Catherine Mills

Futures of Reproduction

Bioethics and Biopolitics

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Futures of Reproduction

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Futures of Reproduction

Bioethics and Biopolitics

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For my mother

Acknowledgements

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Introduction

1.1 Disability, Gender and Selective Termination

Recently, a young woman was referred by a private ultrasound clinic to the maternal health unit at a large public hospital in Sydney, Australia, following an abnormal foetal morphology scan at 19 weeks gestation. While the nuchal translucency screening at 12 weeks had indicated a low risk for Down's Syndrome, the later screen showed that the foetus she was carrying was missing its left hand. Such cases of missing limbs are rare, with only about 3–8 occurring per 20,000 births, and can be caused by teratogenic exposure, compromised vascular development, amniotic bands, or chorionic villus sampling before day 66. The absence of extremities is not usually genetic, but can in some cases be related to chromosomal anomaly. The cause of the missing hand in this case was not clearly determined. However, upon diagnosis following a third scan, the woman and her partner were referred to a limb clinic at another public children's hospital, which provides counselling for prenatal diagnoses of limb reduction as well as support for postnatal care. They were provided with information about prostheses that would reduce the impact of the missing hand upon the child's physical capacities after birth. Nevertheless, the parents decided to terminate the pregnancy. This decision to terminate was, the case notes indicate, strongly influenced by the knowledge that the foetus was female.[1]

What role should a diagnosis of foetal disability or abnormality play in decisions about terminations, especially those later in the pregnancy? In bioethics, two approaches to the issue of selective termination help to map out the broad terrain of responses to this question. One of these is the idea that a termination is justified when continuing the pregnancy threatens the health or wellbeing of the woman; this is encapsulated in the notion of maternal interest. A case for maternal interests prevailing in decisions about abortion at any stage of pregnancy has been made by Julian Savulescu, who argues that the only criterion used in determining the ethics of abortion should be that of maternal interests, that is, risks to the mother's health

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[1] Joshi, Sneha, and Talat Uppal. 2010. Absent fetal hand: A case report. *Australian Journal of Ultrasound Medicine* 13(2):24–26.

and wellbeing where those risks and their impact are hers to judge according to her own beliefs and values. Interestingly, in making this case, Savulescu rejects the suggestion that foetal abnormality should play a role in justifying abortion, on the basis that it would be discriminatory and eugenic.[2] Specifically, he opposes the use of the severity of abnormality as a criterion for allowing some terminations and disallowing others. This is because permitting terminations for serious abnormalities where they are not permitted when a foetus has a mild or no abnormality would effectively discriminate against the severely disabled.

A different approach, proposed by Frank A. Chervenak and Laurence B. McCullough, leads in the opposite direction, making the severity of a disability key to the ethics of selective termination.[3] They argue that obstetric ethics entails two key principles – the principle of respect for autonomy, which ensures that the integrity of the woman's values and beliefs and her own perspective on her interests are given sufficient weight in treatment decisions, and the principle of beneficence. This latter principle requires that the physician act in the best interests of the patient, which in pregnancy can include both the woman and the foetus. Viability plays a central role in establishing patient status for the foetus. For the pre-viable foetus, patient status is entirely dependent on the pregnant woman's decision to confer that to the foetus. After viability, however, the patient status of the foetus is simply dependent upon the medical technologies and practitioners that can sustain its life.[4] In elaborating on beneficial treatment of the foetus as patient in the situation of a diagnosis of an abnormality, Chervenak and McCullough differentiate between abnormalities on the basis of severity. They argue that the certainty or very high probability of death, or of a 'severe and irreversible' deficit in cognitive development would justify termination of pregnancy after 24 weeks gestational age.[5] Importantly, these conditions are both sufficient and necessary: an abnormality that did not meet these standards would not provide grounds for an ethically permissible termination.

Despite the fact that these approaches appear to head in different directions in relation to foetal abnormality, neither of them allows an appreciation of what makes the case I started with troubling. Indeed, both effectively render the case neutral, since both make it turn on maternal interests – the first by excluding all other considerations, and the second by setting the bar for other considerations to enter the picture at viability. As the foetus in this case is pre-viable, its moral status is entirely dependent on its conferral by the mother, and thus, the withdrawal of that moral

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[2]Savulescu, Julian. 2001. Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion. *Journal of Medical Ethics* 27(3), 167.

[3]See Chervenak, Frank A., and Laurence B. McCullough. 2004. Ethical issues in the diagnosis and management of genetic disorders in the fetus. In *Genetic disorders and the Fetus*, ed. Aubrey Milunsky. Baltimore, MD: Johns Hopkins Press; Chervenak, Frank A., and Laurence B. McCullough. 1999. Ethics in fetal medicine. *Balliere's Clinical Obstetrics and Gynaecology* 13(4):491–502.

[4]Chervenak and McCullough, Ethical issues, 1138; Chervenak and McCullough, Ethics in fetal Medicine, 493.

[5]Chervenak and McCullough, Ethical issues, 1150; Chervenak and McCullough, Ethics in fetal Medicine, 494.

status is also subject to her determination of her own interests. This allows us to see that these approaches share a number of common failings. For one, both approaches evince a constricted ability to imagine the phenomenology of pregnancy and its place in establishing ethically significant relationships. Consequently, moral status is primarily aligned with a vision of an independent individual, one whose interests are determined in isolation from and often in conflict with those of others. Moral status is made contingent upon internal characteristics of the being in question, and the relationships that make moral status worth having at all are almost completely occluded. However, it may be that the conferral and withdrawal of moral status in the mother's relationship to an early foetus provides a more accurate model of the achievement of moral status more generally. This suggests that moral status – and correlative concepts such as autonomy – is always already relational; it suggests that ethics cannot be lived outside of such relationships, and that our sense of ourselves as moral agents is always confronted and delineated by our dependency on and vulnerability toward others.

Second, neither approach can account for the impact that social norms may have on individual decisions about termination, or the role that such norms play in establishing the conditions of what appear as reasonable decisions in the first place. However, it is questionable whether the existential significance of missing a hand can be understood at all without reference to the social conditions under which the person affected would live. Those conditions would necessarily involve the norms that delimit our understanding of normal human bodies, of bodies that are desirable, and those that are socially repudiated. In this case, the importance of such norms is made especially clear in the link that is made between disability and gender, where it is thought that the cosmetic impact of missing a hand would be greater for a girl. It is of course difficult to imagine the reasoning of the parents involved, but on the face of it, it rests on assumptions about gender and disability that one may well wish to challenge. It would seem to exaggerate the importance of sexual attractiveness in female gender identity, and at the same time diminish the possibilities for sexual attractiveness of people living with disabilities. This gives too much credence to stereotypical gender norms, as well as to restrictive ideas about the possibilities for rich and varied lives that exist for people with disabilities.

In attempting to articulate what is troubling about this case, it is warranted that we ask under what conditions a missing a hand can be imagined to constitute a sufficiently serious disability so as lead to terminating a pregnancy. For while it may be legally important to protect access to terminations on the basis of women's autonomy, from the perspective of ethics, it may also be legitimate to question the norms and values that underpin the kinds of decisions that seem reasonable to make in the first place. This case is troubling not specifically because of what it indicates about abortion per se, or even about the termination of pregnancy relatively late in the gestational process. Rather, it is troubling because of the questions it raises about the selection of future children and, underlying this, the imperative of normality that appears to have taken hold of our reproductive imaginaries. To the extent that reproductive decisions are decisions about who comes to exist, technologies such as ultrasound and preimplantation genetic diagnosis (PGD) often appear to contribute

to a restriction of our sensibilities about acceptable bodies. This poses questions about the social regulation of forms of embodiment, as well as about the ethical orientations embedded within our relations with others.

