28 Eric Parens and Adrienne Asch, *Prenatal Testing and Disability Rights.* Washington, DC: Georgetown University Press (2000).

29 I phrase the question in this way because in the present discussion I want to avoid trying to disentangle whether the question is really about benefit to the individual, or to the mother, family, or society, or a mixture of all of those.

30 See Françoise Baylis and Jason Scott Robert, Radical rupture: exploring biological sequelae of volitional inheritable genetic modification (Chapter 7, this volume); Christoph Rehmann-Sutter, Controlling bodies and creating monsters: popular perceptions of genetic modifications (Chapter 4, this volume).

31 Noam J. Zohar, Prospects for "genetic therapy" – can a person benefit from being altered? *Bioethics* 5 (1991), 275–7; Robert Elliott, Identity and the ethics of gene therapy, *Bioethics* 7 (1993), 27–40.

32 Hans-Jakob Müller, Treatment of human disorders with gene therapy and its consequences for the human gene pool. In: Klaus Wöhrmann and Jürgen Tomiuk (eds.), *Transgenic Organisms.* Basel: Birkhäuser Verlag (1993), 229–44.

33 See Adrienne Asch, Reproductive technology and disability. In: Sherrill Cohen and Nadine Taub (eds.), *Reproductive Laws for the 1990s.* Clifton, NJ: Humana Press (1988), 69–124; Deborah Kaplan, Prenatal screening and its impact on persons with disabilities, *Fetal Diagnosis and Therapy* 8 (1993), 64–9; Nancy Press, Assessing the expressivist character of prenatal testing; the choices made or the choices made available? In: Erik Parens and Adrienne Asch (eds.), *Prenatal Testing and Disability Rights.* Washington, DC: Georgetown University (2000), 214–33.

34 See Eva Feder Kittay with Leo Kittay, On the expressivity and ethics of selective abortion for disability: conversations with my son. In: Erik Parens and Adrienne Asch (eds.), *Prenatal Testing and Disability Rights.* Washington, DC: Georgetown University (2000), 165–95; Allan Buchanan, Choosing who will be disabled: genetic intervention and the morality of inclusion, *Social Philosophy and Policy* 13 (1996), 18–46; James Lindemann Nelson, Prenatal diagnosis, personal identity, and disability, *Kennedy Institute of Ethics Journal* 10 (2000), 213–28; James Lindemann Nelson, The meaning of the act: reflections on the expressivist force of reproductive decision making and policies. In: Erik Parens and Adrienne Asch (eds.), *Prenatal Testing and Disability Rights.* Washington, DC: Georgetown University (2000), 196–213.

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36 Theresa M. Marteau and Harriet Drake, Attributions for disability: the influence of genetic screening, *Social Science and Medicine* 40 (1995), 1127–32; Rosemarie Tong, Traditional and feminist bioethical perspectives on gene transfer: is inheritable genetic modification really *the* problem? (Chapter 9, this volume).

37 For more detailed discussion, see Jackie Leach Scully and Christoph Rehmann-Sutter, When norms normalize: the case of genetic enhancement, *Human Gene Therapy* 12 (2001), 87–96.

11

Regulating inheritable genetic modification, or policing the fertile scientific imagination? A feminist legal response

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11.1 Introduction

The past few years have seen an explosion of legislative activity around developments in genetics and assisted reproduction. In this chapter we examine recently passed legislation in Australia and Canada in the area of genetic modification technologies and reproductive genetics. We demonstrate that legislative control in this area has a twofold purpose. Less controversially it is aimed at providing limits to scientific innovation for the purpose of ensuring safe and ethical research and experimentation. More controversially it is concerned with what should be the proper "nature of reproduction," namely, how it happens (sexually), between whom (a man and a woman, both human), in what kinds of relationships (heterosexual), such that progeny, the product of reproduction, inherit the blood/genes (bodily substances) of only two biological progenitors. It is to this latter purpose that we turn our attention in this chapter, analyzing the role of law in limiting, determining, and constituting reproductive possibilities in an age of genetic modification. Our focus is on new and potential technologies that enable inheritable genetic modification (IGM) of humans, but we read these, and their legislative limits, in the context in which they appear medically and legally, namely alongside other assisted reproductive technologies (ARTs) such as reproductive cloning. We ask what is at stake in the new legislative limits, who benefits, who loses, and what kinds of humans are we left with?

11.2 The nature of reproduction

Beginning in the 1970s, it became routine to screen pregnant women in high-risk groups using blood tests, sonograms, and other, more invasive techniques. Amniocentesis and chorionic villus sampling (CVS) are now used to detect fetuses with anomalies, and therapeutic abortions are offered to women whose fetuses express chromosomal abnormalities. More recently, people have begun to use *in vitro* fertilization (IVF), coupled with preimplantation genetic diagnosis (PGD) and selective abortion. Those who are at a serious risk of passing on an undesired genetic condition have the option of using PGD to identify embryos without the condition for implantation.

IGM techniques represent the next stage in ARTs. Instead of aborting affected fetuses or deciding not to implant those embryos identified as carrying a genetic mutation, it may be possible to prevent the development of an affected fetus through IGM. While this is only one of the many ways in which IGM might be utilized, it is clear that any legislation prohibiting or regulating its use will impact on reproduction. It is no coincidence, therefore, that the only documented instance of human IGM that has occurred so far is in the context of reproduction, namely IVF. Researchers at the Institute of Reproductive Medicine and Science of St Barnabas in New Jersey undertook a controversial procedure known as ooplasmic transplantation. The process, which has led to 30 births, is now known to have resulted in children who have a small quantity of additional mitochondrial DNA not inherited from either parent.[1] We will discuss this case in more detail later in the chapter. Legislation in Australia and Canada has recently made such procedures illegal.[2]

We argue that regulatory discourses around IGM inevitably affect the nature of reproduction. The most common type of IGM is germ-line modification. Germ-line modification epitomizes the connection between reproduction and genetics as it is conventionally understood. It involves the manipulation of genetic material in the germ cells themselves, that is, the reproductive cells of an organism, the sperm, and egg cells. Germ-line modification can also include, in some definitions, the early 8-cell stage embryo which, when genetically altered, will probably develop with that alteration in all its cells including the germ cells. It may also refer to the cells of the embryo that will ultimately develop into the sperm or egg cells. The technique to which germ-line modification is often ethically, socially, and scientifically compared is somatic cell gene transfer (SCGT) which, it is argued, affects only the individual being treated.

The view that somatic cells and germ-line cells are not only distinct but have completely different trajectories is sometimes offered as scientific fact. Somatic cells, it is said, cannot be passed from one generation to another and therefore have a finite life. Germ-line cells, on the other hand, have the potential to be endlessly passed along to future generations. On the basis of this scientific distinction, some ethicists and state regulatory regimes make an ethical distinction between interventions that modify the germ line compared with those that modify somatic cell lines. SCGT is viewed as less problematic since, it is argued, only the person who is the subject of the intervention can hope to benefit from it (or be harmed by it) now and in the future. We suggest, however, that the distinction relies on a particular construction of identity and reproduction that need not be, and should not be, assumed. Take for instance the

example offered by W. French Anderson, an advocate of SCGT. He describes the difference as follows:

> Inserting a gene into somatic cells affects only the patient being treated, similar to when a patient undergoes surgery, takes a medication, or receives a limb prosthesis. However, with germ-line gene therapy (GLGT), a gene is inserted into the DNA of an egg or sperm so that children of the patient will have the inserted gene.[3]

Despite the apparent simplicity of the statement that SCGT affects only the patient being targeted, the kind of therapy that Anderson himself proposes belies it. He intends to cure adenosine deaminase (ADA) deficiency by a direct injection of a retroviral vector carrying a normal copy of the human ADA gene into 13–15-week fetuses. Of course there is no way to "directly" inject a 13–15-week fetus. Rather, injection must occur indirectly through the mother's body.

Clearly, then, at least in the case of *in utero* SCGT, it is nonsense to suggest that only the individual who is being treated is affected.[4] It would be easy, of course, to dismiss this as irrelevant because the essential distinction is at the cellular level. However, this distinction relies on a molecularization of human identity that is not appropriate. In the case of a pregnant woman, there is no separate person until the fetus is born. Up until that time, even though there may be the capacity to identify different cellular components, those components are nevertheless inextricably integrated. The relationship has been described by one of us (IK) as "not-one-but-not-two."[5] Somatic individuals then are not always just that.[6] The erasure of the female body and person in both scientific and legal discourse about genetics is something we find very troubling, particularly when the link is made between genetics and reproduction. We will return to this point in our examination of the legislation in Australia and Canada.

