womb is given an external persona through these visualising technologies. Embryos, on the other hand, existing prior to the possibility of recognisable (in the sense of looking human) ultrasound renderings, are instead given material realisation by the way in which they are given articulation through legal and scientific accounts which are then circulated in the media.

Turning then to the way in which the *non-prohibited* technologically produced human embryo is managed in the law, it is hard to avoid slippage between embryos and fetuses.²¹ This slippage, however, is analytically useful. It signals the impossibility of containing the symbolic weight that ideas like embryo and fetus have to carry. For the purposes of the argument that follows, I want to suggest that the embryo and the fetus occupy similar symbolic ground, both giving force to a phantasmal premonition of a person. This is despite the fact that, as noted earlier, the technologically produced embryo is literally extra-uterine and less easily anthropomorphised while the fetus resembling a baby is only visually separated from the female body. Both still rely upon the disappearance of the pregnant woman.

Marie Fox has described the status of this embryo as “hover[ing] uneasily between personhood and property”²² despite the consistent failure in the legal context to establish fetal personhood. In the Australian legal context this acceptable embryo and later the fetus hovers closer to legal personhood than property. It has, I would argue along with Fox, taken hold of the legal and cultural imaginary in such a way that it has attained a subjectivity that gives it legal purchase if not legal personhood. Fox drawing on Condit puts it like this:

Gradually, the symbolic meaning of the fetus is being radically transformed. Where the abstract idea of the fetus once signified an invisible, unknowable potential, it is coming to designate an extant, corporal entity with a knowable autonomous identity as a baby (Condit, 1995: 32). (footnotes omitted)²³

Discourse in the 1980s” in *Technoculture* ed. Andrew Ross and Constance Penley pp27-56 (1991) both of whom have provided valuable insights into the way in which fetal visualizing technologies have been used by the religious right and anti-abortion activists to argue the status of the fetus as something not only separate from the gestating woman but her adversary.

²¹ Typically, an embryo is distinguished from the fetus, both in law and science, by time. An embryo becomes a fetus after eight weeks of development. The definition of ‘human embryo’ as it appears in the *Prohibition of Human Cloning Act* and the *Research Involving Human Embryo’s Act* is, according to the Lockhart review, a very broad definition, which “reflects the common understanding of ‘embryo’ as the developing organism from fertilisation until about eight weeks of development (after which it is a fetus).” Lockart Review p.94 See also Morgan D. and Lee, R. (1991) *Blackstone’s Guide to the Human Fertilisation and Embryology Act*. London: Blackstone Press.x–xi; for a similar definitions in the UK context.

²² Marie Fox “Pre-Persons, Commodities or Cyborgs: The Legal Construction and Representation of the Embryo” *Health Care Analysis* 8 171-188, 2000 at p172

²³ Fox *supra* n22 at p. 174

It is not surprising then that in its review of the *Prohibition of Human Cloning Act 2002* and the *Research Involving Human Embryos Act, 2002* the Lockhart Committee focussed on the definitional question of what a human embryo is as a means to achieve greater research flexibility for scientists. By giving articulation and emphasis to the state that is less than an embryo but more than gametes, the Lockhart Committee opened up the potential research terrain without the need to suggest a different value to the embryo itself. They said:

Adopting an independently developed definition of a human embryo to a slightly later stage in the fertilisation process (first cell division) would allow much of the research described ...to occur without falling outside the [Research Involving Human Embryos] Act.²⁴

Under the amending legislation the Lockhart Committee Review definition of an embryo has been adopted. Whereas previously the definition of a human embryo as set out in both section 8(1) of the *Prohibition of Human Cloning Act* and section 7(1) of the *Research Involving Human Embryos Act* read:

a live embryo that has a human genome or an altered human genome and that has been developing for less than 8 weeks since the appearance of 2 pro-nuclei or the initiation of its development by other means

the new definition is as follows:

"human embryo" means a discrete entity that has arisen from either:

- (a) the first mitotic division when fertilisation of a human oocyte by a human sperm is complete; or
- (b) any other process that initiates organised development of a biological entity with a human nuclear genome or altered human nuclear genome that has the potential to develop up to, or beyond, the stage at which the primitive streak appears;

and has not yet reached 8 weeks of development since the first mitotic division.

Significantly the definition of a hybrid embryo does not include the revised requirement that the first mitotic cell division has taken place. The definition of a hybrid embryo as set out in section 8(1) of the PHCR and 7(1) of the RIHE is as follows:

²⁴ Lockhart Committee Review supra 4 at page xv.

"hybrid embryo" means:

- (a) an embryo created by the fertilisation of a human egg by animal sperm; or
- (b) an embryo created by the fertilisation of an animal egg by human sperm; or
- (c) a human egg into which the nucleus of an animal cell has been introduced; or
- (d) an animal egg into which the nucleus of a human cell has been introduced; or
- (e) a thing declared by the regulations to be a hybrid embryo

It may be that "embryo" in parts (a) and (b) will be interpreted in line with the revised definition of a human embryo but it is by no means a certainty. As a consequence, when it came to the amending legislation, the legislature considered it necessary to specifically allow the creation of certain kinds of hybrid embryos for research purposes only. As I noted earlier, the scope of allowable hybridity was narrowed by amendments to the legislation in the Senate. However, section 23B(3) of the PHCR Act and s20(1)(f) of the RIHE Act together allow the creation of a hybrid "embryo" for the purposes only of testing sperm quality up to but not including the first mitotic cell division. Again first cell division seems to be determinative.

The Committee suggested first cell division as determinative on the basis that the community consensus is a "new and unique genetic entity is formed" only after the genetic material from the male and female pronuclei combine.²⁵ One might ask, however, why a new and unique genetic identity is key to embryonic status. It seems clear that genetic identity is here standing in for the individual. In this moment, then, a particular scientific account of selfhood as synonymous with DNA is being privileged over all others.

This focus on the uniqueness of genetic identity accords with the observation by Dorothy Nelkin and Susan Lindee that DNA is "today taking on the social and cultural functions of the soul."²⁶ Similarly, Christine Hauskeller has identified "the tradition of protecting individuality that has become secularized and this means nowadays based on matter, as it is."²⁷ She goes on to argue that government practices of regulating genes and genome identity discourses belie an underpinning ideology "that molecular biology can deliver the material foundation of concepts of what being human is and what it should be."²⁸ David Le Breton too, critically describes this process when he says of the desire of 7% of Americans to be cloned one day,²⁹ that the

²⁵ Lockhart Committee Legislation Review Report supra n24 at p.xv

²⁶ Dorothy Nelkin and Susan Lindee *The DNA Mystique; The Gene as Cultural Icon* at p. 67 (1995)

²⁷ Christine Hauskeller, "Genes, genomes and identity. Projections on Matter" *New Genetics and Society* Vol. 23, No. 3, December 2004 at p.296

²⁸ Hauskeller supra n27 at p. 297

²⁹ *Nature*, 6 March 1997

understanding is that the “body is merely a decorative container that holds the soul, which is to say DNA. One’s body is mortal and imperfect and only the DNA is immortal...”³⁰

While I am not suggesting that the previous definition of a human embryo is better, I would want to contest the assumption that individuality is born into being in the moment of the first mitotic cell division. Rather, not surprisingly, I would want to suggest it happens much later in the process after female gestation.

Interestingly, a similar debate took place in the context of the enactment of the UK *Human Fertilisation and Embryology Act* (1990). Sarah Franklin tracks that debate and the contest between those who argued a unique individual was formed only at the point of the emergence of the “primitive streak” (spinal column) and those who argued that it was formed when a unique genetic blueprint emerged at fertilisation.³¹ In both cases the key is the moment that a unique biogenetic entity can be discerned. Franklin describes this as “establishing biogenetic individuality as the basis of personhood” and contributing to “the geneticisation of both kinship and identity.”³² The Lockhart Committee similarly highlights the moment of biological individuation as key but finds its occurrence in the first cell division.

If the Lockhart Committee is correct in its assessment of community values, then, in Australia being human in embryonic form means having a new and unique genetic identity. This moment of becoming embryonic necessarily evokes the further development of the fetus and, if brought to term, the child. Although that trajectory is far from certain, the embryo (now synonymous with a “new and unique genetic entity”) stands for all that it might become. Unhinged from the all-encompassing female body, equipped with its own genetic identity, it attains an individuality that prefigures its birth. In this way, even in the absence of a mother, the embryo is assigned a holding place in the (human) family.

Turning then to the question I posed earlier, namely how do we define what it is to be a human person before the law in the context of new genetic technologies, it is now clear that in order to answer it we must examine the kind of legislative and cultural work that takes place around how we use and manage embryos, whether we are enhancing, cloning, manipulating, harvesting, implanting or destroying them. This then needs to be mapped alongside how the legislation functions to give the future embryo an uncanny pre-existence, the status perhaps of a premonition that in turn marks some of them for exclusion from the human family before they even exist.

³⁰ David Le Breton *Genetic Fundamentalism or the Cult of the Gene Body and Society* Vol. 10 No. 4 at p. 16

³¹ Sarah Franklin “Making Representations The Parliamentary debate on the Human Fertilisation and Embryology Act” in J. Edwards et al. (Eds), *Technologies of Procreation: Kinship in the Age of Assisted Conception*. Manchester: Manchester University Press at p. 133

³² Franklin *supra* n31 at p. 134

In the case of *in vitro* fertilisation (IVF) and ARTs generally, Irma Van der Ploeg argues that through the disappearance of women and women's bodies in the language of fertility treatment, the foetus comes to exist prior to its actual incarnation.