Throughout this book, I aim to develop an approach to the ethics of reproductive decision-making that emphasises the role of social norms as non-determining conditions of ethical practice. Further, I take as a starting point that ethical practice only takes place within the context of human relationships. Such relationships entail significant dependencies and vulnerabilities, and while the specific nature of such dependencies and vulnerabilities varies across relationships, dependency and vulnerability per se are inescapable for ethical subjects. In developing this approach, I draw on the work of theorists who are not frequently taken up within bioethical discussions, including Michel Foucault, Jean-Luc Nancy, Judith Butler and other feminist theorists of embodiment. One of my general aims is to show something of the potential value of these theoretical resources for thinking through the ethics of human reproduction. It almost goes without saying that new technologies produce new possibilities for ethical decision-making (though the actual implications of this connection between technology and ethics are less obvious). What is perhaps neglected within bioethics so far is the possibility that new technologies also produce opportunities for new ways of thinking about ourselves and our ethical practices. I try to outline some of these possibilities here. In doing so, I do not wish to simply ignore what are currently the central debates in and theoretical approaches of contemporary bioethics, and particularly reproductive ethics. Instead, I develop my approach in conversation with some of the pre-eminent commentators in reproductive ethics, specifically through the recent debates on the prospects of a 'liberal eugenics'.

1.2 Liberal Eugenics

Formulated in 1883 by Francis Galton, the term 'eugenics' has an inglorious history. First associated with the movements for population health established in the United Kingdom and United States of America in the late nineteenth century, its most potent referent is German National Socialism and the policies of enforced sterilisation and 'euthanasia' adopted by the Third Reich. While the notion of eugenics fell out of favour after World War II and the term is now often used as a form of moral condemnation, interest in eugenics has been revived by advances in genetics and associated reproductive technologies. Focusing on various technologies and their usage in different contexts, a number of commentators have raised the question of whether new genetic technologies are eugenic or not. To a large extent, this debate has turned on identifying differences and continuities between contemporary genetic screening programs and technologies, including sex selection and prenatal and pre-implantation identification of carrier genes, and eugenic programs such as those undertaken in National Socialist Germany and early twentieth century America. The more sophisticated of these accounts take care to maintain the specificity of different technologies, and emphasise differences in the sociopolitical contexts of their

usage. For example, historians of genetics such as Diane B. Paul and Paul Kevles highlight the discursive and historical points of differentiation, while sociologist Thomas Lemke has argued that modern genetics is distinct from Nazi eugenics programs in the latter's entanglement within a broader regime of the liberal government of risk.[6]

Within this approach to the question, the claim that new genetics are eugenic often operates as if it had the force of immediate censure – the driving but usually implicit idea is that if genetic technologies and practices are eugenic, then they are also morally indefensible or at the very least morally problematic. This assumption raises the question of just what is morally wrong with eugenics.[7] While it is certainly the case that Nazi eugenic programs were morally abhorrent in their blatant disregard for the life and interests of those persons killed or forcibly sterilised, it is possible to argue that these are historically contingent wrongs rather than an indication of the inherent wrong of eugenics. That is, it was the particular rationalisation, formulation and implementation of the Nazi programs that was abhorrent and not the underlying eugenic principles of 'good birth', population health and wellbeing and the desire to 'eliminate reproductive uncertainty'.[8] Not dissimilarly, the wrong of eugenic programs in the United States of America lay in the enforcement of programs of sterilisation without regard for the first-person perspective – expressed in terms of autonomy and interests – of those so sterilised. If this is the case, then it may still be possible to articulate a form of eugenics that does not suffer from the wrongs of Nazi eugenics and the like.

Perhaps motivated in part by the recognition of the difficulty of identifying an intrinsic wrong in eugenic principles, some commentators have taken a different line in the debate on whether contemporary genetics are eugenic or not, suggesting that 'some form of eugenics is inescapable'.[9] For advocates of such an approach, the historical precedent of Nazi eugenics is instructive, but does not determine the moral acceptability of eugenics. The real task, then, is not to try to avoid eugenics in toto, but to 'discover where among the available options we can find the safest home'.[10] The novelty of this approach is that it attempts to neutralise the normative

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[6]Kevles, Daniel J. 1998. *In the name of eugenics: Genetics and the uses of human heredity.* Cambridge, MA: Harvard University Press; Paul, Diane B. 1994. Is human genetics disguised eugenics? In *Genes and human self-knowledge: Historical and philosophical reflections on modern genetics*, eds. Robert F. Weir, Susan C. Lawrence, and Evan Fales, 67–83. Iowa City, IA: University of Iowa Press; Lemke, Thomas. 2005. From eugenics to the government of genetic risks. In *Genetic governance: Health, risk and ethics in the biotech era*, eds. Robin Bunton and Alan Petersen, 95–105. New York and London: Routledge.

[7]Wikler, Daniel. 1999. Can we learn from eugenics? *Journal of Medical Ethics*, 25(2):183–194. Also see the discussion in Buchanan, Allen et al. 2000. *From chance to choice: Genetics and justice.* Cambridge, UK: Cambridge University Press, 46–52.

[8]King, David. 2001. Eugenic tendencies in modern genetics. In *Redesigning life: The worldwide challenge of genetic engineering*, ed. Brian Tokar, 173. London: Zed Books.

[9]Kitcher, Philip. 1996. *The lives to come: The genetic revolution and human possibilities.* London: Penguin Press, 204.

[10]Ibid.

force of the identification of new genetics as eugenic, and instead argues for a more internally differentiated understanding of what eugenics might be.[11] This approach aims for a moral and political recuperation of the term 'eugenics' in relation to new genetic technologies. It has led to the formulation of notions such as a 'laissez faire' or 'liberal' eugenics to describe the possibilities for improving human wellbeing that such technologies afford. The suggestion of this approach is that there is little intrinsically wrong with eugenics per se and the moral acceptability of such practices hinges on the ideologies that guide their enactment and institutionalisation. Thus the idea behind a liberal eugenics is that, 'the addition of the word "liberal" to "eugenics" transforms an evil doctrine into a morally acceptable one'.[12]

Broadly, two closely related principles of moral or political liberalism provide the central platforms for a defence of liberal eugenics. The first is value pluralism, and the second is the moral and political priority of individual liberty. With regard to the first of these, the general idea is that rather than enforcing a particular conception of the good life, liberal eugenics remains neutral on the question of how people should live, leaving value orientations and life plans up to the individuals themselves. Moreover, a liberal eugenics should not encroach upon individual liberties, but should instead expand or at least protect the freedom that each individual has as a rational agent to make important reproductive decisions for themselves, in accordance with their own values and deeply held beliefs. Two significant aspects to concerns about individual freedom can be identified in debates on liberal eugenics. On the one hand, emphasis may fall on the freedom of parents to make reproductive decisions for themselves, unencumbered by state regulation. On the other hand, emphasis may be given to the prospective freedom of the children that result from those decisions, or what has come to be known as the 'right to an open future'.[13] Interestingly, while advocates of a liberal eugenics tend to place greater weight on parental freedom, critics often draw upon the notion of a right to an open future of children to suggest constraints upon parental freedom. As this suggests, within this nexus of value pluralism and individual freedom, the principle of harm often provides the means of limiting freedom – in short, each person is free to do as they wish up until the point at which their actions harm others.