Scientific facts then are themselves disputable. The purported factual distinction between SCGT and IGM is itself founded upon assumptions about the "nature of reproduction." For instance, arguments made by John Harris suggest that were we to permit reproductive cloning, the factual distinction between GLGT and SCGT would be undermined by the capacity to turn those very same somatic cells into germ cells:

> … inserting the mature nucleus of an adult cell into a de-nucleated egg turns cells thus formed into germ-line cells. This has three important effects. First, it effectively eradicates the firm divide between the germ-line and somatic-line nuclei because each adult cell nucleus is, in principle, "translatable" into a germ-line cell nucleus by transferring its nucleus and creating a clone. Secondly, it permits somatic line modifications to human cells to become germ-line modifications … If you … cloned a permanently genetically modified bone marrow cell … the modified genome would be passed to the clone and become part of his or her genome, transmissible to her offspring indefinitely through the germ-line … The third effect is that it shows the oft asserted moral divide between germ-line and somatic-line therapy to be even more ludicrous than was previously supposed.[7]

In an attempt to overcome the limits of this distinction, scientists and others now refer to IGM rather than using the more limited term "germ-line modification." Mark Frankel states, for instance, that IGM "encompasses modifications both of nuclear and of extra-nuclear genomes, and modifications that are inadvertent side effects of other, deliberate genetic interventions (of, for example SCGT)."[8] The moral divide becomes that between heritability and non-heritability, which in turn becomes the basis of a distinction embedded in recent legislation in Australia and Canada.

The purported ethical or moral distinction that has been erected rests on assumptions about the "nature" of reproduction. As we noted at the outset, legislative impulses are also geared towards ensuring that the old parameters of reproduction, so-called "natural reproduction," continue to be mapped across new technological possibilities and provide appropriate limits. 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. Changes that come about by so-called "natural" reproduction are not viewed with the same kind of anxiety as those brought about artificially and with direct intervention.

The idea of natural reproduction itself has shifted, however, with the advent of new technologies. New ARTs, such as IVF and artificial insemination (AI), once considered unnatural and interventionist, have become accepted forms of natural reproduction (in part because they mimic sexual reproduction) although many legislatures have been at pains to ensure that only heterosexual couples use them.[9] Human IGM is the latest source of insecurities about the impact of technology in the realm of reproduction. It has become aligned with transgressive reproductive practices and technologies such as cloning, the creation of human/non-human hybrids, and the creation of chimeras. IGM, like other ARTs, challenges us to rethink the normativity of the established relations of conception, gestation, and *in vivo* reproduction, in other words, to question the very "nature" of reproduction.

Genetic and reproductive technologies force us to rethink not only the limits of the possible in reproduction, but also the boundaries of what it is to be human. The anthropologist Sarah Franklin describes how our sensibilities have already shifted significantly when we can view "a cryopreserved embryo suspended in a liquid nitrogen tank (as) a biological relative," as do many couples undergoing IVF. Franklin describes this as "kinship shorn of a sense of natural limit, but (maintaining) surely a sense of relatedness based on shared bodily substances and genetic ties."[10]

The anthropologist David Schneider has suggested that "kinship is whatever the biological relationship is. If science discovers new facts about biogenetic relationships then that is what kinship is and was all along."[11] Implicit in Schneider's understanding of the relationship between biology and kinship is the existence of a pre-discursive nature or biological order that is revealed as our scientific understanding becomes more sophisticated. On this view, then, not only do we, as Franklin describes the position, "embody scientific knowledges" in that "they describe the nature of our very being"[12], but our conceptions of relatedness or kinship also spring into being when scientific knowledge or natural facts are "discovered." Within this framework, kinship is the "social construction of natural facts."[13] While we do not agree with the relationship between kinship and biology described by Schneider, his account certainly characterizes much of the current Euro-American understanding about the relationship between the "facts" of sexual reproduction and the biological kinship relations it produces. As argued elsewhere by one of us (RM):

> by presuming that biological ties and the "facts of life" exist [and are fixed], we have created a strong rationale for foundational arguments which favor the "naturalness" of family and kinship relations. What has been construed within our understanding of kinship as "natural," then, is a normatively essentialist position having direct bearing upon the way we understand gender and sexuality within the reproductive context.[14]

The biological kinship relation, as described above, is thrown into sharp relief, when as Franklin puts it, "science discovers new facts about biogenetic relationship." For instance, when science discovers new facts that allow a human to be crossed genetically with a pig or a mouse, we must ask whether this alters our cultural conception of who we may call kin. And what are we to make of the way that such new relations also challenge our commonly held understandings of "natural" limits? In an ironic twist, as Franklin suggests, "the very ways in which we are today connected and related through biology undoes the very fixity the biological tie used to represent."[15]

When biological science is deployed to disturb the familiar categories of relation and identity, it troubles mainstream understandings of the role of "scientific truth." Underlying all this is a profound discomfort about the connection between relationship and identity. There is a kind of pervasive anxiety that identity can only be secure if relationships are fixed. Up until now this fixity was assured by the belief that biogenetic relationships were "found," revealed in "nature," and not *made*. We suspect this anxiety stems from the latent threat to liberal notions of identity and individuality bound up with explicit recognition of the inevitability and inescapability of relationship. This concept of inevitability is only acceptable when it can be removed from the realm of choice and instead firmly ascribed to a very particular construction of "nature" that favors the liberal subject but yet, in the lexicon of naturalness, is beyond our capacity to influence or change.

From this perspective, as IGM has the potential to create new kinds and forms of biological kinship, it may also encourage us to revise kinship along radically different lines. In our view, we must not recreate the errors of past legal and social reasoning by attempting to "find" kinship on the basis of processes at the cellular or molecular level. Kinship is, and should be, based on social relationships established by embodied persons. The fear that motivates legislative prohibitions of IGM is based on the spurious construction of human kinship on the basis of invisible processes at the sub-cellular level.

Legal developments that prohibit and regulate the panoply of technologies associated with (or dreamed of) as emanating from recent successes in cloning, stem cell research, and embryonic and gene therapy attempt to reinstate the very limits of the human that Franklin describes as no longer present or at least under threat. Our focus is on the appropriateness of this role for law and why it might be utilized to these ends. The legal scholar Derek Morgan sees the role of law in this context as twofold: first, "not just as an autonomous body of knowledge, but as a factor that contributes to – which, indeed, facilitates – the so called public understanding of science." At the same time, law has a role in declaiming "who we are and whom we want to become, giving a moral and symbolic emphasis to law."[16] The aim of the current chapter is to make sense of the current legislative fixation with policing the limits of heritability and coextensively, we argue, with declaring what kind of human (or perhaps post-human) may be reproduced. It will become clearer just what those limits are understood to be when we examine the legislation in detail. In addition, we contend that feminists should look more closely at the way in which science is being deployed to construct law, and probe more carefully what norms of reproduction are being read into law.

It is imperative, for instance, to consider the position of women in the context of these recent regulatory moves. As we shall see, while much of the legislation that has been passed recently or proposed in this area concerns interventions involving embryo implantation and the manipulation of egg cells, there is little or no mention of the female body or female persons within the legislation itself, particularly in the case of Australian legislation. The Canadian legislation is notable for its specific recognition of the role that women play in reproduction. In the Assisted Human Reproduction Act discussed in detail below, a set of principles are articulated.[17] Principle c states: "while all persons are affected by these technologies, women more than men are directly and significantly affected by their application and the health and well-being of women must be protected in the application of these technologies." In both cases what is overtly policed is the fertility of the scientific imagination. As we shall argue, more often than not the body as flesh is unhinged from any self. In this chapter, we offer an alternative feminist legal response that does not reify a specific construct of nature.

The initial and most intriguing question, however, is the following: what is it about technologically-induced IGM that could call an unusual coalition of feminists and conservatives into being and get them to push collaboratively for legislative change?