In examining the parts of the IVF treatment that concern getting the oocytes into the laboratory, that is, the hormonal stimulation of ovulation in the woman and the retrieval of the oocytes from her body, we find another example of reconceptualizing the bodily interventions in the IVF procedure. In contrast with how these stages of treatment are likely to be experienced by the woman involved, these stages appear to be reduced to the status of *preparation*, necessary to start with the 'real' treatment: the laboratory work.³³

She goes on:

From a partial perspective which considers women as the central patient, and which regards their individuality and physical well-being as issues that matter, individual women are seen walking in and out of waiting and treatment rooms, climbing on and off gynaecological chairs, letting themselves be monitored, medicated, anesthetized and operated on. From the equal partial perspective of medical technoscience presented in its literature, these practices constitute events in which hardly anything seems to happen to women."³⁴

Van der Ploeg argues that in the context of assisted reproduction by deleting the interventions on female bodies that are necessary to *make* the foetus, its artificial construction is erased. She says: "Once they [the foetus] have acquired 'natural' status in this way, the process in which they are constructed can then be presented in reverse, as a consequence of a prior existence."³⁵

Van der Ploeg's identification of this ontology is also perceptible in the Australian legislative language.³⁶ In both the PHCR and the RIHE Acts 2002 the word "woman" is mentioned only a few times and on each of those occasions she is not the subject of the legislation but the object. The embryo is either created for or outside a woman or placed into or taken out of the body of a woman. It appears that the woman herself is subsidiary to the action.³⁷ The consequence of this disappearance of the woman's body is, as Van der Ploeg argues, that the embryo acquires a natural status which is then presented "in reverse, as a consequence of a prior existence."³⁸As

³³ Irma Van der Ploeg "Only Angels Can Do Without Skin': On Reproductive Technology's Hybrids and the Politics of Body Boundaries" in *Body and Society* Vol. 10(2-3): 152-181 at p. 162

³⁴ Van der Ploeg *supra* n. 33 at p.177

³⁵ Van der Ploeg *supra* n. 33 at p. 176

³⁶ Van der Ploeg *supra* n33 at p177

³⁷ See sections 8, 16, 19, 21 and 22

³⁸ Van der Ploeg *supra* 33 at p 176

noted above there is a distinction between the embryo *in utero* and *ex utero* that enables this process to occur in the legislative context. And yet of course the embryo cannot come to be anything unless a woman does ultimately offer to gestate it. **In or out of the body it is always inevitably connected with its potential for personhood only by female embodiment.** The connection between the pregnant woman and the *in vitro* embryo is further attenuated in the context of genetic manipulation technologies. Unlike IVF and traditional ART practices, where the woman is the primary target of interventions to produce a child, the interventions that operate in the context of genetic manipulation technologies take place almost entirely in the clinic, away from women's bodies and completely decontextualised from them. Although the work of women to produce the gametes has taken place prior to this moment, genetic interventions tend to be on the embryo itself. This shifts the emphasis slightly. Van der Ploeg identifies the reverse order construction of the fetus as leading to a shift from fetuses as a result of interventions on women's bodies to fetuses as the reason *for* interventions on women's bodies. In the case of genetic manipulation technologies, one might argue that the pre-existing foetus stands to be offended or hurt by genetic interventions on its embryonic form before it comes into being. This is because it has not only achieved a pre-existent status, but it is given status outside its biological contingency. Though not a legal person in the strict sense its personhood is omnipresent. One might go so far as to argue that the foetus appears to be able to exert a greater claim to non-intervention than the woman. This may be why these kinds of manipulation have provoked legislative bans. In contrast, the regulation of interventions on women for the purpose of producing and harvesting gametes has been ad hoc and fairly limited in scope within Australia. Indeed, the federal regulatory regime seems to exacerbate the potential harms to women rather than afford them protection. The Lockhart Committee's review of the federal legislation identified this in a number of places and recommended amendments to the legislation that would in fact serve the interests of women. For instance the recommended alteration in the definition of the embryo to a slightly later stage, namely the first cell division, which has now been adopted would have enabled researchers to undertake research on the quality of sperm without the need for human eggs if the definition of a hybrid embryo had also been amended to the first mitotic cell division. Instead, a further amendment to allow the testing of sperm on animal eggs up to the first mitotic cell division had to be drafted and agreed upon. Another issue raised by the Lockhart Committee was the burden placed on women to donate eggs for research, and the suggestion that animal eggs could be used to create SCNT cloned embryos was meant to ameliorate that burden. However, as discussed above the rights of animals were found to be paramount and this amendment was removed from the amending bill before it passed through parliament in December 2006.

A Feminist Regulatory Response

A feminist regulatory response might begin by challenging the primacy of the disembodied embryo. Indeed it would challenge both its physical detachment from the female body and its social detachment from the parental relation.

The next step might be to replace the phantasmic preomitional embryo with an alternate phantasm: that of the *not- yet- pregnant, pregnant woman*.³⁹ Utilising Van der Ploeg's analysis of the problematic naturalization of the fetus in reverse as a consequence of its prior existence, I want to argue that we transpose the pregnant woman for the embryo/fetus. In this way the pregnant woman becomes the omnipresent personhood that regulates and determines who and what we may call kin. While the spectre of female decision-making replacing legal determinations may alarm some I am not convinced that it is a lesser form of ethical restraint.

What then would the legislative landscape look like if this alternate phantasm was given primacy?

The PHCR Act is written so that certain key relationships are submerged. These are relationships that might do the work of exposing the political motivations or at least accidental discriminations that have resulted. Law's capacity to intervene is curtailed at the point where the embryo is implanted in the woman's womb. Coerced abortion would, one has to think, be extremely controversial. So it is not surprising that the gametes regulated by the Acts are disembodied so that any kind of fertilisation process that is adverted to must be taking place, not only within a laboratory but also without reference to the particular individuals who might be seeking the unauthorised fertilisation. In most cases too there is a great deal of embodied work that has gone on prior to this legislative moment and a great deal to come afterwards.

What difference would it make if the bodies involved were foregrounded? Sections in the Australian legislation that prohibit the intentional development of these prohibited embryos would have to explicitly state, for instance, how it might be that an embryo so created could be "intentionally developed". How could it be done beyond the very earliest stages without the assistance of a woman who was willing to gestate the entity? The reason for the omission is obvious. It would highlight the necessity for some kind of reproductive coercion. I am, of course, not advocating the criminalisation of women who agree to gestate prohibited embryos (or the related spectre of coerced abortions), but I am trying to illuminate the way in which these legislative prohibitions intrude into the reproductive capacities and rights of women without our

³⁹ In Van der Ploeg's analysis the woman has not just been replaced by the fetus but also by the conceptual apparatus of "the couple." Since it is clear that some account needs to be taken of the role that men must also play in the determining who we may call kin it might have been useful to talk of the not-yet pregnant pregnant couple. However, I have not chosen to take this route because the only certainty at this technological moment is that women will be the ones gestating and developing the fetus. Indeed part of what I have been trying to challenge is the primacy of the heterosexual dyad as the dominant reproductive model.

noticing. We need to challenge the otherwise unacknowledged status of the embryo legally, culturally and medically as a radically contingent premonition or phantasm.

By recognising it as uncanny, without a home and requiring first a welcome before it can be brought into being, we are able to appropriately realign the legislative focus to reflect its dependent status. In this way the means to determine how or what kinds of regulatory limits to engage in deciding who we may call kin presents itself in the form of the *not- yet- pregnant, pregnant woman*. As I stated earlier, in or out of the body the embryo/foetus is always inevitably connected with its potential for personhood only by female embodiment. The embryo, radically disconnected from the body that gives its premonitional possibility a real future, or any body that might welcome them in, is uncanny in the Freudian sense of the unheimlich. Rather than allowing the uncanny embryo to occupy the central focus of new legislative responses I am calling for the (re)instatement of the *not- yet- pregnant, pregnant woman* as the omnipresent figure. The not- yet- pregnant, pregnant woman is a phantasm too but one that presupposes that embryos only come into being through the desire of women to become pregnant with them. These women already have status as legal persons in our community and as such it is them and not the premonitional fantasy of the uncanny embryo that should occupy the central determinative frame of legislative responses. It is this position that women occupy outside the context of assisted reproduction every day when we are called upon to decide whether, in light of the information presented to us, it is appropriate to continue to make the kin that we are making.

Commentary by Duff Waring

My aim here is to highlight some of the challenging issues this paper raises as a stimulus for your dialogue with Dr. Karpin. I know that I won't be able to do this rich analysis justice in the short time I'm going to speak today but I also want to give you a sense of how much this paper has left me to think about.

This analysis offers a critique of the legal and scientific articulations by which prohibited embryos are given an uncanny material realization in the media. This realization emphasizes disconnection from the female body, as if the embryo were already born. Unhinged from the female body and equipped with its own unique genetic identity, the embryo stands for all that it may become and attains an individuality that prefigures its birth. There is a sense in which it is given a holding place in the human family even in the absence of a mother.¹

The point of legislative prohibition and containment is to keep the uncanny embryos on hold while prefiguring the alien persons they could become. Through prohibition and containment, some technologically produced embryos become vivid, phantasmal premonitions of a type of child which must *not* be born. This is Dr. Karpin's admittedly radical view of the law as engaged in fictional productions of unacceptably human persons. Thus hybrid or genetically enhanced embryos raise what the law enshrines as the disturbing possibility of hybrid or genetically enhanced persons.

One challenge this paper presents is the task of thinking creatively about the values we ought to affirm when we decide upon the conceptions of the person and the human family with which we ought to go forward. In a world in which these genetic transformations are possible, that would be no small task.

To that end, I want to suggest that we push the envelope even further. Let's consider in greater detail what should be the guiding values of a feminist regulatory response that is open to the transgressive other. I think a lot of fascinating work can, and I hope will, come out of this paper by expanding on the final section which begins to address the question of what this response might look like. Along the way, I'm going to raise some interpretive possibilities that we might consider and then I'm going to leave it to Dr. Karpin, and to each of you, to begin your dialogue.

Let me just go back and recapitulate a bit. On Dr. Karpin's account, these prohibited, technologically produced embryos become, in the Freudian sense, uncanny incarnations; the

¹ Isabel Karpin, "The Uncanny Embryos: Legal Limits to the Human and Reproduction Without Women". *Sydney Law Review* 28 (2006), 599-623 at 607

material realization of a disturbing promise of a life that is legally decreed to be unacceptably human. Again, this radical view of the law as engaged in the fictional productions of unacceptable humans negates the woman who could, if she chose, gestate these embryos. Absent artificial wombs, gestation is how embryos embark on the path to personhood. Thus gestation is how these embryos should be understood as acquiring a holding place in the human family.

One way of seeing this analysis is to think of it as aiming to avoid the fallacy of abstraction, that is, the consideration of an object as if it exists without a context. *As if* there are fetuses that exist apart from women. *As if* unacceptable embryos could ever come to exist as transgressive persons marked as “Other” without a woman who chooses to gestate them.²

But if the mother is foregrounded, then not all technologically produced embryos will have this holding place in the human family if they are embryos that women do not choose to gestate. So this analysis reasserts the biological contingency of the technologically produced embryo through its relation with the encompassing female body. Only after gestation and birth will we confront the person who actually embodies the dreaded potential of the transgressive Other and who personifies what the legally prohibited embryo has finally become.

How should the value of a prohibited embryo that is brought to life be adjudicated by the law? Dr. Karpin takes a cue from Jacques Derrida’s account of hospitality, by which configurations of otherness can present alternative and transgressive ways of being if we welcome them. I take it that the feminist legal response Dr. Karpin is working out aims to extend a hospitable welcome based on an openness to difference. This openness would owe little to the comfort of homogeneity and would expose ourselves and our collective standards to the risk of the unforeseeable. This hospitality comes into play precisely where the conventional juridical and moral discourse reaches its limit.

I take it that Dr. Karpin’s feminist regulatory response, to the extent that it strives for openness to the transgressive other, would enable women who gestate genetically manipulated embryos and those who support their reproductive autonomy to expand these conventional juridical and moral limits depending on the embryos the women choose to reproduce.