These three principles – of value pluralism, individual liberty, and harm – are the focus of the first three chapters of this book. My aim in addressing these though is not to simply reject the key tenets of liberalism, or the ways in which they are taken up within reproductive ethics. Rather, I am interested in the points at which the arguments based on these tenets give way to a different kind of analysis, one which starts from the conceptual instability and historical specificity of notions of value pluralism, of individual liberty, and of harm. This analysis resists the doxic status of such

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[11] Though some have also argued more directly against the extension of 'laissez faire' eugenics. See King, Eugenic Tendencies, 178–79.

[12] Agar, Nicholas. 2004. *Liberal eugenics: In defence of human enhancement.* Oxford: Blackwell, 135.

[13] See Feinberg, Joel. 1980. The child's right to an open future. In *Whose child? Children's rights, parental authority, and state power*, eds. William Aiken and Hugh LaFollette. Totawa, NJ: Rowman and Littlefield.

ideas while also acknowledging their significance as guiding principles of modern life, which profoundly shape contemporary political and ethical subjectivities.

Additionally, in each chapter I emphasise in different ways the importance of placing these tenets within a broader social and political context – and not simply within the frame of liberal moral and political philosophy, but as they are operationalised within a context of *biopolitics*. The notion of biopolitics has become popular within the past decade or so, and there are currently several competing accounts of what the term identifies. Of these accounts, I find the one provided by Foucault to be by far the most useful for thinking about problems in bioethics. Interestingly, this account has been extremely influential in sociological studies of biotechnology, bioscience and biomedicine in recent years. However, despite their ostensibly shared concern with the referent of the prefix 'bio', the fields of bioethics and biopolitics have been much less amenable to miscegenation. This lack of integration has, in my view, much to do with the different ways of thinking about norms and normativity that are prominent in each.

1.3   What is Biopolitics?

In the final chapter of *History of Sexuality*, Foucault claims that politics in the West assumed a new form in the late eighteenth century. He argues that the Aristotelian conception of 'man' as an animal with the additional capacity for politics was rendered obsolete, and biological life itself became the object and target of political power. The transformation of politics was, Foucault argues, brought forth by a fundamental shift in the operative rationalities of technologies of power, from a power of deduction to one of production. Two particular historical events were involved in this shift, the first of which was the emergence of disciplinary techniques of power geared toward mastering the forces of the individual body. The second was a 'biopolitics' geared toward the regulation and management of the life of a new political subject, the population. Linked at the level of concrete arrangements, including the deployment of sexuality, these two axes or events lead to the emergence of a technology of power aimed at life, which Foucault identifies as a regime of 'biopower'.[14] This power operates according to the maxim of 'fostering life or disallowing it', and signals for Foucault the threshold of our modernity. It entails new forms of government and social regulation as well as new forms of subjectivity. In particular, power no longer operates through a violence imposed upon subjects from above, but through a normalising regulation that administers and fosters the life of subjects. In this new regime, power incorporates itself into and takes hold of the body of the citizen through the discreet force of normative regulation or 'the normalization of life processes'.[15]

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[14]Foucault, Michel. 1981. *The history of sexuality, volume 1: An introduction* (trans: Hurley, Richard). London: Penguin, 257–272.

[15]Canguilhem, Georges. 1997. On *Histoire de la folie* as an event. (trans: Hobart, Ann) In *Foucault and his interlocutors*, ed. Arnold I. Davidson, 32. Chicago, IL: Chicago University Press.

Foucault's analysis thus places norms at the centre of the operations of biopower, and Judith Butler has provided a useful elaboration of the notion of social norms at work here. Echoing Foucault's nominalism in relation to power,[16] she argues that norms themselves do not have an independent ontological status, but are only manifest in social practice, even while analytically distinct from that practice. While norms govern social action, they are nevertheless irreducible to that action, and the independence of the norm means that the norm 'governs intelligibility, allows for certain kinds of practices and action to become recognizable as such'. As Butler writes, norms 'operate within social practices as the implicit standard of *normalization*' by 'imposing a grid of legibility on the social and defining the parameters of what will and will not appear within the domain of the social'.[17] In other words, norms operate as regulative ideals against which forms of embodied subjectivity can be rendered legitimate or illegitimate. As a mode of organising power relations and social norms, biopower structures the space of the appearance of political subjects, constituting itself in the very process of regulation. That is, it attains and maintains its reality through the constitution of subjects, including the self-reflexive constitution of oneself as subject.

Importantly, focusing on norms and their role in the social regulation of forms of embodiment does not have to preclude a concern with normative ethical questions. Arguably, with the development of technologies that challenge our ethical intuitions, the traditional (bio)ethical conceptions of ethical subjectivity and normative constraints such as individual autonomy, the dichotomous formulation of nature and culture, and the trade-offs of liberty versus harm are also coming under challenge. In their stead, new formulations that emphasise embodied singularity, relationality and an inescapable responsibility for others provide new ways of addressing the ethical problems of contemporary life. That such formulations have had little impact on bioethics to date is perhaps not surprising if we consider that they are directed more toward ontological questions than normative ones. However, it is wrong to imagine that ontological presuppositions do not impact upon normative resolutions. Such presuppositions frame the very way in which normative questions can be posed, and consequently, how one might respond to them. Hence, a reluctance to use the terminology of rights, interests and harms so central to liberal moral philosophy does not indicate a lack of concern with the normative. Instead, it points to the development of a new grammar and a new vocabulary of the normative,[18] one that

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[16]In *History of Sexuality vol. 1*, Foucault insists that it is necessary to be nominalistic in relation to power; power is not an institution or structure and nor an internal strength. Instead, he argues that it is simply 'the name one attributes to a complex strategical situation in a particular society' (93). Thus, power is not substantive (it does not exist in itself) but is simply the name or term used to describe a relational complex. This underpins Foucault's view that what is required is not a 'theory of power' that explains what it is but an analysis of local effects, which focuses on what 'it' does.

[17]Butler, Judith. 2004. *Undoing gender*. New York and London: Routledge, 41, 42; emphasis in original.

[18]See Butler, Judith. 2002. What is critique? An essay on Foucault's virtue. In *The political: Readings in continental philosophy*, ed. David Ingram, 212–226. London: Basil Blackwell.

revolves around notions of vulnerability, interdependence, embodiment, singularity, and biopolitics. Working within this vocabulary, I hope this book contributes to the project of re-imagining what form ethics, and particularly bioethics, might take in the future.

However, it should also be noted that I do not strive to provide an overarching theoretical framework, developed systematically throughout the book. Rather, each chapter constitutes a kind of 'experiment', which, while drawing on and contributing to discussions in other chapters, can also be read independently of them. The first three chapters are most explicitly directed toward key concerns in bioethics today, especially within debates on liberal eugenics and reproductive ethics. In the first of these, I address the issue of value pluralism as it emerges in relation to human enhancement. I particularly focus on the role that the concept of the normal is taken to play in this and argue for an approach that is sensitive to the integration of social and biological norms in the idea of normality. The second chapter builds upon this, but turns more directly to the question of reproductive freedom. I challenge the idea that reproductive freedom is – and must be – wholly negative, arguing instead that a rich account of reproductive freedom has to acknowledge the positive dimensions of this freedom. Specifically, I use Foucault's later work on ethics to argue that reproductive freedom entails a form of ethical self-constitution. The third chapter addresses the problem of the limits of freedom, particularly through an examination of the way in which the principle of harm is mobilised in discussions of parental liberties to choose children with traits that are typically considered to be disabilities. I also discuss the expressivist critique, arguing that there are theoretical resources available that enable a stronger defence of the expressivist critique than has hitherto been provided. Specifically, I suggest the importance of attention to the relational basis of ethics, or what we might call alterity, as well as the role of norms in shaping ideas about acceptable forms of embodiment. In the final two chapters, I discuss each of these issues in turn, alongside a focus on PGD and obstetric ultrasound.