11.3 What's wrong with artificial inheritable change?

A large cohort of feminists, disability activists, and progressive thinkers are lining up with moral conservatives to argue for the legal prohibition of human IGM and cloning technologies. To the extent that their reasoning derives from concerns that human cloning and IGM may promote unethical experimentation on women and children, and that both are grossly underdeveloped and even dangerous, it is clear the argument is unimpeachable. Feminists are on firm ground opposing unauthorized experimentation on the bodies of women and children in the name of genetic technology and scientific development. But why is a general prohibition favored, rather than a regulatory regime in which practice and research is subject to ethics approval? In both Australia and Canada, medical practice and scientific research are governed by ethical guidelines applied by university, hospital, and other institutional ethics committees. In the case of publicly-funded research, research funding is dependent on requisite approval by the relevant ethics committee and adherence to professional and regulatory guidelines. In the case of IGM, it is clear that even if the research or practice was shown to be safe and developed in accordance with approved ethical guidelines, it would nevertheless be argued that it should be prohibited. In other words, the concern here is not just with safe and ethical conduct of experiments and medical treatment on humans. Instead, IGM is seen in and of itself as a moral wrong.

11.3.1 Designer babies: simply unnatural?

A number of feminist commentators have argued that the use of IGM will alienate women from the reproductive process. It would, they argue, fundamentally undermine maternal autonomy and result in market control of baby design and production.[18] Further, there is a fear that genetic technologies will go beyond "therapeutic" purposes – to prevent the inheritance of lethal genetic diseases in families – and rather be used to "improve," as Frankel writes, "human traits that without intervention would be within the range of what is commonly regarded as normal, or improving them beyond what is needed to maintain or restore good health."[19] Desirable characteristics will be chosen not by governments, as they were in eugenic programs of the past, but by individuals exercising free choice to enhance the life chances of their offspring. The offerings of the marketplace will create the citizen with the best advantage in the global marketplace: the compliant corporate citizen.

Disability activists perceive the idea of "enhancement" as fundamentally flawed in its overvaluation of certain traits and undervaluation of others.[20] They rightly point out that discourses and practices aimed at enhancement reinforce an individualized and medicalized model of disability, rather than locating disability in a network of exclusionary attitudinal, environmental, and economic barriers.[21] Moreover, as the President's Council on Bioethics in the U.S.A. noted: "both enhancement and therapy are bound up with, and absolutely dependent on, the inherently complicated idea of health and the always controversial idea of normality … The distinction rests on the assumption that there is a natural human "whole" whose healthy functioning is the goal of therapeutic medicine."[22] Kerry Taylor and one of us (RM) have argued that:

> "Normalcy" is used to rationalize medical attempts to eradicate our differences, and to render all bodies alike – healthy and interchangeable … It is conceivable that genetic enhancements of normal human functions, if sufficiently valuable and widespread, might lead us to revise upward our conception of normal species functioning, with the result that where we draw the line between health and disease, and hence between enhancement and treatment, would correspondingly change. If this occurred, we might come to view certain interventions as being required by justice … if such enhancements became widespread, we might come to regard a person who lacked them as suffering from an adverse departure from normal functioning.[23] The normal is a cultural and biological imperative, which represents the average, both physically and morally. It also is a means to justify and preserve the status quo. The "average man" [sic] was constructed based on the average of all human attributes in a given country.[24] Thus, the average body became the ideal against which all others are measured. All variations within bodies became characterized in terms of variation from the normal state … It also creates the existence of deviations from that norm – or, when applied to the body as the site of identity, the presence of "abnormal" persons within a population. In addition to being a quantitative marker of human variability, the normal is a powerful normative tool that is used to determine and rationalize the extent to which certain persons fall *outside* the boundaries of moral responsibility.[25]

It is not surprising then that feminists, disability activists, and other progressive thinkers are concerned about the deleterious social and justice impacts of enhancement technologies associated with IGM. However, we need to ask whether there is anything new in the differential distribution and valuation of particular traits. Or, is the difference in the case of IGM one of luck versus design, nature versus artifice? The legitimate concern described above veers into dangerous terrain, when the defense of human rights, especially women's rights, is conflated with the defense of "nature." Typical objections about enhancement seem to fit that bill. This occurs for instance, when feminists including Judith Levine are concerned that "genetic engineering designs in inequality." She argues that genetic engineering "will artificially confer heritable advantages only on those who can afford to buy them",[26] and implies that natural advantages are neutral and have no impact on social justice and equity. Obviously, it needs to be asked how heritable advantages came to be "advantages" in the first place.

In addition to this implicit valorization of the natural, some radical feminist critiques explicitly rely upon it. They critique various forms of reproductive technologies as fundamentally disruptive of the natural and proper link between the woman and her maternal identity.[27] However, the problem with this sort of argument is, as Margrit Shildrick writes, that "it assumes certain fixed modes of female being … it implicitly counterposes natural with technological reproduction … [and] relies on a closure of identity that in fact may inhibit women's interests."[28]

11.3.2 The critique of genetic determinism

Having argued that the problem with genetic enhancement technologies is that they have a differential impact in terms of equity, it should be noted that feminist and progressive thinkers are also critical of the accuracy of this kind of determinist genetic discourse. In other words, in the act of formulating a considered response to the claims being made regarding what is scientifically possible, one quickly falls into the trap of accepting the outcome (i.e., genetically-enhanced individuals) as a concrete possibility. Critical pressure must also be brought to bear on this assumption. A focus on genetic enhancement could, as Frankel suggests, "… lead us to devalue various social and environmental factors that influence human development in concert with genes." Further, as he cautions, "a preoccupation with genetic enhancement may place too much emphasis on the genes and ultimately prevent us from solving problems that are really embedded in the structure of our society."[29]

At various times in the history of genetic research, claims have been made about possible indicators, markers or genetic identifiers for things such as alcoholism, homosexuality, violence, criminality, and so on. The effect of these kinds of claims has been to displace or dismiss more speculative, analytical discourses such as psychoanalysis, psychology, sociology, and anthropology. We need to remind ourselves that what we understand as "criminal," for example, is indeed academic. It is a concept that only makes sense within the sociological discourse that produced it. Genetic discourse borrows from the social sciences, identifies particular sociological traits as genetic, and then looks for a gene. Traits such as violence, intelligence, and so on, are treated as if they have a kind of scientific actuality without subjecting them to interpretive work. Richard Lewontin reminds us, however, that "science, like other productive activities, like the state, the family, sport, is a social institution completely integrated into and influenced by the structure of all our social institutions."[30] Claims about genetic modification and what can be achieved thus must be viewed as contingent, always contestable, and remarkably political.

11.3.3 What is *so* distinctive about IGM?

Responses to IGM must also be read against the technologies that currently exist and are legal. Why does IGM generate more concern than existing technologies that demand what some have termed "responsible" reproduction through selective abortion? Put another way, these arguments, while important, are not distinctive to IGM but are equally applicable to a wider range of practices that affect somatic cells. Nikolas Rose argues, for instance, that "by the start of the twenty-first century, hopes, fears, decisions and life-routines shaped in terms of risks and possibilities in corporeal and biological existence had come to supplant almost all others as organizing principles of a life of prudence, responsibility, and choice."[31] Technologies such as CVS, amniocentesis, and PGD are becoming routine, particularly for pregnant women over the age of 35. Then why does the specter of changing the germ-line animate legislatures to act prohibitively?[32]

One argument for the differential response is offered by Frankel, who claims that:

> enhancement by genetics is … qualitatively different from enhancement by other means. Existing methods of enhancement … are not biologically intrusive in a manner that will significantly shape our evolutionary course. Inheritable genetic enhancement would have long-term effects on persons yet to be born. Thus we have little, if any, precedent for this way of using IGM. We would be venturing into unknown territory, but without any sense of where the boundaries should lie, much less with an understanding of what it means to cross such boundaries.[33]

But we routinely make decisions that will have long-term consequences on persons yet to be born – we make decisions to procreate and give life to individuals without their consent (the adolescent refrain "I never asked to be born" is evidence enough). We routinely alter environments with irreversible consequences (think of any number of activities – pollution, building high-rises, sending rockets to the moon), and intervene in political activities, but because these are changes to the environment, they are somehow less constitutive of the individual, somehow less integral to identity. Not only are environmental factors significant on their own, but the new genetics itself reveals the extent to which phenotypes result from complex interactions between genes and environment. This should caution us to investigate what resides at the intersection of genes and environment, and not to focus on one over the other. What Frankel's words indicate instead, we suggest, is an alarmist concern with the scrutiny of boundaries and the dangers of boundary transgression. In our view, this anxiety stems from fears about the vulnerability of bounded notions of the liberal self in the face of new genetic combinations. Later in this chapter, we return to this central anxiety which motivates much of the legislation in the area and claims for law the role of policing those boundaries against *unnatural*[34] transgression.