By foregrounding the embodied woman via the alternate phantasmal premonition of the Not Yet Pregnant Pregnant Woman (hereinafter NYPPW), we highlight the biologically contingent status

² Mary B. Mahowald, “As If There Were Fetuses Without Women: A Remedial Essay” in *Reproduction, Ethics, and the Law: Feminist Perspectives* (Bloomington: Indiana University Press, 1995), 199.

of the embryo's potential for personhood. The embryo is only connected with this potential by female embodiment. A woman has to decide to gestate it.³

This means that we can introduce symbolic and ethical differences between those embryos for which gestation is a real trajectory and those embryos for which it is not. At present, only women can decide whether gestation is a real trajectory. As Dr. Karpin avers, those who argue that "all embryos have equivalent value do so only by rendering the female body irrelevant".⁴

In sum, by foregrounding the NYPPW and making embodied gestation relevant, we have a basis on which to argue *against* the claim that all embryos have equivalent value.

If we shift away from the question "What kind of embryo should be made?" to the question "What kind of embryo will women want to reproduce?" then we make the autonomous reproductive choices of women the primary consideration in deciding what life forms are offered a holding place in the human family. That might enable us to establish moral differences in value between embryos that might just be made, say for research, and embryos that women want to reproduce.⁵

I wonder then whether the NYPPW has to be seen as evoking the underlying assumption that "where there are embryos, there are also women who *will* [italics mine] become pregnant with them".⁶ I understand that the role of this phantasm is to underscore biological contingency but I wonder whether it goes far enough in capturing the contingency of a woman's decision, i.e., the woman who decides between those embryos for which gestation is a real trajectory and those embryos for which it is not.

We might construe the NYPPW as evoking the assumption that where there are embryos, there are women who *may* choose to become pregnant with them. This might be a way of highlighting even further the provisionality of technologically created embryos⁷ and reinforce Dr. Karpin's argument that they should not continue to occupy the same symbolical, or even the same ethical range as "the embryo destined for gestation".⁸

One implication we can explore today is that a holding place in the human family ought to be understood as provided by the woman who chooses to gestate. If so, then one might think that gestation is one pivotal aspect of the natural that has survived the so-called fragmentation of

³ Karpin, 2007 at 603

⁴ Ibid.

⁵ Ibid., 604

⁶ Ibid., 599

⁷ Ibid., 603

⁸ Ibid.

motherhood that has resulted from the dispersal of different aspects of maternal procreation via new reproductive technologies.⁹

Unless we raise the spectre of forced abortions, the forced implantation of embryos or the criminalization of women who choose to gestate prohibited embryos, we can see gestation as an aspect of the natural over which women should have exclusive decision-making control.

But I don't think this analysis is meant to entail the conclusion that women who choose to gestate an embryo should ignore everybody else in working out the conception of the human with which we choose to go forward. The decision to gestate does not preclude the possibility that others in the human family will have their own views about the conception of the human with which we should proceed. Their reasons for holding these views may be good or bad, but this is the sort of thing about which family members deliberate. I agree that women's reproductive choices should occupy the "central determinative frame of legislative responses".¹⁰ But I note as well that women's reproductive decisions should be made "in light of the information before them".¹¹ That information can include conceptions of the human that are endorsed by persons other than women who choose to gestate an embryo. Further, the analysis alludes to the deficit of community input on genetically manipulated and hybrid embryos that results when the law predetermines and propagates negative responses to them.

As Dr. Karpin notes the response to the birth of a person who was once a prohibited, genetically manipulated or hybrid embryo might be one of either "horror or hospitality depending on the account of the human with which *we* [italics mine] choose to move forward".¹² While the plural subject "we" need not displace the centrality of female reproductive decision-making, let alone criminalize women who might choose to gestate unacceptable embryos, it raises the possibility that we as a community might still face unresolved moral questions about the value frameworks which we think should guide or influence these choices.

Indeed, Dr. Karpin notes that "community responses to the possible development of genetically manipulated embryos [have] not managed to enter the lexicon of a new natural".¹³ This despite the notion, argued by Donna Haraway, "that the moment of the natural as some kind of non-hybrid organic identity has long since passed".¹⁴

⁹ Michael G. Peletz, "Kinship Studies in the Late Twentieth Century Anthropology" *Annual Review of Anthropology* 24 (1995)343-372 at 365

¹⁰ Karpin., 623

¹¹ *Ibid.*, 599

¹² *Ibid.*, 614

¹³ *Ibid.*, 620

¹⁴ *Ibid.*, 609

At least one legislative review committee in Australia (the Lockhart Committee) has noted a wide diversity of views on embryo research “with the exception of human reproductive cloning which appears to be widely condemned”.¹⁵

While Dr. Karpin concedes that the replacement of legal determinations with female decision-making might alarm some, she is not convinced that female decision-making is a lesser form of ethical restraint.¹⁶ Neither am I, but this paper prompted me to think harder about why I’m convinced of that.

Consequently, I started thinking about how to clarify the initial, normative premises of the regulatory response from which we evaluate the status of embryos. It seems to me that the Derridean notion of hospitality is epitomized by the woman who welcomes the embryo into her body and through gestation offers it a place to grow into the human family. This is where we might reflect further on the justificatory reasons for a feminist response that is open to the transgressive other.

One way to think about this is to ask what that feminist perspective should aim to restrain through ethics and law. A number of interpretive possibilities come to mind. It should aim to restrain the intolerance to and suppression of difference that some feminist philosophers equate with oppression. It should aim to restrain social institutions and behaviour that create particular circumstances for groups or persons marked as deviant or “Other” which disadvantage them in their opportunity to develop their capacities, many if not most of which capacities they might be able to share with the rest of us.¹⁷

It should aim to restrain the idea that if transgressive persons would face a less than hospitable social response, then that social response should count as a sufficient reason to not bring them into the world, to not value their differences and fight for their rights. Perhaps work from the disability rights community would be relevant here.

By analogy, that movement aims to restrain practices based on the idea that if so-called disabled persons would face a less than hospitable social response, then that negative response should count as a sufficient reason to not bring them into the world, to not value their differences and fight for their rights. As a person, you don’t have to hail from a legally prohibited embryo to be labeled as unacceptably “Other.”

¹⁵ Ibid., 620

¹⁶ Ibid., 621

¹⁷ Iris Marion Young, *Justice and the Politics of Difference* (Princeton: Princeton University Press, 1990). 164.

It could also aim to restrain any legal demand that the phantasmal embryo or fetus ought not to be recognized as a person.

We might also think about what a feminist regulatory response that is open to the transgressive other should aim to affirm. A number of interpretive possibilities come to mind, not the least of which is an emancipatory politics that asserts a positive sense difference.

It should also aim to affirm that “community responses to the possible development of genetically manipulated embryos” have at least the opportunity to enter the lexicon of a new natural.

Some of you may want to discuss the idea that labels like “transgressive person” are socially constructed and that what can be socially constructed can, and in some cases should, be socially deconstructed. As the philosopher Ian Hacking notes, we are affected by the ways in which being female or having a disability are conceived, described and ordained by ourselves and the network of milieus in which we live.¹⁸

But one liberating idea of social constructionism is the idea that these meanings are not fixed and inevitable. “They are,” he writes, “the product of historical events, social forces and ideology”.¹⁹ Since ought implies can, it is important to remember that those meanings can be changed.

This paper also reminds us that there is still an influential ideology of genetics and molecular biology that constructs a completely genetic basis for personhood which again ignores the contingency of the embryo through its relation with the woman who may choose to gestate it. We may want to discuss whether, and if so how, this construction should be challenged.

Put another way, we all have a stake in deciding upon the conception of the human with which we choose to go forward and we should do our best to make sure that the conception is not narrowly construed. I understand the type of feminist regulatory response that Dr. Karpin is proposing to be one that reflects that aim.

¹⁸ Ian Hacking, *The Social Construction of What?* (Cambridge: Harvard University Press, 1999), 2

¹⁹ *Ibid.*, 104

Better than normal: Choosing to self-construct¹**Isabel Karpin**

This paper is written as a response of sorts to troubling questions raised in a paper that precedes it. That paper was on the topic of inheritable genetic modification and was co-written with Roxanne Mykitiuk². In that paper we engaged with the transgressive possibilities of germ line or inheritable genetic modification in the form of clones, hybrids, chimeras, children born from multiple genetic progenitors, children born from the fusion of same sex germ cells and so on. Our aim was in part to challenge the programmatic normalcy upon which the various legislative instruments insist by prohibiting certain kinds of reproductive possibilities.³ That normalcy, we argued, involved judgments about “natural” characteristics that were in fact based on cultural and ideological determinations about what is socially desirable. We argued that apart from the obvious need for controls on scientific research in reproduction to ensure safe and ethical research, the moral basis for prohibitions against inheritable genetic modification, cloning and other new reproductive possibilities were less obvious. We discovered that instead, the prohibitions were based on “purported ethical or moral distinction[s] ...about the “nature” of reproduction”. As we argued there:

these parameters include the requirement that reproduction is sexual – meaning, between a man and a woman (not cloning) and that the man and the woman are in a heterosexual relationship (some countries and jurisdictions have legislated to limit the use of IVF and related technologies to heterosexual couples) with each other and that, the product of that technologically-enhanced reproduction, has a blood/genetic line that only traces back to two progenitors. Kinship relationships and relationships of inheritance are established on the basis of this “truth” about the “nature” of reproduction, such that it becomes impossible to think about kinship being established, or reproduction taking place, in other ways...⁴

¹ Within this article there are some sections reproduced or adapted from Karpin I “Choosing Disability: Preimplantation Genetic Diagnosis and Negative Enhancement” (2007) Vol. 15 Journal of Law and Medicine 89. © Lawbook Co, part of Thomson & Legal Regulatory Limited. <http://www.thomson.com.au> Reproduced with permission. For an expanded discussion of the last section of this chapter dealing with body modification and cosmetic surgery see Isabel Karpin “Constructing the Body Inside and Out: Genetic and Somatic Body Modification in Belinda Bennett, Terry Carney and Isabel Karpin (eds) *The Brave New World of Health* (Federation Press, Sydney forthcoming 2008).

² Karpin, I and Mykitiuk, R, 2006, “Regulating Inheritable Genetic Modification, or Policing the Fertile Scientific Imagination? A Feminist Legal Response” in J Rasko, G O’Sullivan & R Ankeny (eds), *The Ethics of Inheritable Genetic Modification*, Cambridge University Press, Cambridge, UK.