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Chapter 2
Normal Life: Liberal Eugenics, Value Pluralism and Normalisation

We no longer ask, in all seriousness, what is human nature?
Instead we talk about normal people.[1]

2.1 Introduction

The development of technologies such as preimplantation genetic diagnosis, reproductive cloning, and genetic therapy and enhancement have prompted considerable public and scholarly concern about a return to the eugenic projects of the early twentieth century. But while there has been much disagreement on whether new genetic technologies are eugenic or not, with the implication being that their moral acceptability rests on this designation, some contributors to this debate have taken a different approach. They argue that while new genetic technologies may well be eugenic, they constitute a new form of 'liberal' or 'laissez faire' eugenics, which are morally distinct from the totalitarian eugenics of the twentieth century. The core idea driving the formulation of this notion is that even if genetic practices are considered eugenic, this is not necessarily an indication that they are morally indefensible, since a certain form of eugenic intervention may be compatible with the key moral principles of liberal democratic societies. In apparent opposition to the more familiar form of eugenics, it is argued that this form of eugenic intervention extends individual freedom in reproductive choices and insists upon state neutrality and value pluralism.

Preserving value pluralism is therefore central to maintaining the liberality of liberal eugenics over and against the older, indefensible, counterpart of totalitarian eugenics. One of the concerns that arises in relation to this is what role the idea of the 'normal' person should play in debates about genetic interventions. The point of contention is whether the standard of normality provides a way of dissecting morally acceptable and unacceptable practices in a way that maintains liberal

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[1]Hacking, Ian. 1990. *The taming of chance*. Cambridge: Cambridge University Press, 161.

value pluralism without ceding to relativistic libertarianism. But the concept of the normal is slippery, and the relationship between notions of biological normality and normative judgements is far from clear. To tease out some of this complexity, in this chapter I consider various approaches to the question of whether the standard of normality can ground ethical limitations on the use of genetic technologies within bioethical debates about liberal eugenics. Through the lens of the controversy over the distinction, or lack thereof, between therapy and enhancement, I briefly consider three different approaches to human nature and normality. I argue that the interaction between social and biological norms is inadequately theorised within these debates, especially since there is little recognition of the operation of social norms in shaping reproductive choices. Consequently, commentators on liberal eugenics often fail to take account of the ways in which genetic interventions can be mobilised in the interests of population normalisation, even when they are directed toward individuals rather than populations.

In the second section of the chapter, I argue that the work of Michel Foucault provides important insights into the 'normalisation of life processes'[2] at stake in this debate. I show that viewed from the perspective of biopower and normalisation, the claim to state neutrality and value pluralism is not as easily made in relation to individual wellbeing as advocates of liberal eugenics suppose. Having pointed out the value of this perspective though, I will also argue against some Foucauldian critiques of genetic technologies that emphasise their eugenic and 'normalising' possibilities at the expense of their potential benefits. I point out that the 'normalisation critique' also fails to adequately address the question of the interaction of social and biological norms, largely due to a widespread theoretical reluctance to discuss 'the biological'. While there are undoubtedly dangers in notions of biological norms, in the third section of the chapter, I will outline a non-reductive, non-deterministic way in which the interaction of biological and social norms can be broached. Specifically, I show that Georges Canguilhem's examination of the concepts of the normal and the pathological in medicine offers important theoretical resources for addressing the labile interaction of biological and social norms.

2.2 Shaping People: Human Enhancement and Normality

If the addition of the word 'liberal' transforms a morally evil practice into a morally acceptable one as Nicholas Agar suggests, then there is considerable pressure to establish the liberality of the new eugenics.[3] In order to do this, those arguing for a liberal eugenics attempt to distinguish themselves from previous generations

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[2]The phrase is Canguilhem's in, Canguilhem, Georges. 1997. On *Histoire de la folie* as an event. (trans: Hobart, Ann) In *Foucault and his interlocutors*, ed. Arnold I. Davidson, 32. Chicago, IL: Chicago University Press.

[3]Agar, Nicholas. 2004. *Liberal eugenics: In defence of human enhancement*. Oxford: Blackwell, 135. For a strong critique of Agar, see Fox, Dov. 2007. The illiberality of liberal eugenics. *Ratio* 20 March 2007, 1–25.

of eugenicists by insisting upon several important points of difference. The most central of these derive from two fundamental principles of liberalism, specifically the related tenets of value pluralism in relation to the good and the priority of individual liberty. These principles give rise to an insistence on state neutrality alongside the minimisation of state intervention in decision-making processes relating to reproduction.[4] In this view, the key moral wrong of the earlier eugenics was the coercive and highly interventionist role the state played in shaping reproductive choices of citizens.[5] The totalitarian characteristics of coercive intervention curtail individual autonomy by enforcing a particular conception of the good, and restrict freedom by narrowing the scope of choices available to prospective parents. In contrast, a liberal eugenics actually enlarges the scope of reproductive liberty by minimising state regulation and coercion of reproductive choices.

There are two aspects to this claim. First, libertarian advocates of technological enhancements emphasise the necessity of restrictions on state intervention per se, such that free or unrestricted parental choice is the final arbiter of moral acceptability. A second, more complex, idea is that the liberal state must maintain a neutral stance in relation to conceptions of the good to be sought through genetic interventions. This means that even if the state plays a regulatory function in relation to reproductive technology, it should not positively intervene to enforce a particular conception of individual wellbeing or population health since it is constrained by the liberal commitment to value pluralism. It is argued that if the state maintains neutrality in this way, then rather than reinvigorating the spectre of Nazism, the new eugenics or liberal eugenics will reinforce and enhance the freedoms associated with reproduction and parenting. It will do so by giving parents more choice in and control over the genetic profile of the child that is born to them, and by reinforcing reproductive rights, such as the right to found a family established in the United Nations Declaration of Human Rights.[6]

While this construal of state neutrality and non-intervention seems to lead away from a totalitarian eugenics and thereby helps to establish the liberality of the new eugenics, value pluralism is more complicated than this supposes. For one, Allan Buchanan and his co-authors in *From Chance to Choice* point out that it is overly simplistic to think that statism itself establishes the immorality of totalitarian eugenics: a strong interventionist state is neither essential to eugenics nor the core wrong of early eugenics.[7] Indeed, the founder of eugenics in Britain, Francis Galton,

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[4]Agar, Nicholas. 1998. Liberal eugenics. *Public Affairs Quarterly* 12:137–155.

[5]See Kitcher, Philip. 1996. *The lives to come: The genetic revolution and human possibilities*. London: Penguin Press, 187–204. Also see Petersen, Alan. 2007. Is the new genetics eugenic? interpreting the past, envisioning the future. *New Formations* 60:80–81.

[6]The right to found a family is especially important in defences of reproductive cloning such as Harris, John. 2004. *On cloning*. London and New York: Routledge.

[7]Buchanan, Allen et al. 2000. *From chance to choice: Genetics and justice*. Cambridge: Cambridge University Press, 51. Also see Paul, Diane B. 1994. Is human genetics disguised eugenics? In *Genes and human self-knowledge: Historical and philosophical reflections on modern genetics*,

rejected coercive decision-making and instead favoured an educational approach predicated on informed voluntarism. Additionally, Buchanan et al. point out that the requirements of pluralism differ for the state than for parents.[8] The former requires non-interference in parental reproductive decision-making, and ensures a domain of individual liberty within which parents are free to make their own decisions about reproduction without the imposition of state sanctioned reproductive goals. However, the standards required by pluralism within parental decision-making may be better understood through the principle of harm and the notion of a 'right to an open future'.[9] Value pluralism therefore pertains not only to states, but also to the nature of the choices made by individuals.