11.3.4 The common heritage pool

Another argument developed (and later discounted) by Mark Frankel and Audrey Chapman in their report assessing the ethical and social implications of human IGM is that future generations have a right to inherit an unmodified gene pool because the gene pool represents their "genetic patrimony" as the "common heritage of our species."[35] The Universal Declaration on the Human Genome and Human Rights seems to accord with that position, for instance when it states in Article 1, that:

> The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.[36]

Frankel and Chapman also point to the claim made in the resolution adopted by the Parliamentary Assembly of the Council of Europe on genetic engineering, which states that:

> … the rights to life and to human dignity protected by Articles 2 and 3 of the European Convention on Human Rights imply the right to inherit a genetic pattern which has not been artificially changed.[37]

In response to this argument, Frankel and Chapman insist that:

> The human gene pool is a heuristic abstraction, not a natural object and lacks a material referent in nature. Individuals inherit a specific set of genes derived from their parents. Thus from a biomedical perspective, there is no intergeneration "human germ line" that could serve as an asset to the future.[38]

A single human gene pool is, as Frankel and Chapman suggest, a linguistic artifice. Yet, there is no doubt that the introduction of inheritable genetically-modified genes will impact on future generations even if only in a miniscule way. It is therefore more useful to think about the modifications themselves as comprising a small pool of genetic resources. Viewed in this way, the concern shifts from one of changing or harming the human gene pool, to one about accessing or controlling the reservoir of genetic material that can be drawn upon to make required modifications. Assumptions should not be made, however, about likely preferences for particular types of genetic modifications. It would be easy to take the view that modifications that correct serious illness should be publicly available and distinguished from those which are merely enhancing and socially desirable. Indeed, one can imagine the latter forming part of a new commodity culture.

However, in our view even this broad distinction is fraught with serious ethical concerns. The line between these two criteria will always be determined at the level of context and situated desire. For instance, while some might consider that deafness is an illness that should be corrected, others may view deafness as an enhancement.[39] Consider for instance the case of a deaf lesbian couple in the U.S.A. who deliberately created a deaf child: Sharon Duchesneau and

Candy McCullough used their own sperm donor, a deaf friend with five generations of deafness in his family, to ensure the birth of a deaf child. They argued that deafness was a defining factor in their cultural identity.[40] In light of examples such as this one, it is far more likely that any market in technologies for IGM will be niche-driven rather than a resource for some non-existent entity called "the common humanity." On the contrary, it is likely that corporations will compete to market genetic traits that serve specific groupings of individuals.

11.3.5 Reproductive agency for women

What about the argument that IGM as a new reproductive technology, like those that have gone before it, is a tool for women that offers them greater control and agency in the reproductive process? These women, it is suggested, would otherwise see themselves as subject to their reproductive biological fate. It is clear that "reproductive choice" is another one of those ideas like health, normality, and naturalness, whose meaning shifts with the technology. Some feminists, including Abby Lippman, see the plethora of "choice" as artificially manufacturing needs. She suggests that women will find themselves increasingly subject to external notions of responsibility and risk avoidance.[41] As each new technological advance is seamlessly incorporated into the experiential matrix of the pregnant woman, it becomes internalized and naturalized, and new demands to reproduce *responsibly* follow. Rose argues for instance that:

> In advanced liberal democracies, biological identity becomes bound up with more general norms of enterprising, self-actualising, responsible personhood.[42]

Importantly, however, Rose goes on to argue that the new biomedicine is not individualizing to the extent that "'at risk' groups are joining into groups and organisations, not merely demanding public provision and rights but making their own claims on the deployment of biomedical technologies and the direction of biomedical research."[43] He sees a contradiction in the new legal species of human rights based on simple existence, or what he terms "biological citizenship." While such rights suggest each human life is of equal worth, he notes that these rights have to be read against an equally powerful "biological ethics and genetic responsibility." According to Rose:

> As biomedical technique has extended choice to the very fabric of vital existence, we are faced with the inescapable task of deliberating about the worth of different human lives … this politics is not one in which authorities claim – or are given – the power to make such judgments in the name of quality of the population or the health of the gene pool. On the one hand, in the new forms of pastoral power that are taking shape in and around our genetics and our biology, these questions about the value of life itself infuse the everyday judgments, vocabularies, techniques and actions of all those professionals of vitality: doctors, genetic counsellors, research scientists and drug companies among them, and entangle them all in ethics and ethnopolitics. And, on the other hand, the politics of life itself poses these questions to each of us – in our own lives, in those of our families and in the new associations that link us to others with whom we share aspects of our biological identity.[44]

Recent legislative interventions in Australia and Canada do, however, suggest that the authorities are claiming a right to make judgments about the worth of different human lives. Indeed, a new tension is emerging between an ethic of choice where, with our internalized responsibilities, we make decisions about our genetic futures that may or may not have us becoming trans- or post-human, and a human rights of genetics, where governments at the national and international level take control of human futures by determining for us the outer limits of how and with whom we may reproduce. In other words, human rights instruments seem more concerned with *policing* the outer limits of the human than protecting those that are born in excess of those limits.

A vignette, recounted recently in the *Village Voice*, helps to illustrate this point. A story about "supertots and frankenkids" reminds us that while we may be approaching that day when wealthy parents may pay to have genetic "enhancements" to their progeny, the law is currently more concerned about "banning their birth than in protecting their interests."[45] There is no guarantee that prohibiting the creation of specified biological entities will, in fact, prevent the feared experiments from occurring. It is possible, instead, that the legislative ban might have the perverse effect of prejudicing the interests of the persons or entities born of such experimentation, thus denying them the status of humans and depriving them of the enjoyment of any ancillary rights. As the *Village Voice* article points out, this is the future conjured up by the comic strip and movie "X-Men" and is modeled on the treatment meted out today to undocumented aliens, illegal migrants, or, in the past, to women, African slaves, aboriginal peoples, and people of color generally. While science looks forward, law looks backwards.[46] Law is more effective in determining and allocating interests than it is at defining possibilities in the real world. It is better at defining "illegitimate" offspring than in preventing them from coming into the world.[47] Policing natural reproduction ends in policing the persons that result from unnatural (transgressive) reproduction. According to Erik Baard, "the rights of such unusual progeny are being curtailed before the people even exist."[48] Far from drawing actual limits on nature and science then, statutory prohibitions that police the boundaries of the human end up determining who we may call kin.

We want to suggest that legal and regulatory responses to IGM ought to embrace "the exhilarating prospect of getting out of some of the old boxes and opening up new ways of thinking about what being human means."[49] In order to understand why this is important to a feminist legal ethic, we need to recognize that, to date, a legal, liberal conception of the human person has prevailed that applies only to a fraction of the population, namely those who can operate as autonomous selves – who are actualizing beings because they have the financial resources, the power, and the time to enact themselves in such a way.

As we suggested previously, we need to be wary of collusion between science and law in the effort to freeze the meanings of categories and remove them from social contestation. Science is often deployed to place facts beyond dispute, while law is deployed to place disputes under restraints. Both may be deployed to "reproduce" the bounded notions of the liberal self.

While feminist responses are, for the most part, aware and critical of the limits of liberal selfhood, in some instances as noted above they fail to move away from a hidden discourse of the *natural*. In line with feminist legal theorists such as Martha Fineman, we argue that a particular conceptualization of *natural maternity* operates for liberal individuals as a hidden repository of all its dependencies.[50] The truth of liberalism is that no one is a truly autonomous or independent self, but some lay claim to that status by masking or privatizing their dependencies. Most commonly, this is done through supportive family structures. Therefore we are suspicious of moves that seem to be legislating a particular kind of reproduction on the basis that it most closely replicates the "natural" and results in "natural reproduction."