³ *Prohibition of Human Cloning Act 2002* (Cth), amended in 2007 to the *Prohibition of Human Cloning for Reproduction Act* (Cth), *Assisted Human Reproduction Act 2004* (Can)

⁴ Op cit n2 at p. 193

In this paper I expand on this critique of normalcy by starting from a stated preference for “abnormality”; namely a choice in favour of disability or what I call *negative enhancement*. I then contrast this with a discussion of legal and scientific responses to non-therapeutic body modifications such as cosmetic surgery. Here again the assumption is that getting to normal should be the primary aim. The goal in most cosmetic or therapeutic modification is achieving a standard of physical attractiveness that is based on general community preferences and avoiding *social undesirability*. In the case of cosmetic alterations, study after study indicates that the people undertaking these are concerned not with enhancement so to speak but with bringing themselves “up to” the norm.⁵ But, importantly, with increasing developments in cosmetic surgery technologies, being able to normalise oneself has become *de rigueur* - an obligation. This is similar to the expectation that people planning a pregnancy will use genetic testing to avoid a disability or to ascertain the risk thereof. People with unsightly moles or large noses, or birth marks or crooked teeth are regarded by some as failing to take reasonable and easy steps “in this day and age” to normalise their appearance. Those who shun that obligation or worse, use cosmetic techniques to undergo procedures that are not socially desirable, like those who use genetic testing to choose abnormality, find themselves either outside the realm of legal protection or in defiance of the law.

Choosing Disability: Choosing to Construct

Genetic technologies enable, perhaps as never before, the possibility of individual control in the pursuit of self-improvement and avoidance of risk. Self-monitoring through genetic testing and analysis at the molecular level gives rise to enhanced expectations of self-mastery through risk minimisation strategies, planned reproductive decision-making and new treatment options, including gene therapy.

It is not surprising then that most academic and scholarly scientific discussion about the appropriate use to which genetic testing technologies may be put in the context of reproduction focus on whether to allow the creation or selection of so-called *designer* babies. In other words, the question has tended to be whether to allow technologies such as preimplantation genetic diagnosis (PGD) to be used not just to identify embryos with the potential to develop a serious disability or disease, but also to identify embryos that have particular favourable traits and to implant only these embryos.⁶

⁵ Of course those who engage in radical piercing etc fall outside this group. Debra Gimlin “Cosmetic Surgery: Beauty as Commodity (2000) 23(1) *Qualitative Sociology* 77 and Patricia Gagne and Deanna McGaughey “Designing Women: Cultural Hegemony and the Exercise of Power Among Women Who Have Undergone Elective Mammoplasty (2002) 16(6) *Gender and Society* 814

⁶ The United States President’s Council on Bioethics, *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (2003) at 30-57, see especially at 40-44.

However, here I want to consider those instances where individuals seek unexpected manipulations with outcomes that are apparently or at least anecdotally, commonly, socially not preferred. This occurs when a person chooses to have or actively select for a gene such as deafness, for example.

The idea of “negative enhancement”, as I have coined it, is both a paradox and a useful means to describe the hidden assumptions behind claims that enhancement technologies can only lead us in one direction – a race of blond, blue-eyed, able-bodied, intellectually magnificent and athletically superior beings.⁷

Negative Enhancement

The most well-known example of “negative enhancement” is that of the deaf lesbian couple who sought to reproduce a deaf child and recruited a sperm donor with several generations of deafness in the family.⁸ While this couple did not utilize prenatal testing or PGD to achieve their desired outcome, the use of such technologies for these purposes is available in some parts of the world. In a recent survey by the Genetics and Public Policy Centre, it was found that three per cent of IVF-PGD clinics in the US report having provided PGD to couples who seek to select an embryo for the presence of a particular disease or disability, such as deafness, in order that the child would share the characteristic with the parents.⁹

In Australia, PGD is limited to selecting against a serious disease or illness,¹⁰ and in most cases “serious” is not defined.¹¹ The National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007) (NHMRC ARTCPR) lay the ground rules for all the States and Territories in Australia regarding ethical practice for ARTs.¹² They are the only source of control for those States that do not have

⁷ Negative Enhancement as I have coined it is to be distinguished from Glen McGee’s distinction between “negative” and “positive” genetic interventions. McGee uses the term “negative” to describe those interventions aimed at curing disease: see Glenn McGee, *The Perfect Baby: A Pragmatic Approach to Genetics* (1997) at 113 and 141, as discussed by Jackie Leach Scully & Christopher Rehmann-Sutter, ‘When Norms Normalize: The Case of Genetic “Enhancement”’ (2001) 12 *Human Gene Therapy* 87 at 91.

⁸ Julian Savulescu, ‘Deaf Lesbians, “Designer Disability” and the Future of Medicine’ (2002) 325 *British Medical Journal* 771.

⁹ Susannah Baruch, David Kaufman & Kathy Hudson, ‘Genetic Testing of Embryos: Practices and Perspectives of U.S. IVF Clinics’ (2006) *Fertility and Sterility* at 5. PGD for aneuploidy was by far the most common use: 93 per cent of IVF clinics providing PGD offered the technology for this use (at 4). The next most common use of PGD was for autosomal disorders (82 per cent of IVF-PGD clinics) and chromosomal re-arrangements (67 per cent). Forty-two per cent of IVF-PGD clinics had provided PGD for non-medical sex selection purposes.

¹⁰ National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007) at [12.2]: Pending further community discussion, PGD must not be used for (inter alia) the ‘prevention of conditions that do not seriously harm the person to be born’.

¹¹ The ‘Explanation of Key Terms’ in the NHMRC ARTCPR Guidelines do not attempt to define ‘serious’.

¹² The NHMRC ARTCPR Guidelines notes that researchers need to also refer to the NHMRC ‘National Statement’: see National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2004) at [1.14]. The NHMRC National

specific legislation (NSW, TAS, QLD, ACT and NT) and in those States where there is legislation they are nevertheless applicable as a guide via accreditation requirements for IVF clinics. All IVF providers, no matter in what State, must be accredited under Federal Law by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia¹³ and the RTAC requires compliance with the NHMRC guidelines.¹⁴ Unlike in the USA, in Australia the NHMRC ARTCPR Guidelines specifically preclude the use of PGD to “select in favour of a genetic defect or disability in the person to be born”.¹⁵ However, they also concede that “what counts as a serious genetic condition is controversial”, that “there are different perceptions of disability” and that the “practice of selecting against some forms of abnormality may threaten the status and equality of opportunity of people who have that form of abnormality.”¹⁶

Despite this vital bit of recuperative work aimed at contextualising disability and acknowledging theoretical critiques of ideas of normalcy there does nevertheless appear to be a shared understanding among clinicians, scientists, and regulators of what constitutes a serious disability.

How then are we to understand the use of these technologies not to achieve some socially acceptable measure of normality but rather within the context of an alternate economy of desires and interests that may be considered transgressive and that privileges non-normative existence?

Concepts such as disability and normality are fluid. They are ideas that are given meaning socially, politically and contextually and they are not fixed but change over time.

Statement is only relevant to Assisted Reproductive Technology (ART) clinics in so far as these clinics undertake research, as opposed to the clinical provision of PGD, and even then, the Statement itself emphasises that research involving the use of gametes or embryos is governed by the aforementioned NHMRC ARTCPR Guidelines: see NHMRC, ‘National Statement on Ethical Conduct in Human Research’ (2007) at 39 (Chpt 3.4, ‘Introduction’).

¹³ This is the outcome of the operation of section 11 – Offence: Use of embryo that is not an excess ART embryo – as defined by section 8 of the *Research Involving Human Embryos Act 2002* (Cth). This is also the position promulgated by the Reproductive Technology Accreditation Committee of the Fertility Society of Australia: see Reproductive Technology Accreditation Committee, *Code of Practice for Assisted Reproductive Technology Units* (2005) at 8 (‘Introduction’). The recent legislative amendments - *Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act 2006* (Cth) – appear to have no impact on this position. Furthermore ART-specific State regimes also mandate, directly or indirectly, compliance with the NHMRC ARTCPR Guidelines. In Victoria, compliance with the NHMRC ARTCPR Guidelines forms one of the licence conditions for ART centres: see Infertility Treatment Authority, *Conditions for Licence: Clinics, Hospitals and Day Procedure Centres* (2006), s 2 (para 1.3). South Australia’s Code of Practice similarly requires clinical practices to accord with the NHMRC guidelines: *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995* (SA), Sch, s 2A. A condition of every Western Australian licence is accreditation with the RTAC, which in turn requires compliance with the NHMRC ARTCPR Guidelines: see *Human Reproductive Technology Act 1991* (WA), ss 33(2)(ea) and 29(5)(aa).

¹⁴ The RTAC requires all ART clinics to adhere to its Code of Practice. The Code of Practice, in turn, mandates compliance with relevant legislation including the *RHIE Act 2002* (Cth): at [1.17] and that all ART clinics follow the NHMRC ARTCPR Guidelines: at [1.18]. Practices that depart from these ethical guidelines are only permitted in limited circumstances: see [1.18].

¹⁵ National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007) at [12.2].

¹⁶ National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007) at [12.1].

The medical model of disability for instance describes it as “an observable deviation from biomedical norms of structure or function that directly results from a disease, trauma or other health condition.”¹⁷ This model is challenged by disability critiques which instead suggest that “far more important is the salient role placed by features of the world built and designed by people in the creation of the disadvantages that people with disabilities experience”¹⁸ Kaplan, for instance, describes the current disability rights movement as moving towards “a more positive understanding of what it means to have a disability”.¹⁹ Asch too argues that “The definitions of terms such as “health,” “normality,” and “disability” are not clear, objective and universal across time and place. Individual physical characteristics are evaluated with reference to a standard of normality, health and what some commentators term “species-typical functioning. [references omitted]”²⁰

Not surprisingly because of this diversity of understandings of disability, there is a vigorous debate within disability communities and amongst disability rights activists concerning the appropriate use and value of genetic testing.

It should also be remembered that social categories of disability carry within them a vast array of different diseases with different clinical and medical implications. For instance, the organisation known as the Little People of America (LPA), as early as 1995 began debating the question of whether to use genetic testing to screen only for fatal forms of dwarfism. In a 1995 article, Ruth Ricker noted that “[m]ost LPA members have been unaware of the potential screening for (non-fatal “regular” or otherwise “healthy”) dwarf fetuses by average size people.”²¹ Only 25% of births to achondroplastic couples will result in a fetus with the fatal condition of a “double dominant” or

¹⁷ Jerome Bickenbach, Somnath Chatterji, E.M. Badley & T.B. Uestuen, ‘Models of Disablement, Universalism and the International Classification of Impairments, Disabilities and Handicaps’ (1999) 48 *Social Science and Medicine* 1173 at 1173.

¹⁸ Ibid; Adrienne Asch, ‘Disability Equality and Prenatal Testing: Contradictory or Compatible?’ 30 *Florida State University Law Review* 315 at 318.

¹⁹ Deborah Kaplan, ‘The Definition of Disability: Perspective of the Disability Community’ (1999-2000) 3 *The Journal of Health Care Law & Policy* 352 at 352.