Seen from the perspective of the necessity of maintaining value pluralism, a central issue in liberal eugenics is the (individual or collective) prerogative to shape the lives of others. The key questions are: what are the limits of state intervention, and conversely, what duties does the state have in relation to maintaining and promoting population health? What are the limits of the prerogative of parents to shape the lives of their children according to their own values? To what extent do parental decisions concerning new genetics foster or restrict the prospective freedoms and rights of their future child? That is, does parental control legitimately extend so far as to allow interventions in the genetic profile of the child born to them? Or, should it be limited to interventions for which it is possible to conceive that the future child would give consent? And if such consent is withheld, for which it is then possible for the child to reject the choices of their parents in morally significant ways? The extent to which new reproductive technologies have become controversial is indicative of the significance of these questions for the moral and ethical inflection of liberal democratic societies.

In addressing questions such as these, those in favour of liberal eugenics tend to reject two 'conventional distinctions in shaping people'.[10] The first of these is the distinction between biological and social influences on childhood development. As Agar outlines, intervention by parents upon the genetic profile of their future child differs from totalitarian eugenics in a number of ways, but is not in itself radically different from other choices and influences that parents have over the lives of their children. While intervention in the genetic profile of an embryo may well be novel, this kind of influence is not qualitatively different from the manipulation of environmental factors in order to enhance a child's natural skill, talent or ability. Thus, genetic enhancement is akin to private education, additional tutoring or experimental diets.[11] This means that certain forms of genetic intervention may be no more morally problematic than practices that are routinely accepted as part of parenting

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eds. Robert F. Weir, Susan C. Lawrence, and Evan Fales, 70–73. Iowa City, IA: University of Iowa Press.

[8] Buchanan, et al. *From chance to choice*, 170–175.

[9] Ibid., 167–172. For more on the notion of a 'right to an open future', see Feinberg, Joel. 1980. The child's right to an open future. In *Whose child? Children's rights, parental authority, and state power*, eds. William Aiken and Hugh LaFollette, 124–153. Totowa, NJ: Rowman and Littlefield.

[10] Agar, Liberal eugenics, 139.

[11] Agar. Liberal eugenics, 139–140.

and may in fact, 'preserve our children's capacity to fully participate in society'.[12] By the same token, it also means that certain exercises of social control by parents over children may be as morally problematic as some genetic interventions.[13] By this light, then, the distinction between the natural and the social is morally insignificant; instead, the point of moral arbitration is simply the *degree* of control a parent may have over the 'life plan' of their child. That is, the measure of parental control is merely quantitative, not qualitative. One consequence of this construal of the social and biological is that it rejects the idea that the 'natural' has any normative force in itself; thus, recourse to the 'natural foundations' of the human being cannot ground moral opposition to genetic interventions.[14]

The second distinction that liberal eugenicists tend to reject is the oft-made moral differentiation between genetic interventions for therapeutic reasons and interventions for reasons of enhancement.[15] In broad terms, this distinction attempts to capture the intuitive difference between addressing deficiencies therapeutically to restore the human body to health on the one hand, and on the other, boosting capacities beyond what is normal. But while that intuitive distinction may seem relatively straightforward at a descriptive level, it becomes more complicated in the context of the moral permissibility or otherwise of genetic inventions. For while therapeutic practices are usually seen as uncontroversial interventions to improve the wellbeing of an individual, enhancements are often seen as a step beyond the rightful limits of human control over others. However, the problem with this characterisation lies in the fact that it proves difficult to identify and isolate therapeutic practices over and against enhancements: in short, one person's therapy is another person's enhancement and vice versa.[16]

Central to the task of disambiguating therapy and enhancement is the standard of 'the normal', whether understood as normal biological functioning or more speculatively (and controversially) as normal 'human nature'. For it is often reference to a concept of normality that allows the identification of therapeutic restoration of a biological function (to its 'normal' level), as opposed to the illegitimate enhancement of a function (that is otherwise 'normal'). But while the idea of the normal is commonplace, it is both more philosophically interesting and more complicated than its everyday usage might suggest. For the concept of the normal incorporates both descriptive and normative implications, with the consequence that it cannot be simply an objective standard from which abnormalities deviate. Thus, it is not clear how, or whether, it helps to distinguish enhancement from therapy.

Three broad types of responses to this conceptual ambiguity can be identified in debates on genetics and eugenics: (1) a restrictive approach to genetic enhancement that maintains the distinction on the basis of a moral conception of human nature;

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[12] Agar, Nicholas. 2006. The debate over liberal eugenics. *Hastings Center Report* 36(2):5.

[13] Ibid.

[14] See Ibid; Agar. Liberal eugenics; Agar. *Liberal eugenics: In defence man*.

[15] Agar. Liberal eugenics, 141–142.

[16] Harris, John. 2007. *Enhancing evolution: The ethical case for making better people*. Princeton and Oxford: Princeton University Press.

(2) a moderately restrictive approach that attempts to base the distinction upon a non-moral conception of normal human functioning; and (3) those who reject the standard of normality and the correlative distinction between therapy and enhancement altogether and adopt a more laissez faire approach. I will briefly discuss each of these in turn.

Perhaps the most popularly resonant argument against dissolving the distinction between therapy and enhancement draws on the trope of 'transforming human nature', to argue that a moral conception of human nature should place limits on the technological intervention into and transformation of the human genome. In this approach, a normative conception of human nature grounds a distinction between acceptable therapeutic interventions and unacceptable enhancements. More grandly, some claim that a normative conception of human nature is required to stave off the threat to liberal democratic values that the project of a liberal eugenics is seen to augur. These arguments take several forms, including the strongly Aristotelian approach of Frances Fukuyama, who posits that a substantive idea of human nature is intrinsic to our conceptions of justice, rights and morality. More Kantian approaches move away from this teleological perspective and argue that the distinctive and essential human feature of autonomous individuality is threatened by technological instrumentalisation. Similar in ways to both these arguments, the most philosophically elaborate intervention in the 'moralisation of human nature' position has been the postmetaphysical arguments of Jürgen Habermas.

The overall thrust of Habermas' argument is that new genetic technologies transform our 'ethical self-understanding' by undermining the Aristotelian distinction between the 'given' and the 'made', which he sees as having a constitutive effect within our 'lifeworld'.[17] To the extent that this distinction underpins our ethical self-understanding and correlative moral and political principles, the 'dedifferentiation' of the given and the made threatens to undermine those principles. In particular, Habermas worries that the dedifferentiation of the given and the made introduces a novel asymmetric relation between the 'designer and the designed' that is contrary to the value of universal egalitarianism. Further, this may prevent the designed from establishing an ethically autonomous or self-defined life for themselves. Because of these worries, he argues that difficult as a distinction between therapy and enhancement may be to maintain at a conceptual level, it is nevertheless practically crucial.

Notably, Habermas' emphasis on ethical self-understanding distinguishes his position from the more straightforward Aristotelianism of Fukuyama. For Habermas, the notion of human nature has an importance within our lifeworld, but it is not tied to ontological claims about human nature per se, whether understood in the form of 'Factor X' or species-typical characteristics.[18] But, regardless of the

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[17]Habermas, Jürgen. 2003. *The future of human nature*. Cambridge and Malden, MA: Polity; also see Fukuyama, Francis. 2003. *Our posthuman future: Consequences of the biotechnology revolution*. London: Profile Books. I will return to a more detailed discussion of Habermas' claims regarding ethical self-understanding in a later chapter.