It is interesting in this light to compare the Australian legislation with its Canadian counterpart. The former was introduced under the auspices of one of the most conservative governments in Australia's history. The latter has been developed with significant input from and participation by feminist thinkers and the women's health community. As will become evident in our examination of the legislation, whereas the Canadian legislation appears to place limits on asexual and species-transgressing reproduction (animal/human), the Australian legislation also prohibits any kind of reproduction that cannot be seen to mirror, in some way, heterosexual monogamous reproduction. On the conservative side, then, there seems to be a panic about the loss of the autonomous liberal subject that "natural" reproduction operates to shore up.[51]

11.4 The legal response in Australia

Prior to the recent legislative developments in Australia prohibiting cloning and regulating embryo research, significant energy was put into legislative provisions that would regulate the control, access, and use of genetic information.[52] The primary outcome of several years' debate over specific (and now defunct) legislation, the *Genetic Privacy and Non Discrimination Bill* 1998 (Cth.), was a 400-page report by the Australian Law Reform Commission recommending, in large part, enhancement of the existing federal and state privacy legislation to manage the use of genetic information. Protecting privacy, rather than property, is the preferred approach, which is justified on the ground that commodification of the human body is a moral wrong. Human dignity, it is argued, demands that we do not treat the body as property.

There is no doubt that information about our genetic profile joins us to others. Each person's unique genetic code perversely reveals who else we are – our familiarly distributed network of identity markers – and who else we might become – the myriad future pathologies lurking down the track. In a sense, then, this is the moment when the liberal individual must face his or her interconnected status. Privacy legislation is a knee-jerk response to the necessary vulnerability we feel when we realize that we are all interconnected. Nevertheless, it cannot work. Under a privacy model, each member of a family not only has the right to choose not to reveal information about themselves but also the right to disclose if they so wish. Disclosure will, however, usually reveal something about other genetically-related family members. Therefore, a different kind of response is required that protects against the discrimination to which the revelation might give rise, rather than protecting against the revelation itself. In the same way, recent legislation around IGM appears to be aimed at protecting the liberal individual not by ensuring safe and ethical conduct of ARTs involving gene therapies, but by prohibiting the therapies themselves. How should we understand this prohibitory legislation? We suggest that in Australia, this legislation is primarily aimed at preserving what has come to be imagined as a kind of "natural maternity," which acts ideologically to preserve the supportive sexual unit for the usually male liberal individual, namely, the heterosexual, monogamous, nuclear family unit.

The new comprehensive Australian federal and state legislation passed over the course of 2002–2004 consists of two primary Acts: the Prohibition of Human Cloning Act (Cth.) and the Research Involving Human Embryos Act (Cth.). Each of the state Acts is a reiteration of the federal legislation.[53] The state legislation is necessary to overcome possible Constitutional limits on the power of the federal government to regulate in this area, and ensure national uniformity. It should be noted at the outset that both Acts provide for a review of their operation as soon as possible after the second anniversary of the day on which the Act received the Royal Assent. A review committee was appointed on 17 June 2005. The committee must present their report to Parliament by 19 December 2005. The review of both Acts must be undertaken concurrently and by the same persons.[54]

The Commonwealth Acts should be read together with the National Health and Medical Research Council (NHMRC) *National Statement on Ethical Conduct in Research Involving Humans*, specifically the notes on the human fetus and the use of human fetal tissue (Supplementary Note 5) and the guidelines for the ethical review of human SCGT and related therapies (Supplementary Note 7). The NHMRC established by the NHMRC Act 1992 (Cth.) is charged with setting down ethical guidelines for research and requires all institutions or organizations that receive funding from it to do research to establish human research ethics committees (HRECs) and to subject all research involving humans – whether relating to health or not and whether funded by the NHMRC or not – to ethical review by HRECs using the statement and supplementary notes as the standard.

While these ethical guidelines are just that – guidelines – the new Commonwealth Acts make certain prohibited acts and offences punishable by imprisonment. Turning then to the Prohibition of Human Cloning Act 2002 (Cth.), section three sets out the object of the Act:

> to address concerns, including ethical concerns, about scientific developments in relation *to human reproduction* and the utilisation of human embryos by prohibiting certain practices. (italics added)

It is within this Act that we find the most comprehensive prohibitions in relation to IGM. While the general prohibition against cloning falls at the margins of what we might describe as IGM, other prohibited practices in the Act are more clearly aimed at IGM. At first blush, one might view these provisions as intended to curtail the production of a radically-modified human being – a hybrid or chimera or trans-human. However, a more considered look suggests that there is also a concern with what might be viewed as deviant reproduction. As stated earlier this seems to be tied to what we would argue is a mistaken correlation between human kinship relationships and how they are worked out at the sub-cellular level.

We should be wary of the mystification of social relations based on the invisible realm of molecular biology. The critique – or embrace – of post-humanism can only be done from the standpoint of embodied persons and the relationships they develop in the social world. It is by foregrounding these relationships when interpreting the Australian Prohibition of Human Cloning Act 2002 (Cth.), for example, that we are able to reveal what may even be unconscious assumptions about the nature or naturalness of reproduction. Those assumptions catch us in a questionable feedback loop where what is viewed as unnatural is already predetermined by particular views about the way reproduction should proceed, namely, sexually between one man and one woman. Consider Section 13:

> A person commits an offence if the person intentionally creates a human embryo by a process other than the fertilsation of a human egg by a human sperm, or intentionally develops a human embryo so created.

It is clear that some kind of interpretive work needs to be done to assess what the words "a process other than" are alluding to. By foregrounding the relationships or embodied identities that must be involved in any process aimed at the creation or development of an embryo, we can see that a requirement for male to female reproduction is being legislated. One of the ways in which the legislation masks this objective is by disembodying the human gametes that are being regulated. The legislation reads as if it had been written from the perspective of a fiber-optic telescope or a laparoscope. If we were to insist upon a perspective that embodies the gametes, the legislation might read quite differently.

This is further reinforced by the fact that the provision starts by referring to the creation of a *human* embryo whereas *hybrid* embryos are specifically dealt with elsewhere (Section 20). Further, a *human embryo* is defined in the Act as "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 two pro-nuclei or the initiation of its development by other means" (italics added). A hybrid embryo, on the other hand, is defined as an embryo created by the fertilization of a human egg by animal sperm, or vice versa, and various other possible chimerical combinations. Clearly, then, what is specifically being policed in this section are deviant forms of human reproduction: non-heterosexual reproduction that transfers genetic heritage. Interestingly, the Canadian legislation does not do this. In other words, it does not mandate a particular kind of reproduction. On its face, the Canadian Assisted Human Reproduction Act, does not appear to contain a provision similar to Section 13.

This conclusion is particularly interesting in light of a recent book by Bryan Sykes, Professor of Genetics at Oxford University, entitled *Adam's Curse*.[55] He predicts the extinction of men unless we can create a designer male gene. He suggests that because of the weakness and singularity of the Y chromosome and the capacity of the two X chromosomes to "pair up and swap genes to minimize bad mutations," the solution might be to fuse genetic material from two women: "the DNA could be extracted from the nucleus of one woman's egg, and made to fuse with the DNA inside another woman's egg."[56] For him, it is a matter of survival of the species, but for now, in Australia at least, such homosexual reproduction is not allowed.

Section 15 of the Prohibition of Human Cloning Act 2002 (Cth.) takes a further step in policing deviant reproduction. It states "a person commits an offence if the person intentionally creates or develops a human embryo containing genetic material provided by more than two persons." Not only is homosexual reproduction banned, but reproduction must continue to be monogamous even at the genetic level. While we know that there may be dangers to any procedure that involves introducing genetic material into a cell, it is not the safety or ethical application of the procedure that is being policed here. Section 15 is a blanket prohibition against use of genetic material from more than two people in any circumstances. As noted at the beginning of this chapter, this is the one area where IGM has already occurred. Micro-implantation techniques already in use make it possible to compensate for mitochondrial genetic diseases either through inserting segments of healthy mitochondria (ooplasmic transplantation) or placing the nucleus of the egg of a woman suffering from the disease into a substitute egg (*in vitro* ovum nuclear transplantation). It is still unclear whether this technology is safe, as there has not been adequate testing. Therefore it would be unethical and premature to allow these techniques to be used on humans as therapeutic procedures, despite the use of this technology to produce 30 babies in 1997, which was reported by research scientists from Saint Barnabas in 2001. The report describes the process and indicates that the babies that have resulted have indeed inherited the mitochondrial DNA from the donor cytoplasm, and will likely produce offspring who will also inherit those genes.[57] These babies have genetic material from three rather than two people. In the context of the Australian legislation, one has to ask again why this particular kind of procedure has been singled out and separately prohibited.[58]

Interestingly, there is no legislation in Australia prohibiting a baby from having three biological progenitors, as opposed to three genetic progenitors. A woman who gestates a baby created from a donor egg makes no genetic contribution to that baby, but nevertheless has a significant biological input through gestation. She nourishes the baby with nutrients produced through her own circulatory system, she carries the baby inside her womb, and the baby is subject to the same environmental changes, positive or negative, to which the woman herself is subjected. Yet the law does not prohibit these exchanges, provided they are not predicated on monetary exchange.[59] In light of the Prohibition of Human Cloning Act 2002 (Cth.), and Section 15 described above, if all three people had instead wished to contribute genetic material to the baby, the law would prohibit the exchange.