²⁰ Adrienne Asch, ‘Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy’ (1999) 89 *American Journal of Public Health* 1649 at 1650. Taylor and Mykitiuk define “species-typical normal functioning” as an expression of normalcy based on statistical articulations which “describes the relationship between health, disease and an individual’s share of the normal opportunity range. In order to inform medical and political knowledge and practice, ‘species-normal functioning’ implicates particular understandings of impairment, equality and opportunity, and renders specific proclamations about the nature and desirability of disability”: Taylor & Mykitiuk, Genetics, Normalcy and Disability” (2001) 2 *ISUMA: Canadian Journal of Policy Research* 65 at 67. Similarly, Scully and Rehmann-Sutter distinguish between species typical functioning and ideas of normalcy arguing that what is “normal” is dependent on the view of the person concerned. They therefore rely on the approach of using “the term ‘normal’ in the sense of a non-defective or non-disease-producing state that lies within the range of variations considered as typical for the species.” Scully & Rehmann-Sutter, above n7 at 91.

²¹ Ruth E Ricker, *Do We Really Want This? Little People of America Inc. Comes to Terms with Genetic Testing* (1995) at <http://home.earthlink.net/~dkennedy56/dwarfism_genetics.html> accessed 1 June 2007.

homozygous achondroplasia.²² More recently, the LPA has produced a “Position Statement on Genetic Discoveries in Dwarfism” in which clear concerns are raised about the potential impact of these tests on their community:

LPA's discussion of these possibilities brought forth a strong emotional reaction. Some members were excited about the developments that led to the understanding of the cause of their conditions, along with the possibility of not having to endure a pregnancy resulting in the infant's death. Others reacted with fear that the knowledge from genetic tests such as these will be used to terminate affected pregnancies and therefore take the opportunity for life away from children such as ourselves and our children. The common thread throughout the discussions was that we as short statured individuals are productive members of society who must inform the world that, though we face challenges, most of them are environmental (as with people with other disabilities), and we value the opportunity to contribute a unique perspective to the diversity of our society.²³

In addition to environmental and cultural facts, technology itself plays an important part in how we understand disability. For instance, the fashion model and elite athlete Aimee Mullins who is also a double amputee is an example of someone who actively refashions disability as *super-ability*. When being a fashion model she uses specially designed legs suitable for high heels (unlike flesh and blood women's legs).²⁴ For running she has specially designed graphite legs modelled on that of a cheetah. Clearly, in her case, her non-normative embodiment is not so easily described as disability.

Oscar Pistorius too, is a case in point. Pistorius is an amputee sprinter who wants to be able to compete in the able-bodied Olympics using his prosthetic limbs. The concern for those who wish to exclude him is that with the prosthetics he is taller than he would have been with “natural legs” and therefore he has a longer stride than he would if his legs were “natural” legs. Jere Longman of the New York Times describes it as follows:

Pistorius wants to be the first amputee runner to compete in the Olympics. But despite his ascendance, he is facing resistance from track and field's world governing body, which

²² *Frequently Asked Questions* (date not provided) Little People of America at <<http://www.lpaonline.org/mc/page.do?sitePageId=44397&orgId=lpa>> accessed 1 June 2007.

²³ *Frequently Asked Questions* (date not provided) Little People of America at <<http://www.lpaonline.org/mc/page.do?sitePageId=44397&orgId=lpa>> accessed 1 June 2007, see especially ‘Position Statement on Genetic Discoveries in Dwarfism’.

²⁴ Rosemarie Garland-Thomson, ‘Integrating Disability, Transforming Feminist Theory’ (2002) 14 (3) *NWSA (National Women's Studies Association) Journal* 1 at 25-27

is seeking to bar him on the grounds that the technology of his prosthetics may give him an unfair advantage over sprinters using their natural legs.²⁵

One of the central tasks of this paper, then, is to radically question the stability of ideas of normalcy and disability and coextensively the capacity of the law to respond appropriately.

Using the idea of negative enhancement as our starting point, then, I am able to radically problematise legal and medical assumptions about what constitutes a desirable or undesirable trait. For instance, we cannot assume in the case of disability that there will always be a desire for its eradication.

In the case of PGD, for example, there are a number of scenarios in which a person might make the choice in favour of disability rather than for its eradication. First is the case described above; namely the kind of desire expressed by Sharon Duchesneau and Candy McCullough, the deaf lesbian couple who sought the assistance of a sperm donor with several generations of deafness in his family to ensure the birth of a deaf child.²⁶ Arguably, it is also the decision any person with an inheritable disability makes when they decide to procreate knowing that their particular disability is more likely than not to be passed on to their offspring.

The second situation is where selection against disability might be rejected. In other words, the potential parent may not wish to select in favour of a disability but they may equally not wish to select against a particular disability. People involved in these kinds of decisions also problematise the assumption of a pre-eminent desire for normalcy by not selecting against abnormality. PGD allows for rejection and selection of particular embryos based on the presence or absence of certain genetic markers. In the hypothetical that I am proposing, a woman, if given the choice, may not decide to reject those embryos identified as having the relevant genetic defect.

In the context of PGD, however, the intervention of the medical practitioner is required to actively implant the embryo, giving rise to two clear points of reproductive decision-making that are not in the hands of the woman. The first is the law that regulates the actions of the medical practitioner (in Australia this would be the PHCR (2002) and the NHMRC ARTCPD guidelines), and the second is the code of ethical practice under which the medical practitioner operates.

The third example is where the woman and her partner may wish to choose an affected embryo rather than have no child at all. They may wish to take their chances on abnormality.

²⁵ Jeré Longman, 'An Amputee Sprinter: Is He Disabled or Too-Abled?' *The New York Times* (15 May 2007).

²⁶ Merle Spriggs, 'Lesbian Couple Create a Child who is Deaf Like Them' (2002) 28 *Journal of Medical Ethics* 283.

The choice to have an “abnormal” child and to actively seek to make that happen comes up against what Nikolas Rose and others have described in the context of emergent genetic testing technologies as the new biogenetic responsibility to make “prudent choices”²⁷. Rose, talking about individuals at risk or contemplating having children that might be at risk, describes a new conception of personhood arising from these technologies as the “human being who is ‘genetically at risk’.”²⁸ He further suggests that

The new genetics links up with contemporary practices of identity. In advanced liberal democracies...genetics takes its salience within a political and ethical field in which individuals are increasingly obligated to formulate life strategies, to seek to maximize their life chances, to take actions or refrain from actions in order to increase the quality of their lives, and to act prudently in relation to themselves and to others.²⁹

Rose does not see this responsibility to act prudently in relation to genetic risk as necessarily creating a closed circuit of action, however. While he acknowledges a genetic identity, he suggests that it is unlikely to supplant other identity claims. Instead he suggests it will “infuse, interact, combine and contest with other identity claims.”³⁰ It is possible therefore to imagine an identity claim based on difference as trumping notions of prudence in genetic risk taking.

Eva Feder Kittay argues that “when parents of a disabled child insist on the normalcy of their special position as parents, they affirm the desirability of normalcy. But what they affirm is an altered conception of the norm.”³¹ Kittay, speaking as a parent with a profoundly dependent adult daughter, is attempting to open up a space in which to insert her own version of what is normal and have it valued. She goes on to say “[w]ith the love we give to those of our children who deviate from standard norms, we exhibit that they are, in fact valuable, valued and desirable [*my emphasis*]. In so doing, we already challenge the norm of normality insofar as that norm carries within it the supposition of its desirability”³².

²⁷ Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (2006)

²⁸ Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (2006) at 107.

²⁹ Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (2006) at 107.

³⁰ Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (2006) at 113.

³¹ Eva Feder Kittay, ‘Thoughts on the Desire for Normality’ in Erik Parsens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (2006) at 102.

³² Eva Feder Kittay, ‘Thoughts on the Desire for Normality’ in Erik Parsens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (2006) at 107-108.

Nevertheless, it is clear that at the level of the social certain value judgments are being made about what are the prudent choices to make. Government funded prenatal testing via ultrasound, cvs and amniocentesis suggests preemptively that certain kinds of embodiment are undesirable.

The prohibition of the use of PGD to select in favour of disability also insists upon a normative idea of embodiment that is not universally supported and worse, may result in the devaluation of those who perceive their lives and their “norm-challenging anatomies,”³³ as Aspinall describes it, as both valuable and desirable.

However threatening transgression of the “natural” appears to be at the genetic level, it is clearly not so at the somatic (corporeal) level where alterations to the body are not so highly regulated or limited. For instance, though it is certainly the case that most medical practitioners are generally unwilling to assist with radical body modification techniques that might easily be described as unnatural, in Australia there are, nevertheless, few State legislative limits on somatic body modification and no Federal legislation.

Such radical body modifications can be broadly described as the alteration of someone’s appearance in a way that does not accord with cultural ideas of the normal and the natural. It includes: piercing (including of the genitals and nipples),³⁴ scarification (cutting to produce scar tissue), tongue splitting, branding (using heated steel or dry ice), braiding (cutting adjacent strips of skin, braiding them together and reattaching them), beading/three dimensional body art, (where the skin is slit and stainless steel beads or other jewellery are implanted beneath the skin), 3D implants (including Teflon or coral horns, stars and ridges and in one case metal screws implanted in the scalp enabling the attachment of metal points to create a metal Mohawk) and radical appearance-altering surgery.³⁵ “Stalking Cat”, for instance, has had several operations to make his features more cat-like: he has had his lips surgically altered to produce a feline cleft; tiger stripe tattoos cover his face and body, he has transdermal implants to allow him to attach whiskers to his face, and his nose and ears have been remodelled along the lines of those of a cat.³⁶

³³ Cassandra Aspinall, ‘Do I Make You Uncomfortable? Reflections on Using Surgery to Reduce the Distress of Others’ in Erik Parsens (ed), *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (2006)

³⁴ Ear piercing is probably not considered radical. However, eyebrow, nose and tongue piercing are borderline.

³⁵ Norton, Q, 2006, “Body Artists Customize Your Flesh” *Wired* (August) and Polymorph, <<http://www.poly-morph.com.au/>> (last accessed 12 August 2007).

³⁶ Stalking Cat, <<http://www.stalkingcat.net/>> (last accessed 8 August 2007)

There are restrictions at common law that limit the provision of consent to some forms of bodily harm; however the range of activities caught by these cases is controversial and ill-defined.³⁷

The way somatic body alteration and modification is regulated by law and medicine in Australia generally reflects a commitment to an ideology of individual choice. What is interesting is where the limits of personal choice are drawn.

There are few direct regulatory controls on the types of body modification allowed. State legislation in each Australian jurisdiction prohibits the practice (variously defined) of female genital mutilation (FGM).³⁸ In all these jurisdictions the legislation prohibits FGM even on consenting adult women. There are noted exceptions. In the NSW legislation the section does not extend to transgender surgery and surgery necessary for the health of the person. It is unclear whether the practice of labiaplasty, involving cosmetic alteration of the labia, would fall within the exception of necessary for the health of the person particularly as health is specifically limited by the Act to “matters relevant to medical welfare” (*Crimes Act 1900* (NSW) s 45(4)). Nevertheless labiaplasty is commercially available in NSW.