[18]See Fukuyama. *Our posthuman future*, 149.

nuances of Habermas' view, or its virtues and vices, the project of developing a species ethic founded on a normative conception of human nature worries some commentators. Their concern is that if substantive content is given to a notion of human nature, then it may be mobilised as a means of political exclusion and, further, appears to contradict the central liberal virtue of value pluralism.[19] And a move away from liberal pluralism threatens to collapse the new eugenics back into the old totalitarian eugenics.[20]

   A second, more moderate, position on genetic interventions including enhancements also draws on a notion of human nature, but one that is understood as non-normative, since it refers only to an empirical ideal of species-typical functioning. Developed by Christopher Boorse,[21] the notion of 'normal species functioning' has been imported into bioethics by Norman Daniels,[22] Daniel Brock,[23] and Buchanan et al.[24] Boorse proposes this notion in the context of developing a functional definition of health and disease, in which diseases are 'internal states that depress a functional ability below species-typical levels', and 'health as freedom from disease is statistical normality of function, i.e. the ability to perform all physiological functions with at least typical efficiency'.[25] Boorse's naturalistic and functional conceptions of health and disease rely upon the identification of statistically ideal characteristics of species or populations. He argues that these ideal-types are neither aesthetic nor moral, but simply non-normative descriptors of typical species characteristics, from which any and all individuals might vary in some way or another, but which provide an abstracted empirical ideal to which judgements about health and disease can refer.[26] This means that health is essentially non-evaluative: for Boorse, because it refers to an empirical ideal, the concept is value free. Further, this leads to the view that 'the normal is the natural' and disease is consequently 'foreign to the nature of the species'.[27]

   Buchanan et al. take up this conception of health as a way of parsing therapy and enhancement without having to posit a substantive view of human nature. Countering the 'shadow' of eugenics, they argue that eugenics may be acceptable if it is driven by concerns with justice. This raises the significant question of the

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[19] See for example, Mendieta, Eduardo. 2003. Communicative freedom and genetic engineering. *Logos* 2(1):135–138; Rabinow, Paul. 2008. *Marking time: On the anthropology of the contemporary*. Princeton, NJ: Princeton University Press, 24.

[20] Agar. Liberal eugenics, 137.

[21] See Boorse, Christopher. 1977. Health as a theoretical concept. *Philosophy of Science* 44(4): 542–573.

[22] Daniels, Norman. 1985. *Just health care*. Cambridge and New York: Cambridge University Press.

[23] Brock, Dan W. 1993. *Life and death: Philosophical essays in biomedical ethics*. Cambridge and New York: Cambridge University Press.

[24] Buchanan et al. *From chance to choice*.

[25] Boorse. Health as a theoretical concept, 542.

[26] Ibid., 557.

[27] Ibid., 554.

extent to which genetic resources allocated by the 'natural lottery' can be subjected to the requirements of distributive justice. Addressing the resulting 'colonisation of the natural by the just', they adopt the notion of 'normal species function' to differentiate between the restoration of normal functioning versus attempts to extend the capacities allocated to a person in the natural lottery beyond the statistically normal range. Within this, disease is defined as any 'adverse departures from normal species functioning',[28] and therapeutic interventions would entail re-establishing normal species functioning. Importantly, the limited defence of the therapy/enhancement distinction that they develop is not supposed to derive moral force from the empirical ideal of the normal per se (the normal is statistically descriptive, not normative), but from a broader argument for a 'social structural' conception of just health care.

That is, genetic therapies provide a means of curing or preventing disease in accordance with Rawlsian principles of justice as fairness, aimed at ensuring equality of opportunity. Hence, it is not the normal per se that acts as a 'regulative ideal', but rather, the imperative of equality of opportunity; normal species functioning is only important to the extent that it contributes to that, by allowing for fair competition in social cooperation. Normal species functioning thus provides one abstract indicator in establishing the 'level playing field' required for equality of opportunity. The implication of this is that interventions may be undertaken that help to establish that measure, particularly by eliminating disease conditions,[29] but genetic interventions should not undermine it by raising some above the bar of the normal. That said, it is worth noting that the equality of opportunity view of genetic interventions offered by Buchanan et al. does not require an absolute equality of genetic resources, since, for one, this fails to appreciate 'the limitations imposed by the fact of value pluralism'.[30] Instead, they suggest that it may aim at something akin to a 'genetic decent minimum' that promotes the prevention or amelioration of the most serious disabilities that negatively impact on an individual's equality of opportunity.[31]

In developing this view, Buchanan et al. adopt and defend the model of just health care proposed by Daniels, in which normal species functioning anchors the obligations of health care. That is, his 'normal function' model of fair equality of opportunity entails for health care the 'relatively modest and limited task of keeping people functioning as close to normal as possible', in order to preserve their 'capacity to participate in political, social and economic life'.[32] Such participation is not, however, guaranteed on the basis of being 'equal competitors' but rather, of being 'normal competitors'. Buchanan et al. thus draw on the conception of normal species functioning posed by Boorse; but they also move away from his strong claim that

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[28]Buchanan et al. *From chance to choice*, 72.

[29]Though, it should be noted that acceptable interventions are not strictly limited to the treatment of disease, but may also include conditions that do not count as disease. Nevertheless, the treatment of disease conditions provides the primary rationale of just health care. See Buchanan et al. *From chance to choice*, 74.

[30]Ibid., 80. In this, it is less expansive than the 'brute luck' view. See the discussion at Ibid., 66–84.

[31]Ibid., 82.

[32]Ibid., 127, 22. Also see Daniels, Just Health Care.

this conception of health and disease is entirely non-evaluative. Instead, they concede that the social context in which adverse departures from normal functioning are manifest will impact upon their specification as disease conditions or not. Further, they note that '*sometimes* values, including prejudices, as well as errors, intrude' into the relatively 'objective and non-evaluative context provided by the biomedical sciences'.[33]

However, several difficulties can be seen in this view. For one, the conception of biomedical sciences indicated here is naïve; as science and technology scholars have shown, (biomedical) science is not a value-free activity, in which values, prejudices and errors intrude only occasionally. Instead, values are intrinsic to the practice of science in a number of ways, from the personal values of individual scientists, the social norms that shape scientific practice through funding priorities and economic and political agendas for example, and the norms that legitimate and support scientific epistemology itself.[34] More importantly for my purposes here, Buchanan et al. forget that the concept of the normal is itself a confusion of fact and value: the term 'normal' derives from the Latin term 'norma', meaning to set right or to straighten, such that the norm (understood as the typical) and the right are etymologically intertwined. As Ian Hacking pithily writes, '[f]rom the beginning of our language the word "normal" has been dancing and prancing all over' the fact/value distinction.[35] This means that a purely descriptive conception of the normal will be difficult to achieve, and it is not at all clear that Buchanan et al. do achieve such a conception.

Disability theorists point to the significant ambiguities embedded in the notion of 'normal species functioning' that underpins the aim of ensuring 'normal competitors'. For instance, Ron Amundson argues that the notion of biological normality is itself part of social prejudices against individuals with certain functional modes or styles. He draws the conclusion that disadvantages and limitations on opportunity cannot be causally linked to biological characteristics, but instead always derive from the environments in which individuals operate and live.[36] Extending on this, Shelley Tremain argues that while the notion of normal species functioning seems to imply a statistical conception of 'the typical' or most common – the statistical mode – it actually operates to indicate something more like the mean or average. Moreover, deviations from this average are negatively evaluated such that the guiding presumption is that 'the more an organism diverges from the species average, the

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[33] Ibid., 122.