Another important section in the Prohibition of Human Cloning Act 2002 (Cth.) reads as follows:

> A person commits an offence if:
>
> (a) the person alters the genome of a human cell in such a way that the alteration is heritable by descendants of the human whose cell was altered; and
>
> (b) in altering the genome, the person intended the alteration to be heritable by descendants of the human whose cell was altered.
>
> … in this section: ***human cell*** includes a human embryonal cell, a human fetal cell, human sperm, or a human egg. (Section 18)

This section specifically targets IGM, but what is particularly interesting is that only *intentional* IGM is prohibited. The legislation is drafted in a way that is clearly concerned not to prohibit SCGT which, some might argue, runs a very small risk of altering the germ line.[60] What it does do, however, is countenance the possibility of heritable change occurring through chance. Change by design is not allowed, but change by accident is. Perhaps this would satisfy those who perceive the problem as related to certain people being allowed to "design in" advantage. If instead the only way in which IGM could occur is if it occurs by accident, then the advantages accrued would be limited to those that have the natural advantage of being the one (in however many thousands) whose germ cells were affected by the modification.

At the same time as the passing of the Prohibition of Human Cloning Act 2002 (Cth.), the Federal government also passed the Research Involving Human Embryos Act 2002 (Cth.). This Act basically sets down rules about how and when an embryo can be used for research purposes. In summary, it limits research only to those embryos created for reproductive purposes that are in excess of what is required by the reproducing progenitors. Licenses that authorize damage or destruction of an embryo so created are allowed under strict conditions and only with respect to embryos created before 5 April 2002. This time limited provision is, however, repealed as of 5 April 2005. The NHMRC also plays a crucial role under the legislation of approving and monitoring the licensing of the use of excess embryos.

Like its counterpart, the Research Involving Human Embryos Act 2002 (Cth.) also defines a human embryo as "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 two pro-nuclei or the initiation of its development by other means." We presume that the inclusion in both Acts of an embryo with an altered human genome within the definition of human embryo aims to cover those embryos that may have been genetically altered in their somatic cell lines through *in utero* processes. It also may be directed at covering non-intentional IGM as countenanced in Section 18(1)(b) of the Prohibition of Human Cloning Act 2002 (Cth.). Given that any other kind of alteration is prohibited, it is unlikely that what is being imagined here is an embryo with an intentionally-altered germ line. However, it is reassuring that were such an embryo to be produced and developed, it would be legally considered to have the status of "human embryo," despite its non-legal creation.

As mentioned above, alongside the prohibitory legislation, and operating in tandem therewith, are research guidelines set down by the NHMRC. The NHMRC has recently issued guidelines which mirror the federal legislation. The *Ethical Guidelines on the Use of Reproductive Technology in Clinical Practice and Research* (the *Guidelines)* are intended to provide comprehensive rules governing activities relating to reproductive technology in clinical practice; research aimed at improving outcomes in clinical practice; and other research involving the use of human gametes, embryos, embryonic stem cells, fetuses, and fetal cells.[61]

It is interesting to note that the *Guidelines* do note the desirability of IGM where it precludes passing on a genetic disorder. It is suggested as a goal of contemporary reproductive technologies that couples avoid passing on a heritable genetic disorder. However, PGD rather than IGM is considered appropriate where a serious genetic condition or disease (including serious chromosome abnormalities not associated with a known condition or disease) is in question. A single thread that is woven throughout the *Guidelines* is the right of a person to know the identities of their genetic parents. This point is presented as an assumption, and is raised in every context where donation of gametes or embryos is examined. Given that one of the possible results of IGM in some contexts is the opportunity for more than two genetic progenitors, it is worth asking how law and social discourse would manage this multiplicity of parental possibilities. Perhaps this is another reason why, so far it, has been directly excluded as a possibility in the Australian legislation.

11.5 The legal response in Canada

In response to growing public concerns about new reproductive and genetic technologies, the Government of Canada appointed the Royal Commission on New Reproductive Technologies in October 1989. In November 1993, under an "ethic of care" framework,[62] the Royal Commission made public 293 recommendations, concluding that "decisive, timely, and comprehensive national action is required with respect to the regulation of new reproductive technologies."[63] In particular, the Royal Commission called for legislation to set clear boundaries around acceptable and non-acceptable uses of ARTs and genetic technologies, and to regulate and monitor the use of acceptable practices and developments in this field. To achieve this goal, the Royal Commission stated that the federal government should use its power under the *Criminal Code* to prohibit practices that "because of their unsafe or unethical character (are) considered unacceptable under any circumstances."[64] In addition, the Royal Commission recommended the establishment of a national regulatory commission charged with the responsibility of setting and enforcing standards for those practices deemed acceptable.

The Canadian government's final response to the Royal Commission is An Act Respecting Assisted Human Reproduction and Related Research (AHR Act) which was given royal assent on 29 March 2004.[65] In 1996, Bill C-47, An Act Respecting Human Reproductive Technologies and Commercial Transactions Relating to Human Reproduction, was proposed.[66] Bill C-47 contained a list of prohibited activities which included, amongst others, implanting animal embryos into humans or vice versa; fusing human and animal zygotes or embryos; maintaining human embryos outside the human body (beyond the 14-day limit); germ-line alterations; fertilizing animals with human sperm, or vice versa; and retrieving the ovum or sperm from a fetus or cadaver with the intention of maturing it. Under the various pressures of an upcoming federal election, the proposed regime failed to materialize, and Bill C-47 died on the order paper in 1997.

Unlike Bill C-47 which was exclusively prohibitory in nature, the AHR Act combines both criminal prohibitions with a regulatory framework. Since the original Bill C-47 died, and the introduction of the AHR Act, significant changes have occurred in the development of reproductive and genetic technologies. Notable among these changes is the growing interest in stem cell research and the increased use of IVF-related technologies. These changes, as well as a shift in attitude towards these technologies, are reflected in the AHR Act. Where the preamble of Bill C-47 began with an expression of grave concern "about the significant threat to human dignity, the risks to human health and safety, both known and unknown, and other serious social and ethical issues posed by certain reproductive and genetic technologies," the declaration of principles in the AHR Act provides that:

> the benefits of assisted human reproductive technologies and related research for individuals, families and for society in general can be most effectively secured by taking appropriate measures for the protection and promotion of human health, safety, dignity and rights in the use of these technologies and in related research.

Another difference between Bill C-47 and the AHR Act is that the former contained a set of legislative objectives. Although the AHR Act is silent about the objectives of the legislation, information published by Health Canada at the time that precursor draft legislation was introduced states that it has two primary objectives: first, to "ensure that Canadians using assisted human reproduction techniques do so without compromising their health and safety," and second, to "ensure that promising research involving human reproductive materials takes place within a regulated environment."[67] This second purpose, while not overtly expressed in the text of the draft legislation, appears to inform many of the activities that would be controlled through license under the Bill.

Rather than a statement of objectives, the AHR Act contains a declaration of principles that informs the Act and guides lawmakers in interpreting and implementing the legislation. Notable principles set out in the Bill include:

> The Parliament of Canada recognizes and declares that:
>
> (a) the health and well-being of children born through the application of assisted human reproductive technologies must be given priority in all decisions respecting their use …
> (c) while all persons are affected by these technologies, women more than men are directly and significantly affected by their application and the health and well-being of women must be protected in the application of these technologies …
> (e) persons who seek to undergo assisted reproduction procedures must not be discriminated against, including on the basis of their sexual orientation or marital status …
> (g) human individuality and diversity, and the integrity of the human genome, must be preserved and protected.