Many activities of body modification may constitute, prima facie, criminal assault by the artist or surgeon, or expose such a person to civil liability, in the form of the tort of battery. Nevertheless it is rare for the criminal law to be invoked to resolve a medical treatment case.³⁹ Instead, concerns as to the availability of a defence of consent for criminal liability usually arise in factual scenarios involving the intentional infliction of physical harm, characterised as outside of the medical arena. For example, in the case of *R v. Brown*⁴⁰, the House of Lords made it clear that certain extreme sado-masochistic acts will not be defensible on the grounds of consent. The courts in Australia⁴¹ have not yet been asked to rule on the commercial activities of tattooing and piercing, but in the English case of *Wilson*, the Court noted that three of the Law Lords in *Brown* considered tattooing a lawful activity, where consent was present, and so reasoned from this, that as the husband’s act of branding the wife’s buttocks was “[no] more dangerous or painful than tattooing”, consent was a legitimate defence for the husband.⁴²

³⁷ see, for example, *R v. Brown* [1994] 1 AC 212; but contrast *R v. Wilson* [1997] QB 47

³⁸ *Crimes Act 1900* (ACT) s 74; *Crimes Act 1900* (NSW) s 45; *Criminal Code Act* (NT) s 186B, Sch 1; *Criminal Code Act 1899* (Qld) s 323A(1), Sch1; *Criminal Law Consolidation Act 1935* (SA) s 33A; *Criminal Code Act 1924* (Tas) s 178A, Sch1; *Criminal Code Act Compilation Act 1913* (WA) s 306, Sch 1.

³⁹ In his dissenting judgment in *Brown* [1994] 1 AC 212, Lord Mustill considered “proper medical treatment, for which... consent is a prerequisite... [is] in a category of its own” (my emphasis): at 266.

⁴⁰ [1994] 1 AC 212

⁴¹ For a thorough analysis of the laws of England and Australia as they relate to consent to infliction of injury upon the person consenting see Freckleton, I, 1994, “Masochism, Self-Mutilation and the Limits of Consent” 2 *Journal of Law and Medicine* 48. This analysis, though written before *Wilson*, provides an important contextual basis for any speculation about how these issues might be decided in the future.

⁴² See *R v. Brown* [1994] 1 AC 50 per Russell LJ (delivering the judgment on behalf of the Court).

Other regulation of cosmetic and other body modification tends to be in the form of health administration laws,⁴³ medical practice guidelines,⁴⁴ infection control⁴⁵ and laws protecting minors.⁴⁶

While positive genetic modifications⁴⁷ and genetic testing and selection technologies are not generally included in discussions about the appropriateness of constraining other body modification practices, such as those that form part of the panoply of cosmetic, reconstructive, and therapeutic body alterations, it is important to ask why it is that genetic modifications are more highly controlled and regulated than other body modification technologies. So why is genetic testing either to select in favour of or against disability highly regulated and inheritable genetic modification prohibited⁴⁸ whereas cosmetic alteration to achieve desired bodies is not?

On one level the answer is simple; genetic selection can have an intergenerational impact.

To leave it at this would be to accept that body modifications other than inheritable genetic modifications do not have an intergenerational impact. If, however, we see body modification such as cosmetic surgery as part of the regulation of social life, indeed as “technologies of the self”, in the same way as genetic technologies, then we can also map out the ways in which they instruct us in which human traits are more desirable than others, and what to aspire to in ourselves and our kin.

Virginia Blum, for instance, writing about her own experience as a sixteen-year-old, describes how, like many of her friends, she was taken by her mother to have cosmetic surgery to deemphasise her “Jewish nose”. She says: “Why did my mother take me to the plastic surgeon... She wasn’t atypical. Many of my friends were taken by their mothers for cosmetic surgery to their noses.”⁴⁹

Kennedy, too, argues that

cosmetic surgery offers an opportunity not to be beautiful, but to be normal. The concept of “passing” is a central trope within the discourse of cosmetic and plastic surgery. Thus, in contrast to stereotypical perceptions, the project is not

⁴³ see for example the *Public Health Act 1991* (NSW) ss 10AC-10AI

⁴⁴ See for example *Medical Practice Act 1992* (NSW),

⁴⁵ See for example *Public Health (Skin Penetration) Regulation 2000* (NSW))

⁴⁶ See for example *Children and Young Persons (Care and Protection) Act 1998* (NSW), s 230

⁴⁷ Here I am referring to all the technologies that have been anticipated as enabling the possibility of creating new kinds of genetically changed human beings from clones and chimeras to designer babies.

⁴⁸ See generally the *Prohibition of Human Cloning for Reproduction Act* (Cth.) 2002

⁴⁹ Blum, V, 2003, *Flesh Wounds: The Culture of Cosmetic Surgery*, University of California Press, Berkeley at p 9

to become remarkable, but rather to appear unremarkable, to go unremarked, to avoid notice, censure, visibility and critical scrutiny.¹

In this way cosmetic surgery, not unlike its genetic counterpart, offers the possibility of overcoming the destiny foretold in one's genes.

Hogle too argues that “[c]osmetic surgery... becomes a technology through which the body is normalized and homogenized as much as enhanced”². Ideas of the normal and the natural body are ironically given reality through the literal construction of certain traits which are desirable. To illustrate this point, Hogle refers to Marilyn Strathern's discussion of the “way produced goods are designed for selling as much as for use”³. Strathern says: “To select an apple for its applesness is to discriminate between those which conform more or less to cultural expectations about what the natural apple should be”⁴. Mapping this across bodies, cultural expectations about what the natural body should resemble leads to the acquisition of body alterations in the pursuit of what nature “should” have given us. In this way the impact is not dissimilar from selecting genes for their perfectibility of the self or indeed selecting out imperfect genes. Yet federal legislation in Australia⁵ directly limits our ability to make the choice to access one form of modification, while not impinging on our ability to access the other.

Here again perhaps the reason is obvious – one would have us altering our children, the other has us altering ourselves. However in Australia, in most instances parental consent is all that is required for body-altering surgery where it is considered medical treatment. Putting aside those circumstances where minors are themselves legally competent to consent to medical treatment because they understand the nature and consequences of the treatment⁶ at common law, parents have the power to consent to or refuse medical treatment and they are assumed to do so in the child's best interests.⁷ However, that power to consent can be overridden by the courts and there are a number of medical procedures for which parental consent is not sufficient. For example, in the case of sterilisation of intellectually disabled girls the Family Court of Australia, under its welfare jurisdiction, has determined that the authorisation of a court is required before a child can be sterilised when it is an intervention that is not for the purpose of curing malfunction or

¹ Kennedy, A, 2007, *Non-Therapeutic Body Modification and the Law* (unpublished manuscript, on file with the author) at p. 31

² Hogle, L, 2005, “Enhancement Technologies and the Body” 34 *Annual Review of Anthropology* 695 at 704.

³ Ibid at p. 703

⁴ Strathern in Hogle ibid at 703

⁵ *Prohibition of Human Cloning for Reproduction Act* (Cth.) 2002, and *Research Involving Human Embryos Act* (Cth.) 2002

⁶ *Department of Health and Community Services (NT) v JWB (Marion's Case)* (1992) 175 CLR 218 at 237-238 and *Minors (Property and Contracts) Act* 1970 (NSW) s 49

⁷ *Family Law Act* 1975 (Cth) s 61B, 61C(1); *Gillick v West Norfolk Area Health Authority* [1986] AC 112; *Department of Health and Community Services (NT) v JWB (Marion's case)* (1992) 175 CLR 218).

disease.⁸ In *Re Alex: Hormonal Treatment for Gender Identity Dysphoria*,⁹ where sex reassignment on a 14-year-old was being requested, the Family Court followed *Marion* and concluded that this was not the treatment of a malfunction or disease and was the kind of treatment for which court authorisation was necessary. Other kinds of procedures that might fall into the category for which court authorisation is required have not been exhaustively set down. The NSW Law Reform Commission, in its Issues Paper *Minors Consent to Medical Treatment* suggested that “a lobotomy is one such medical procedure that could be argued to come within the category of a special case”¹⁰ and the Family Court has indicated that court authorisation might also be required for treatment involving the use of radiation and pharmaceuticals with irreversible effects.¹¹

Depending on the State jurisdiction involved, tattooing and piercing of a minor is either prohibited, prohibited without parental consent or prohibited without parental consent where it involves the genitals. There do not, however, appear to be legislative limits on parental capacity to consent to ordinary cosmetic procedures undertaken by a medical practitioner, such as rhinoplasty, apart from the general requirement that the best interests of the child are paramount.¹² In most instances, therefore, parental consent is key and as we can infer from the anecdote provided by Blum, parental pressure to conform to particular norms is not without precedent. Indeed, we might reasonably surmise that the kind of pressure applied in Blum’s case has broader application and, though beyond the scope of this paper, this is an area worthy of further exploration.

Our approach to the body through body modification technologies, whether they be cosmetic and aesthetic, reconstructive and therapeutic, or aimed at enhancement of normal or disabled bodies, is an approach to the body as a project, as something that can be molded and changed, perfected towards particular cultural ends.

Arthur Frank, adopting the language of a Vogue magazine story on toe tailoring for designer shoes, describes the use of cosmetic surgery as “technoluxe”,¹³ a consequence of neoliberal

⁸ *Marion’s Case*. See also in NSW the *Children and Young Persons (Care and Protection) Act 1998*, s 175 which requires authorisation by the Guardianship Tribunal of NSW for “special medical treatment” on a child which is defined as including rendering a person permanently infertile not for remediation of a life-threatening condition amongst other things. See also the *Children and Young Persons (Care and Protection) Regulation 2000* r 15.

⁹ [2004] Fam CA 297,

¹⁰ New South Wales Law Reform Commission, 2004, *Minors’ Consent to Medical Treatment*, Issues Paper no. 24, NSWLRC, 4.15

¹¹ (*Re Alex: Hormonal Treatment for Gender Identity Dysphoria* [2004] Fam CA 297 at para 178 (Nicholson CJ)).

¹² *Marion’s Case*

¹³ Frank, A, 2003, “Connecting Body Parts: Technoluxe, Surgical Shapings, and Bioethics” in London School of Economics, *Papers Presented at the “Vital Politics” Conference* (London, September) at 71.

medicine that facilitates people's response to their bodies as projects. The toe is designed to fit the shoe and not the reverse.