[34] This insight is commonplace in science and technology studies, but for especially interesting examples see Latour, Bruno. 1986. *Laboratory life: The construction of scientific facts*. 2nd edn. Princeton, NJ: Princeton University Press; Rabinow, Paul. 1999. *French DNA: Trouble in purgatory*. Chicago, IL: Chicago University Press; Fox Keller, Evelyn. 2003. *Making sense of life: Explaining biological development with models, metaphors and machines*. Cambridge, MA: Harvard University Press.

[35] Hacking. *Taming of chance*, 163.

[36] Amundson, Ron. 2000. Against normal function. *Studies in the History and Philosophy of Biology and Biomedical Sciences* 31(1):33, 51.

worse it will function'.[37] The worry underlying this critique relates to the interaction of the ostensibly biologically derived 'species-typical' norms and the 'normal' understood as a regulative ideal that is externally applied as a means of delimiting the socially accepted standards of bodily capacities. What is embedded within the critique of the mobilisation of the statistically typical as an evaluative tool is the concern that the 'normal' is no longer taken as a normatively neutral indicator but is instead conflated with a social ideal, such that the formula of 'species-typical characteristics' actually operates as a normative conception of human nature, rather than as a 'purely' statistically descriptive one.

Whether Buchanan et al. fall foul of this critique or not would be a question worth exploring in more detail, though I cannot attempt such an exploration here. The question that would have to be asked is whether the notion of statistical normality can do the work that they wish it to do without recalling the fact/value confusion that Hacking suggests is intrinsic to the concept of the normal. Does the emphasis on intervening therapeutically to ensure that an individual attains a condition akin to, or at least in the vicinity of, normal species functioning as a matter of justice mean that the normal is implicitly taken as the right or even the ideal? Does this view presuppose that being 'normal' is better than being 'abnormal', such that deviation from the normal is itself negatively evaluated? And if so, what are the implications of this for an understanding of just health care in the context of a new eugenics? Their limited defence of the therapy/enhancement distinction through the notion of normal species functioning, and elaboration of a 'normal function' model of just health care, thus raises complex questions for anyone interested in the political implications of the concept of the normal.

The primary concern of Buchanan et al. is to establish a social and political obligation to provide therapeutic measures that restore normal functioning as a matter of justice, while avoiding claims for a comparable obligation to undertake enhancements (apart from in exceptional cases). The third approach I wish to consider here takes a stronger line, to argue for an obligation to enhance. One of the key proponents of this approach is John Harris, who has recently attempted an extensive justification of human genetic enhancement. In this, he argues that references to the normal should play no role in establishing the moral permissibility of either therapy or enhancement. Harris emphasises the indistinction between therapy and enhancement, and, moreover, argues that enhancement technologies have long played a fundamental part in human life. Vaccinations, for instance, are not simply therapeutic, since they provide an ability to resist disease that humans would not otherwise have, and yet they are generally seen as not only beneficial but also morally acceptable. By extension, he also implies that all other enhancements are similarly morally acceptable. But Harris' argument is not only for the *freedom* but the *obligation* to undertake enhancements. He contends that insofar as enhancements are beneficial – which they are by definition – then individuals and governments should pursue

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[37]Tremain, Shelley. 2006. Reproductive freedom, self-regulation and the government of impairment in utero. *Hypatia* 21(1):43.

them, since there is a similar obligation to confer benefit as there is to avoid harm. For him, 'the moral imperative is the safety of the people and the duty to compare risks with benefits, not on the basis of the normality of the risks or of the benefits, or of their contribution to equality of opportunity, but on the basis of their magnitude and probability'.[38] Harris' use of the principle of harm, drawn from John Stuart Mill, eschews any conception of the normal, whether understood as descriptive or normative, and instead simply emphasises the calculation of likely harms and benefits. Thus, he adopts a libertarian position in which the only potential limit on an individual's freedom to enhance is the likelihood and magnitude of harm.

However, while Harris explicitly rejects any reference to normality, it may be that he nevertheless implicitly relies upon some conception of the normal. For one, this is because the designation of interventions as beneficial or harmful seems to require some standard against which to judge whether they are in fact benefits or harms. While Harris avers that, 'normalcy plays no part in the definition of harm and therefore no part in the way the distinction between therapy and enhancement is drawn',[39] it is difficult to see that he provides a compelling alternative standard by which harms can be identified. What he does offer as a way of identifying a harmed condition is the 'emergency room' test. He elaborates the test: 'if a patient was brought unconscious into the ER department of a hospital in such a condition and it could be reversed or removed, the medical staff would be negligent if they failed to reverse or remove it'.[40] Even so, while this test suggests that the failure to reverse a condition would indicate negligence (because the condition is deemed harmful), it does not clarify why the condition is thought of as harmful in the first instance, such that the failure to reverse or remove it would be negligent.

There is, then, a significant circularity in this test – a condition is considered harmful if the failure to remove or reverse it is negligent. But that failure is only negligent because the condition is intuitively understood as harmful in the first place. This circularity appears again when Harris writes, 'a harmed condition is defined relative both to one's rational preferences and to conditions which might be described as harmful'.[41] It is surely truistic that a harmed condition refers to a condition that might be described as harmful. But even if this definition is granted, a question remains about the work that the idea of harmed conditions referring to rational preferences does for Harris. The emergency room test is, for Harris, a way of determining that disabilities are and should be treated as harmed conditions. While it might seem that the rejection of a notion of biological normality might lead Harris to an extreme position of abjuring the very idea of disability – since ostensibly he has no criteria against which to identify some bodily capacities as diminished in

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[38] Harris. *Enhancing evolution*, 54.

[39] Ibid., 46

[40] Ibid., 91, 92–93.

[41] Ibid., 92.

relation to others – this is not the case. Instead, the reference to rational preferences is central to his definition of disability and provides him with that criterion.

While rejecting reference to biological functionality for defining disability, Harris does not therefore take up the opposing social model of disability either. In this model, disability is the social condition of discrimination that attaches to biological conditions of impairment. Thus, disability is to impairment what gender (understood as socially constructed) is to sex (understood as an irreducible biological substrate). But as such, the identification of impairment still seems to require reference to biological functionality. In rejecting such reference, Harris instead proposes to define disability as 'a condition that someone has a *strong rational preference not to be in* and one that is moreover in some sense a harmed condition'.[42] In this 'harmed condition' model of disability, the important point of reference for identifying disability is 'alternative possibilities' of bodily capacities, where harm is established through the above mentioned emergency room test. A bodily capacity is considered a disability if it is conceivable that someone could have a strong rational preference not to be in that condition, where that condition can in some sense fail the emergency room test such that it would be negligent to fail to remove or reverse the condition.

Apart from the fact that some disabilities are neither reversible nor removable, this construal of the emergency room test as a way of identifying harmed conditions reveals several points about it. For one, it highlights the significantly counterfactual nature of this model: that is, a given condition is identified as a disability because it is seen as undesirable or harmful in relation to a counterfactual alternative existence without the condition. Further, when this is combined with the standard of rational preferences, it becomes clear that Harris' approach to disability is, for want of a better term, 'able-centric'. That is, it is from the perspective of a rational, *able-bodied* person, and in relation to such a counterfactual alternative person, that a condition is seen as rationally desirable or not. Hence, while Harris rejects recourse to the 'subjective experience' of a disabled person as a relevant factor in reproductive ethics, he nevertheless implicitly relies on the (notional) subjective experience of an able-bodied, rational person as the measure against which disability is considered harmful. That is, he implicitly relies on a conception of a 'normal' person.