Because these principles are enshrined in a statutory declaration, they have greater legal force than if they were set out in a preamble to the legislation. As stated earlier, principle c is significant and noteworthy in its deliberate recognition of the unique position that women occupy in relation to the application of reproductive and genetic technologies. As far as we can determine, Canada is unique among nations in signaling that women, more than men, are impacted by the development and use of reproductive and genetic technologies. How this principle will be interpreted, and therefore the direct effect that it will have on decisions about applications of the technologies, remains to be seen. However, its inclusion as a statutory principle means that courts interpreting this legislation will be called upon to take seriously and account for the embodied and social situatedness of women in relation to the use of such technologies in both the reproductive and research context.

Principle e of the AHR Act, which provides that "persons who seek to undergo assisted reproduction procedures must not be discriminated against, including on the basis of their sexual orientation or marital status," is noteworthy in light of the comments made above in relation to the Australian legislation. Whereas one of the unstated, but nonetheless we argue animating, concerns in Australia is the regulation, indeed prohibition, of homosexual reproduction, it is important to ask whether similar procedures, if performed in Canada, would or could escape prohibition where they conflict with this principle. This is not to suggest that procedures that would facilitate homosexual reproduction and that might be rightfully regulated due to health and safety concerns would be forced to be on offer. But one could argue that where the safety of such procedures had been demonstrated, their use could not be prohibited solely because they facilitated homosexual reproduction.

Finally, the inclusion of principle g in the AHR Act, which provides that "human individuality and diversity, and the integrity of the human genome, must be preserved and protected" highlights the individual as worthy of protection and objectifies the human genome as worthy of the same. While at first blush this principle looks to be reinforcing a liberal humanist conception of the bounded individual while simultaneously clinging to the fiction of the human genome, one could argue that this principle reflects a healthy ambivalence and tension about both entities and concepts. The Canadian legislation draws attention to the issue of diversity which may be important in developing an interpretation in line with the feminist arguments developed in this chapter. At best, diversity, as set out in this principle, is of equal importance to human individuality and the integrity of the human genome. Arguably then, novel forms are also worthy of protection when they contribute to diversity. According to more conventional interpretations, interests of diversity such as sexual preference, disability, race, and color are also to be protected in the application of the reproductive and genetic technologies regulated by the legislation.

As stated earlier, the AHR Act identifies both prohibited and controlled activities. Those activities prohibited under the legislation include creating a human clone or transplanting a human clone into a human being; creating *in vitro* embryos for any purposes other than creating a human being; improving or providing instruction in assisted human reproductive procedures, germ-line genetic alteration of a cell of a human being, or *in vitro* embryo such that the alteration is capable of being transmitted to descendants; transplanting a sperm, ovum, embryo, or fetus of a non-human into a human being; for the purpose of creating a human, using any human reproductive material or any *in vitro* embryo that is or was transplanted into a non-human; creating hybrids for the purpose of reproduction; or transplanting a hybrid into a human or non-human. While most of these prohibitions cover the same procedures banned in the Australian context and are motivated by a similar aim – to curtail the production of a radically-modified human being, a hybrid, or a chimera – there are several notable differences. On its face, the AHR Act does not appear to contain a provision similar to that section in the Australian Prohibition of Human Cloning Act 2002 (Cth.) which prohibits the intentional creation of a human embryo by a process other than the fertilization of a human egg by a human sperm, or the intentional development of a human embryo so created. Thus, while the Canadian legislation is animated by a fear of species transgression and a concern about cloning (asexual production), it is less concerned about homosexual reproduction.

For purposes of the AHR Act, chimera means "(a) an embryo into which a cell of any non-human life form has been introduced or (b) an embryo that consists of cells of more than one embryo, fetus or human being." While hybrid is defined as a human ovum that has been fertilized by a sperm of a non-human life form, or into which the nucleus of a cell of a non-human life form has been introduced, it also includes an ovum of a non-human life form that has been fertilized by a human sperm, or into which the nucleus of a human cell has been introduced. Finally, the definition of hybrid in the AHR Act also includes a human ovum or an ovum of a non-human life form that otherwise contains haploid sets of chromosomes from both a human being and a non-human life form. Accordingly, the AHR Act's prohibition on the creation of hybrids is very strong.

The same is not true of the prohibition on the creation of chimeras. As Jason Scott Robert notes: "the definition of 'chimera' in the AHR Act does not capture the insertion of human cells into non-human embryos, or the implantation of a creature so created in a human or non-human life form." He goes on to explain that "according to the AHR Act, it is prohibited to insert non-human cells into human embryos or to insert human cells into human embryos, while it is not prohibited to insert human cells into non-humans."[68] Unless this omission is an oversight, the most likely explanation for this kind of transgenesis is the creation of human-to-animal chimeras to be used to conduct research on human biology, as Robert argues. What is striking about the AHR Act, therefore, is that while the creation of human-to-human chimeras is prohibited, the coming into being of novel beings, provided they involve the insertion of human cells into non-human embryos, is not. While at first glance, what appears to motivate most of the prohibitions in the AHR Act is a desire to protect the sexual conjugation of human gametes with the result being genetic recombination with its unpredictability of a new phenotype, what is also permitted is the limited exercise of the scientific imagination provided it protects the boundaries of the liberal legal subject.

11.6 New genetic futures: a postmodern feminist legal ethics

In the new genetic future then, so-called "natural maternity" is increasingly undermined by moves toward deviant reproduction, be it homosexual, asexual, monosexual, or clinical. Bart Simon describes the postmodern subject as "an unstable, impure mixture without discernable origins; a hybrid, a cyborg."[69] It is this same subject that conservatives fear we will become if reproduction is "de-naturalized." For instance Joan Didur argues, "[g]enetic engineering in the lab ... is represented as a violent assault on nature and a form of contamination invading the otherwise pure and untainted boundaries of the body of the liberal subject."[70] Liberal subjectivity depends on the exclusion of the other and the capacity to insist upon an autonomous, individuated "I." This kind of "I," however, cannot be sustained by many of us when we are pregnant or live with a disability, for example. Rather, in these contexts subjecthood has to accommodate the other. This, we argue, is not a bad thing. On the contrary, dependency and connection are inevitable relations for us all. If our conception of selfhood was not limited to untainted bounded bodies but instead incorporated dependency and transgression, we suggest we would have a more just society.[71] It is precisely those people whose embodiment transgresses the liberal norm who are the most disempowered in our society. Katherine Hayles argues for instance that "what is lethal is not the post-human as such but the grafting of the post-human onto a liberal humanist view of the self."[72] It is this very liberal humanist view of the self that permeates legal thinking.

Against this liberal view of selfhood, Shildrick argues "the postmodernist approach necessitates an ethic of openness and responsibility towards differences where none is given prior privilege ... acknowledgement of difference deconstructs any reliance on subject/object distinctions, and uncovers the assumption of the subjective autonomy as a mechanism to police boundaries." Shildrick confronts the inviolability of the liberal self with "the leakiness between one's self and others."[73] While critics of the unstable subject of postmodern theory charge postmodern feminism with an ethics of arbitrariness not far removed from nihilism, we argue to the contrary that postmodern feminism is not lacking in ethics, but instead has an ethics radically at odds with the ethic of liberal individualism or humanism. We affirm (with Shildrick) the basis for a more appropriate ethic is a "responsibility towards differences not as the disembodied site of diverse claims, but as an awareness of the irreducible but fluid bodily investments which ground our own provisional being in the world and our interaction with others."[74]

The same concerns are echoed by Marilyn Strathern, and Margaret Davies and Ngaire Naffine. Franklin describes Strathern, for instance, as interested in the way that Western knowledge practices operate to rework the inevitable interconnections of bodies and identities through forms of possessive individualism.[75] This is similar to the analysis that Davies and Naffine offer of legal understandings of identity. As they write: "our jurisprudential understanding of the person is that of a proprietor of self and of the external world. In modern Western law, to own is to be. We are quintessentially possessive individuals."[76] Interestingly, however, this does not translate into a property right over the self. Indeed, as Davies and Naffine argue, the "dogmatic legal position is that persons are *not* property."[77] To be constituted as property raises the possibility of becoming the property of another, and that would not accord with autonomous liberal selfhood.