However, while not all surgical interventions can be described as technoluxe, he goes on to describe surgical intervention as one of a series of available choices for "fixing some part of one's life"¹⁴. Moving on from toe tailoring, to limb lengthening for achondroplasia (dwarfism), Frank has previously described the way in which "[a]chondroplasia is seen as another problem requiring a medical solution, which is recognised as an available choice: thus being achondroplastic becomes, curiously, a sort of choice."¹⁵

Being able to design ourselves might be characterised as the ultimate evolutionary achievement. The issue then is why do we regulate genetic testing technologies such as PGD with vigour and why do we draw the line at genetic modifications. Why do these erect a barrier to which we say this far and no further?

The idea of the natural and the normal or the essential is, as suggested above, a manifestation of what is culturally understood; the apple that looks like an apple. In the context of both genetic testing and the prohibition of inheritable genetic modification and the facilitation of cosmetic, therapeutic and reconstructive body modification, it is clear that one of the key aims is to facilitate the choice to be "normal". In this context, what is understood as normal is based on what is perceived to be necessary for a properly functioning body. As Hogle puts it, "notions of sufficiency change as expectations of what it takes to sustain life changes in various political, economic, and social contexts and across time periods"¹⁶ For instance she notes :

What might enhancement mean in a poor society where an artificial limb specially designed for working in rice fields or a bicycle designed to provide mobility means the difference in a person's ability to make a living? Compare these situations with a wealthy society, where an amputee might own multiple artificial limbs with sophisticated bioengineering designed for various sports.¹⁷

A properly functioning body then, is one that is moulded (enhanced) to fit the requirements of the social context in which it operates. Other bodies that don't fit are deficient.

Empirical research conducted by Rhian Parker on Australian cosmetic surgeons and their patients bears this out. In her research examining 19 doctors who carry out cosmetic surgery and 32 women who had undergone such surgery, she found that

¹⁴ Ibid at p. 78

¹⁵ Ibid at p. 8

¹⁶ Supra n2 at p 712

¹⁷ Supra n2 at p. 701

women's rationale centred on wanting to fit in with what they saw as normal in their environment. Doctors...described women's need for cosmetic surgery as a psychological intervention achieved through physical change.¹⁸

What seems to be crucial in answering my initial question is not what techniques are prohibited and what are allowed, but rather whose body is the subject of modification and what do they want to become. Becoming "normal" is valorised and encouraged, whether by means of genetic *deselection*, cosmetic alteration or therapeutic modification. This is why there are very few legislative limits on cosmetic, as opposed to radical, body alteration. As noted earlier, those instances where the legislature has been motivated to act tend to be where non-normative body modification practices are involved. For instance, tattooing and piercing of a minor is subject to some limits and even taken out of the hands of the parents in some states, whereas cosmetic surgery on a minor is not so regulated. Becoming disabled is also discouraged as we have seen, and prohibited through regulation and guidelines that prohibit the use of PGD to select in favour of a disability. At the same time, deselection of genetic traits considered defects is allowed. Finally, some practices which have overtones of sexual deviance are criminalised both at the somatic and genetic level – sadomasochistic practices and creation of hybrids for example.¹⁹

By contrasting the regulatory regimes around genetic testing for disability and the selection and deselection of non-normative disabled bodies and the regulation of radical, cosmetic, therapeutic and enhancing body modifications, it is clear that the boundaries between these procedures are fluid. Certain forms of bodily interventions and constructions are left to the domain of individual choice, while others are considered appropriate for state regulation and prohibition. The defining factors in these determinations are culturally and ideologically constructed ideas of the natural, which, unexamined, become the normal.

¹⁸ Parker, R, 2007, "Cosmetic Surgery and the Construction of the "Normal" Female Body" presented at the feminism and the Body Conference, Kings College London, unpublished manuscript on file with the author

¹⁹ See *R v. Brown* [1994] 1 AC 50 and the Prohibition of Human Cloning for Reproduction Act (Cth.) 2002

Commentary by Geoffrey Reaume

Everyone who is reading this should recall the story of Ashley X and the barbaric treatment inflicted upon her at the behest of her parents and doctors. When this story broke in the news media in early 2007, Ashley was nine years old. She is a person with developmental disabilities, has static encephalopathy (severe brain damage) and is dependent on others for her daily care. Ashley underwent surgery, was sterilized and had hormonal “treatment” from the age of six to prevent her from physically maturing into a woman. This medical “treatment”, which was approved by a hospital ethics board in Seattle, Washington, is further evidence, as if the world needs it, of the impact of an engrained eugenic agenda towards people with disabilities.¹²⁷

Isabel Karpin’s presentation which preceded this paper shows how this agenda continues unabated in other ways. As an historian, my remarks will be focused on the historical connections to this topic and then end with some comments on this contemporary debate that Isabel’s paper highlights. As Isabel Karpin explained in her paper, talking about people with disabilities as having socially undesirable physical traits is something which has many precedents in disability history and which has had a terrible impact on people with disabilities.

How many times have the physical traits of people with disabilities been held up to contempt, scorn, ridicule, voyeurism and general disdain in the past? Certainly the point that Isabel mentions about the nature of a “serious” disability is something that has been the focus of previous policy makers in the history of eugenics.

The message has been clear: people with disabilities do not have “normal” bodies and minds that non-disabled people do – they aren’t part of the community, at least not to the extent the so-called “able-bodied” are. This has “justified” some of the most barbaric interventions towards people with disabilities in history with the 20th century, a century full of more horror stories than just about any other period in the long, wretched history of persecution, segregation, incarceration, sterilization and outright murder in the history of disability.

When discussing issues around **negative enhancement**, the link to eugenics is therefore obvious. It is helpful to remember that people used to debate the relative merits of what was called **negative eugenics** versus **positive eugenics**. So when thinking of terms such as

¹²⁷ Carl Meyer, “Ethics Debate”, *Excalibur*, January 17, 2007, p. 3. There are numerous articles on the internet which can be located by typing in “Ashley X Treatment.”

“negative enhancement” we can draw a straight line from earlier periods of hate and prejudice towards people with disabilities, including right here in Canada.¹²⁸

Eugenics means “improvement of the race” and was explicitly race- and class- based, filled with contempt for people who weren’t white, of European descent or of low class. **Negative eugenics** was intended to keep people who were labeled as disabled from procreating, most notably through sterilization, as was the case in Alberta (1927-72) and BC (1933-72), as well as in over 30 US states and elsewhere. **Positive eugenics** was intended to encourage people considered “genetically fit” to reproduce to “improve the human race”. These ideas were promoted by Francis Galton (1822-1911) in the late 19th century. Galton and his followers wanted an elite, meretricious society and through their advocating these ideas found their way into public policies during the 20th century.¹²⁹

While eliminating people on the basis of class or race is not part of the official discourse around de-selecting people, we know it exists around gender, and people are properly horrified by stories of how girls have been eliminated through selective abortion in parts of India, for example.¹³⁰ Widespread expression of horror where de-selecting for people with disabilities is concerned has yet to be loudly heard outside of disability rights circles and apart from some religious-based objections, however.

Today, part of the dreadful eugenic legacy is being challenged by people with disabilities who accentuate difference as being socially desirable, rather than agreeing with those who have argued that people with disabilities should be wiped out, or at least significantly curtailed from coming into existence in the first place. Isabel Karpin’s discussion of how “negative enhancement” regarding the lesbian couple, Sharon Duchesneau and Candy McCullough, who are deaf and who wanted a deaf sperm donor to increase their chances of having a deaf child, resonates from a historical context in which so-called “negative characteristics” previously served another purpose deemed socially useful – entertainment for non-disabled people, most notoriously in so-called “freak shows.”

¹²⁸ P.M.H Mazumdar, *Eugenics, Human Genetics and Human Failings: The Eugenics Society, its Sources and its Critics in Britain* (London: Routledge, 1992); Michael Burleigh, *Death and Deliverance: 'Euthanasia' in Germany, 1900-1945* (Cambridge: Cambridge University Press, 1994); Henry Friedlander, “The Exclusion and Murder of the Disabled”, in *Social Outsiders in Nazi Germany*, eds., R. Gellately and N. Stoltzfus. Princeton: Princeton University Press, 2001: 145-164.

¹²⁹ Angus McLaren, *Our Own Master Race: Eugenics in Canada: 1885-1945* (Toronto: McLelland and Stewart, 1990); Deborah C. Park and John P. Radford, “From the Case Files: Reconstructing a History of Involuntary Sterilisation”, *Disability and Society* 13:3 (1998): 317-342; Jana Grekul, Harvey Krahn and Dave Odynak. 2004. “Sterilizing the “Feeble-Minded: Eugenics in Alberta, 1929-1972”. *Journal of Historical Sociology*. December. Vol. 17. No. 4. 358-384.

¹³⁰ Neil Samson Katz, “Abortion in India: Selecting by Gender”, *Washington Post*, May 20, 2006, p. B09

As Robert Bogdan and Rosemarie Garland Thompson have detailed, people with physical and mental disabilities have been held up to gawk at precisely to “enhance” and emphasize their characteristics that are viewed as negative and repulsive.¹³¹ This was done to make the most negative traits of people with disabilities into some kind of public statement of what people were not supposed to look like.

The couple who are deaf are doing the precise opposite of this – celebrating a person with a disability as someone of value. Thus “negative enhancement” is disability made positive by the experts who know these “conditions” best – people with disabilities themselves. Note that many deaf people do not consider themselves disabled and would object to my identifying them as such.¹³² I am using this term in regard to deaf people only because that is how most of society views them – as disabled – but not to deny their self-definition.

More recently, “negative enhancement” has also been challenged by people with physical disabilities to promote physical disability in a more attractive manner, complete with sex appeal. Examples of this can be seen on the covers of “Caliper” magazine over many years.¹³³ However, this has been done more for the target audience of people with disabilities themselves and those who work with them. It is not usually intended for the general population who are not themselves disabled.

These examples go to show that at least in recent disability history, physical disability has been promoted as “normal” and something to value and find good looking. You can be disabled and enjoy life, in other words. It also ties in with Isabel’s point that concepts such as disability and normality are fluid and change over time. Sixty years ago, who would have considered a person with a disability in a wheelchair as someone who could engage in rafting, skiing and racing activities? Part of it has also been the general change in social attitudes, at least towards physical disabilities and their place in society. Part of this change also has to do with changing technology and how it has been used by people with disabilities to advance their place in society.

Ironically, technological developments that have expanded the choices in life for people with physical disabilities in certain areas – more efficient wheelchairs most obviously – have also led on the other hand to technology that restricts how many people with disabilities are being carried to term by expectant mothers. To be sure, these depictions can also be critiqued as portraying

¹³¹ Robert Bogdan, *Freak show: Presenting human oddities for amusement and profit* (Chicago: University of Chicago Press, 1988); Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997).

¹³² Lois Bragg, ed., *Deaf World: A Historical Reader and Primary Sourcebook* (New York: New York University Press, 2001), readings in Part V.