It is one of those disturbing paradoxes of liberal identity, therefore, that in order to retain one's subjecthood, identified by Davies and Naffine as the person as mind, there must be individual control of one's object body. It is the boundaries of our bodies therefore that must be relentlessly and vigilantly policed. But this view of the self as a unitary, bounded, self-possessing autonomous individual fails to account for myriad relations of dependency and interconnection. Davies and Naffine argue that:

> the person does not have to be viewed as a unitary, bounded, self possessing autonomous individual, always in command of his own being and always able to exclude others. The relationship of the pregnant woman to her foetus reveals just some of the failings of this view. So too does the relationship of persons in the acts of sexual intercourse.[78]

With the development of IGM we are challenging liberal selfhood in its very production. There is something fundamentally disruptive for liberal selfhood in the congruence of boundary transgression through reproduction that the manipulation of genetic identity brings about. While some have described this transgressivity as giving rise to the post-human, we want to make a clear distinction between critical post-humanism – a variant of postmodernism hinted at in our discussion of Hayles above – and extropianism, the completion of the enlightenment project and the perfection of the liberal self. This latter post-humanist project is susceptible to an apocalyptic outcome. Liberal selfhood and transgressive or hybrid selfhood can only go together to the detriment of those who cannot transcend their interconnected subjectivity. Indeed the likely outcome of the liberal self-grafted onto the transhuman is the feminist nightmare of reproduction co-opted to the needs of global capital, producing genetically-engineered hybrids that are compliant corporate citizens. However, as Simon asks, are "revulsion, rejection and exclusion the only viable modes of resistance to corporate technoscientific practice"?[79]

Any post-humanist future worthy of embrace needs to be carefully distinguished from one that simply attempts to actualize the liberal humanist fantasy of the self. That self typically aims to transcend its material limits. Critical post-humanism, on the other hand, emphasizes that being human means being embodied. It offers the possibility of breaking out of the constraints that liberal humanism has placed on being human. IGM also offers emancipatory potential in its refusal to close the parenthesis of relationship and kinship. The resulting transgressive kinship can become a step towards the recognition of a plurality of relationships and forms of kinship. What needs to be critiqued more fully is the impulse to limit legal and social recognition to kinship ties of a restrictive type.

NOTES

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2 For Australia see the Prohibition of Human Cloning Act 2002 (Cth.) at http://www7.health.gov.au/nhmrc/embryo/; and for Canada see Bill C-6, An Act Respecting Assisted Human Reproduction and Related Research 2004 at http://www.parl.gc.ca/LEGISINFO/index.asp?Lang=E&Chamber=C&StartList=2&EndList=200&Session=12&Type=0&Scope=I&query=4096&List=toc (last accessed 31 March 2005).

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4 In addition, Anderson notes that there is a small chance that a low level of inadvertent gene transfer into germ-line cells may occur. See also 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.

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8 Mark S. Frankel, Inheritable genetic modification and a brave new world: did Huxley have it wrong? *Hastings Center Report* 33 (2003), 31–6, p. 32.

9 See for example Section 8(1) of the Infertility Treatment Act 1995 (Vic.) which provided: “A woman who undergoes a treatment procedure must – (a) be married and living with her husband on a genuine domestic basis; or (b) be living with a man in a *de facto* relationship.” This was successfully challenged, however, in *McBain v. State of Victoria* [2000] FCA 1009 (28 July 2000) as contravening *The Sex Discrimination Act 1984* (Cth.).

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11 D. Schneider, *American Kinship: A Cultural Account*. Chicago: University of Chicago Press (1980), p. 23, quoted in Franklin, Biologization revisited, p. 3.

12 Franklin, Biologization revisited, p. 3.

13 Marilyn Strathern, *Reproducing the Future: Essays on Anthropology, Kinship and the New Reproductive Technologies*. New York: Routledge (1992), p. 17.

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17 Bill C-6, An Act Respecting Assisted Human Reproduction and Related Research, date of Royal Assent: 29 March 2004.

18 Marcy Darnovsky, Human germline manipulation and cloning as women’s issues. In: *Our Bodies Ourselves: Inspiring a Movement of Women’s Health around the World*, 20 November 2000, http://www.ourbodiesourselves.org/clone2.htm (last accessed 30 March 2005).

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21 See also Rosemarie Tong, Traditional and feminist bioethical perspectives on gene transfer: is inheritable genetic modification really *the* problem? (Chapter 9, this volume), and Jackie Leach Scully, Inheritable genetic modification and disability: normality and identity (Chapter 10, this volume).

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29 Frankel, Inheritable genetic modification, p. 33.

30 Richard Lewontin, *Biology as Ideology: The Doctrine of DNA*. New York: Harper Perennial (1991), p. 3.

31 Nikolas Rose, The politics of life itself, *Theory, Culture and Society* 18 (2001), 1–30, p. 18.

32 In Australia to date, each of the states has taken a different approach. In NSW, for instance, there has been no specific regulation of reproductive technology. In Victoria, on the other hand, there has been regulation but it has been aimed at controlling rather than prohibiting the work of fertility clinics, Infertility Treatment Act 1995 (Vic.); see also Reproductive Technology (Code of Ethical Research Practice) Regulations 1995 (SA) and Human Reproductive Technology Act 1991 (WA).

33 Frankel, Inheritable genetic modification, p. 34.

34 Here we are using "unnatural" to refer to non-normative reproduction.

35 Mark S. Frankel and Audrey Chapman (for the American Association of the Advancement of Science), *Human Inheritable Genetic Modifications: Assessing Scientific, Ethical, Religious and Policy Issues*, 2000, http://www.aaas.org/spp/sfrl/projects/germline/report.pdf, p. 33 (last accessed 29 March 2005).

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37 The Council of Europe Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine. Parliamentary Assembly of the Council of Europe, Recommendation 934 on Genetic Engineering. Adopted 26 January 1982 in *Texts Adopted by the Assembly 33rd Ordinary Session, Third Part* (Strasbourg: The Council, 1982), recommendation 934, Article 4(i). The Convention on Human Rights and Biomedicine is slightly less specific in outlawing interference with the germ line but not indicating why this kind of interference should be prohibited; Article 13 states: "An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants," see "Convention on Human Rights and Biomedicine," 1997, http://conventions.coe.int/treaty/en/Treaties/html/164.htm (last accessed 31 March 2005).

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53 Health Legislation (Research Involving Human Embryos and Prohibition of Human Cloning) Act 2003 (Vic.); Prohibition of Human Cloning Act 2003 (SA); Research Involving Human Embryos and Prohibition of Cloning Act 2003 (Qld.); Human Cloning and Other Prohibited Practices Act 2003 (NSW); Human Cloning and Other Prohibited Practices Act 2003 (Tas.); Human Embryonic Research Regulation Act 2003 (Tas.); Human Cloning and Embryo Research Act 2004 (ACT); and Human Reproductive Technology Amendment Bill 2003 (WA). The Northern Territory is in the process of drafting legislation.

54 See Section 25, Prohibition of Human Cloning Act 2002 (Cth.) and Section 47 of the Research Involving Human Embryos Act 2002 (Cth.). A six-person review committee chaired by the Hon John Lockhart AO QC was announced on 17 June 2005. An issues paper was released on 4 August 2005 and is available at http://www.lockhartreview.com.au (last accessed 19 August 2005). The timetable for the review includes submissions to be made by 9 September 2005 and a final report by 19 December 2005. Notably the review is aimed at "assessing the scope and operation of the existing regulatory framework. It is not the purpose of the review to revisit underpinning community debate and rationale for the legislation." (issues paper).

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the Use of Human Fetal Tissue (1992), and Supplementary Note 5 of the *National Statement on Ethical Conduct in Research Involving Humans.*

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63 RCNRT, *Proceed With Care*, p. 107.

64 *Ibid.*, p. 108.

65 In October 2003, the Bill was passed by the House of Commons; however it died on the order paper (after its second reading in the Senate) on 13 November 2003, when Parliament was prorogued in the wake of a leadership change precipitated by Prime Minister Jean Chretien's retirement. The House of Commons reinstated the Bill, renumbered as Bill C-6, at the same state as it had been when the previous session was prorogued.

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79 Simon, Introduction, p. 8.

The Ethics of Inheritable Genetic Modification

A Dividing Line?

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and Rachel A. Ankeny

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