¹³³ *Caliper* was the national magazine of the Canadian Paraplegic Association from 1946-1999. Since 1999, the title of the magazine is *Total Access*.

people with disabilities as “super-crips” who can do anything just by persevering. This is the old “overcoming disability” approach which has been critiqued by disability studies scholars and activists, such as Simi Linton.¹³⁴

You could say that the crude and cruel reference to “deformer babies”, a term coined by the online magazine “Slate” in which the popular press have disparaged the idea that people with disabilities want to have a baby like themselves, has its opposite comparison in regard to people with disabilities who enhance their physical disabilities in a way that accentuates their abilities as a person with a disability.¹³⁵

When reading Isabel’s paper one can’t help but wonder how different might be the attitudes and choices of people who perceive disability in a negative light only, if they re-considered their (our) own prejudices by looking at what people *can* do rather than what they *can’t* do and what they contribute as members of society. It would also be worthwhile to educate people about what we envision as what is, or is not, an ideal society to live in, such as one where babies with disabilities are not welcome – clearly such a society would be a nightmare for people with disabilities, or anyone who truly values the worth of human beings in all our diversity, including people with disabilities from birth to death. We know where that has led in the past, and people with disabilities are entirely justified in fearing where it could lead in the future.

To get back to the point that Isabel Karpin makes about problematizing the difference between “disability” and “serious” or “severe” disability, this is an issue that comes up frequently in my own area of experience and research – mad people’s history. I cannot tell you how many times I and others in the psychiatric survivor community have heard people draw a supposed comparison between people with what is described as having chronic mental health problems and people who are regarded as “high-functioning” mad people. The line being drawn is of course supposedly between people who are in hospital for longer periods than those who have been or are now in hospitals for shorter periods. This is also meant to claim that people with a “chronic” condition are more likely to be in need of some long-term care. Yet it neglects to consider the fact that people move between these categories in ways that are not so easy to separate. By this I mean that people experience madness at different times of their lives and for a health care professional to decide whether someone is supposedly among the “high functioning” ignores the fact that humans experience this distress at different times and in different ways. It also ignores the fact that even the most privileged mad people who supposedly “recover” their sanity, endure mental

¹³⁴ Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998, p. 17-22.

¹³⁵ This offensive term has been repeated elsewhere in the media, such as: Associated Press, “Designer babies with made-to-order defects? Prenatal testing creates controversial options for parents with disabilities”, December 21, 2006.

anguish afterwards – Clifford Beers for example, the first mad best-selling author in North America with his 1908 book “A Mind That Found Itself” and who went on to found mental health committees, went mad again eventually and died in an insane asylum in 1943.¹³⁶ In reality, recovery can be elusive and even not a worthwhile goal in itself in a world which should accept madness as a valued part of the human condition.¹³⁷

Terminology regarding “high-functioning” and “chronic” mad people is also very patronizing to say the least, as it suggests that someone who is “high-functioning” is a better ideal of a human being than someone who is not, and ignores the manifold abilities of people who come under the “chronic mentally ill” label.

When considering the point in Isabel’s paper regarding opting in favour of genetic transmission of a potentially disabling trait, we also need to remember the political and legal pitfalls that this can cause for people today. For example, the claim by some researchers that there is a gene for schizophrenia will inevitably lead to the implication that it should be identified and eliminated.¹³⁸ Of course, this claim is absurd as there is no gene for schizophrenia, but let’s say there was – what would happen if two people who had been diagnosed with schizophrenia decided to have children with the intention of increasing the chances of having a child with this supposedly genetic (though unproven) condition?

The public debate over the couple who wanted to give birth to a baby who was deaf like they were is instructive to consider if we think of how this might relate to people diagnosed with schizophrenia. How would the world react if they knew of a couple who deliberately set out to have a mad baby like them? Or should I say, like us – since I am considering one of the high-functioning people with a psychiatric history.

As anyone who has ever been in a mental institution for any length of time knows, there is a lot of consensual sex between patients, both homosexual and heterosexual sex. Thus males and females with the label of schizophrenia or other diagnoses, both in mental health facilities and outside in the community, have most certainly had children, though whether they planned on it is impossible to say in most cases. Nevertheless, challenging this notion further in which a person with a legally recognized psychiatric disability wanted to have a mad baby on the basis that mad

¹³⁶ Clifford Beers, *A Mind That Found Itself: An Autobiography* (New York: Doubleday, 1908 & 1953); Norman Dain, *Clifford W. Beers, Advocate for the Insane* (Pittsburgh: University of Pittsburgh Press, 1981).

¹³⁷ There are numerous accounts, far more than can be cited here, in which mad people re-claim madness from pathological interpretations. A good start from a Canadian perspective is, Bonnie Burstow and Don Weitz, eds., *Shrink Resistant: The Struggle Against Psychiatry in Canada* (Vancouver, New Star, 1988); Irit Shimrat, *Call Me Crazy: Stories from the Mad Movement* (Vancouver: Press Gang, 1997).

¹³⁸ Critiques of the supposed “scientific” basis of schizophrenia include: Mary Boyle, *Schizophrenia: A Scientific Delusion?* 2nd Edition (London: Routledge, 2002); Richard P. Bentall, *Madness Explained: Psychosis and Human Nature* (London: Penguin, 2003).

people have brought, and continue to bring, much good to the world and to each other's lives, would also challenge this notion that somehow having a disability is bad or something to be avoided. Certainly it would create a world in which all the talk about madness equated with badness would be more directly challenged, just as it would challenge the age-old efforts to de-select people with disabilities through genetic counseling. There is a marvelous button that was distributed at Mad Pride events in Toronto in 2007 which gives eloquent expression to this most basic human desire in the context of psychiatric survivor sexuality: "Have mad sex – make lunatic babies".

So in this sense, promoting negative enhancement as a positive social good for people with disabilities as being other than "genetically abnormal" would be a force for potential positive good – both for loving parents who accepted their mad baby as he or she is and for society in general whose prejudices were directly challenged in the most intimate part of family planning.

Having said all this, it leads back to my concern that making this choice will also buy into the age-old stereotypes that people with disabilities really are genetically determined by their forebears, something which Francis Galton and his followers were only too happy to promote, leading to disastrous social consequences in the 20th century. This idea that there can be something like a schizophrenia gene which can be identified is offensive to many people that I know of who have had this label attached to them, never mind the fact that a gene for schizophrenia has never been found after a century of scientific investigation into locating this elusive biological bombshell.

Isabel's essay makes the point regarding how prenatal screening of children for disabilities is stigmatizing and harmful for people with disabilities in the world today. This is based on the fact that this practice clearly implies that their lives aren't worth coming into being, not like so-called able-bodied people, many of whom will develop disabilities in their life – but that is more acceptable since it is part of later life. Thus pre-natal screening carries on an "acceptable" notion of prejudice towards people with disabilities just as the ugly history of eugenics did the same beginning in the late 19th century. It is a similar set of attitudes now carried on through more technologically sophisticated and socially "acceptable" methods, but the aim is the same – to get rid of as many people with disabilities as possible with the result that the world will be better off. But of course we know that isn't true – don't we?

De-selecting people on the basis of real or supposed genetic traits as being disabled will not make the world a better place, it never has and it never will. After all, most of the horrible acts in history have been committed by so-called "normal people" – Hitler and his followers being the

most obvious.¹³⁹ Instead, de-selecting people with disabilities will make the world a colder, more calculating place where difference based on physical or mental disability is less and less tolerated such that it becomes the norm for genetic counselors to advise parents to eliminate their potentially disabled offspring while he or she is still in the mother's womb.

Isabel asks the question, after noting Roxanne Mykitiuk's concern about the impact of de-selecting genetic conditions that are known to cause a disability, of whether **selecting in favour of disability** will help to reduce these concerns by creating a "niche group for which disability is in fact socially desirable."

While I don't pretend to have a clear-cut answer to this question, I can't help but think that, no, it won't solve these problems of prejudice at all. Rather, people who want to continue to eliminate potential children with disabilities will not be affected by this change in emphasis by a select group of people who view disability as a positive social good. It will more likely be people who have experienced disabilities who opt for this positive disability selection choice in the first place since they are more inclined to think about wanting such children in the first place.

Those potential parents who de-select a fetus based on a so-called "genetic abnormality" will more likely be individuals who are able-bodied and whose views of disability are formed either by ignorance or first-hand experience in which such a child is seen as a burden by their care-givers. Indeed, if I may go back to where I started – the eugenic operation on the nine-year-old girl known as Ashley X; rather than this news being a forum for the widespread horror which it deserves, two recent stories indicate to me that the admittedly unscientific, widespread acceptance of this "treatment" is more often viewed as appropriate by the non-disabled population.

This is suggested in the fact that *Globe and Mail* columnist Andre Picard, who wrote a column on January 11, 2007 condemning what happened to Ashley, said that he received more angry emails

¹³⁹ Over the years, it has been common for me to hear people express the view that Hitler was insane and this therefore explains his crimes, a view which ignores two significant points: 1) There is no evidence from the historical record that he was mad (save for the last few months of his life when his world was literally crashing down around him when Hitler did become more mentally disturbed, but only long after he had implemented his genocidal policies); nor were his millions of followers gripped by mass madness, including the men and women who engaged in horrific atrocities in Nazi-occupied Europe. It is an inconvenient fact for people who wish to have their history told in simple tales of "mad acts" supposedly explaining "bad acts", that the most horrific of atrocities have indeed been committed by "normal people", that is, people who were not insane, with the atrocities of the Third Reich being a sickening example. Of course, there are many more examples ranging from the history of slavery to the history of imperialism and colonialism where prim and proper aristocrats, well-healed establishment politicians and financiers initiated and bankrolled the destruction of millions of lives around the globe for their own rapacious desires. 2) Hitler is the single greatest mass-murderer of mad people and people with disabilities. He held such people in the utmost contempt. To ascribe to Hitler the qualities of a madman, while at the same time knowing that he was the bloodiest mass-murderer of mad people in history, is an insult to his victims.

than supportive emails in response to his column.¹⁴⁰ Another story that appeared at the same time in the Guardian reported that parents of children with disabilities similar to Ashley's are interested in finding out if they can access this same treatment for their child.¹⁴¹

Sadly, selecting in favour of disability is not likely to make much difference in alleviating the barriers and discrimination faced by people with disabilities from people who are unsympathetic to the arguments of the disabled community against pre-natal selection in the first place. This will only come about by wider systemic and attitudinal changes among those people who would opt to de-select given the choice to do so.

¹⁴⁰ Andre Picard, "It's wrong to keep disabled girl as an 'angel'", *Globe and Mail*, January 11, 2007; email communication from Andre Picard at 8:32 PM, January 11, 2007 after I sent him a copy of my letter supporting his column (the letter was not published).

¹⁴¹ *Guardian Weekly*, Jan. 12-18, 2007, p. 2 "The roundup – Parents seek Ashley treatment".