In more general terms, the problem with Harris' approach is that he fails to grasp the ways in which social norms shape the very desirability of a condition as compared with counterfactual alternatives. That is, he fails to see that what might be rationally desirable is itself normatively framed. Clearly, the sense in which I use the

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[42]Ibid., 91; my emphasis. See Harris, John. 2001. One principle and three fallacies of disability studies. *Journal of Medical Ethics* 27:387. Also see the alternative formulation of this definition in Bortolotti, Lisa and John Harris. 2006. Disability, enhancement and the harm-benefit continuum. In *Freedom and responsibility in reproductive choice*, eds. J.R. Spencer and Antje Du Bois-Pedain, 32. Oxford: Hart Publishing; where it is argued that, 'conditions are disabling if they are physical or mental conditions that constitute a harm to the individual which a rational person would wish to be without' (32).

term 'normative' here does not simply refer to more or less explicit formulations of moral principles or declarations of what ought to be distinct from what is. Instead, I refer to an understanding of social life itself as fundamentally normative. One characteristic of this view is that it insists on the pervasive and ineluctable power of norms in shaping which bodies appear within the social field as desirable possibilities for living. Judith Butler poses this claim most forcefully, when she argues that the materiality of the body is fundamentally shaped by the reiteration and enactment of regulatory social norms. She writes that 'bodies only appear, only endure, only live within the productive constraints of . . . regulatory schemas'[43] such that the appearance of the body within the social sphere is simultaneous with the attribution of value or worth. For Butler, norms impose 'a grid of intelligibility' on the social and, in doing so delineate possible modes of bodily life. One consequence of this is a blurring of the distinction between the descriptive and the normative – bodies that appear within the social field embody the norms that productively constrain their own intelligibility and recognisability. Additionally, norms are embedded within the practical exercise of power across various institutions such as law and medicine, and as such, they can be mobilised – explicitly or implicitly – as standards of evaluation and exclusion.

In relation to Harris, this perspective makes it clear that his abstraction from the social operation of norms in shaping the desirability of bodily forms hides a deeper attachment to normality than he acknowledges. More generally, this perspective shines light on the constitutive effect of social norms in shaping reproductive choices and the widespread neglect of these in the liberal eugenics debate. Unfortunately, though, the evasion of questions about the ways in which social norms shape and constrain the intelligible possibilities for livable lives risks undermining the value pluralism that advocates of liberal eugenics want and need to protect. But while the productive role of social norms – and specifically the relationship of norms, power, and bodily and social life – has been obscured in the liberal eugenics debate, these concerns have been central for other scholars critical of the directions that the implementation of genetic technologies can take. In particular, the work of Michel Foucault has been used to reveal the ways that new genetic technologies are harnessed to biopolitical strategies for governing the health of individuals and ipso facto, the population. From this, it is claimed that such technologies effectively become, or risk becoming, *normalising*. Focusing on this idea, in the following section I take up questions of norms in the constitution of social and bodily life through Foucault's work and the 'normalisation critique' that has emerged in reference to it. I argue that while the normalisation critique addresses the role of social norms in shaping desirable bodily forms and reproductive choices, it fails to fully address the interaction of social and bodily norms, largely because of a reluctance to discuss 'the biological'.

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[43]Butler, Judith. 1993. *Bodies that matter: On the discursive limits of 'sex'*. New York and London: Routledge, xi.

2.3 What is Normalisation?

The idea of 'normalisation' used in contemporary scholarship usually derives from Foucault's analyses of the transformations in political power and techniques of governance in the modern West (dated from the late eighteenth century). While it is not always easy to specify the precise relations between Foucault's various formulations of technologies of power as discipline, governmentality or biopower, to some extent the notion of normalisation cuts across these. The idea highlights the way in which norms are mobilised to regularise individuals in relation to each other and in reference to a standard as a means of control and political subjection. In general terms, normalisation refers to a mode or practice of power that centres on the *norm* in contrast to the rule or law. Within this, a norm is neither prohibitive nor universally applicable, but is instead a flexible, context specific principle or standard of evaluation in relation to which individual divergences can be identified, measured and corrected. As Foucault notes, the function of the norm is not to 'exclude and reject'; instead, 'it is always linked to a positive technique of intervention and transformation, to a sort of normative project'.[44] That is, the identification and measurement of divergences from the norm allows for the mobilisation of programs, techniques and practices geared toward the correction and regularisation of an individual in relation to the norm, to bring the divergent body back into coherence with the abstraction of the norm. Further, because the application of a norm allows for the identification of divergence and deviation, it gives rise to the categorisation of the 'abnormal': the abnormal individual is both the direct consequence and integral object of the power of normalisation.

Several points can be made about this characterisation of the power of normalisation. First, normalisation is directly related to the historical emergence of statistics as a means of measuring populations in the interests of governing them. As Hacking has shown in *The Taming of Chance*, the modern notion of the normal human being was given great impetus by the French statistician Adolphe Quetelet, who, in the 1830s and 1840s, applied the 'curve of error' from astronomy to biological and social phenomena to yield his idea of 'the average man' ('*l'homme moyen*'). Indicating the statistical mean of a set of attributes not of the human species, but of a nation or 'race', Quetelet introduced a new apparently objective and comparable measure of a people and in doing so, contributed to the development of eugenics.[45] But Galton, the founder of anthropometrics as well as eugenics, went further by reorienting the notion of the normal away from the statistically typical toward deviations from the mediocre middle, and especially toward ideal traits. In this, Galton reiterated the idealised conception of the normal introduced by Auguste Comte, who in turn drew upon the concept of 'normal states' developed by advocate of the

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[44]Foucault, Michel. 2003. *Abnormal: Lectures at the College de France, 1974–1975*, eds. Valerio Marchetti and Antonella Salomoni (trans: Burchell, Graham), 50. New York, NY: Picador.

[45]Hacking. *Taming of chance*, 105–114. I draw extensively on Hacking's history of the concept of the normal in this paragraph. Also see Davis, Lennard. 1995. *Enforcing normalcy: Disability, deafness and the body*. London: Verso, 23–49.

organic 'physiological' theory of disease, F.-J.-V. Broussais, in the 1820s.[46] Thus, the modern usage of the word 'normal' derives from medicine, and contains within it a tension between objective measure and idealisation. Hacking writes, the normal 'stands indifferently for what is typical, the unenthusiastic objective average, but it also stands for what has been, good health, and for what shall be, our chosen destiny'.[47] It is, he suggests, precisely because of this tension that the apparently 'benign and sterile-sounding word "normal" has become one of the most powerful ideological tools in the twentieth century',[48] as it may well also prove to be for the early twenty-first century.

In light of this history of the concept of the normal, it is worth reflecting on Foucault's comment that the nineteenth century eugenics movements were linked to the rise of psychiatry, through the development of the doctrine of 'degeneration'. Through this notion, psychiatry gave rise to a new racism against the abnormal, the function of which 'is not so much the prejudice or defence of one group against another as the detection of all those within a group who may be carriers of a danger to it. It is a racism that permits the screening of every individual within a given society'[49] in the interests of population health and wellbeing. By 'racism', Foucault does not simply mean the doctrine of biologically based racial types and the hatred to which this has given rise. Rather, he uses the term in a broader sense to indicate a system or systems of detection that operate within a culture and that may or may not refer explicitly to race, but which do entail the political capture and intensification of biological difference.

To be clear, I am not suggesting that the doctrine of degeneracy has a contemporary resonance or relevance, for the language of degeneracy plays no part in defences of liberal eugenics. However, Foucault's account of normalisation as giving rise to an internal system that seeks to 'improve life by eliminating accidents, the random element, and deficiencies',[50] does have a bearing here. This is not because liberal eugenic projects for the improvement of human wellbeing by genetic means seek to undercut or eliminate individuality per se. However, to the extent that justification for eugenic genetics relies – whether implicitly or explicitly – upon a norm for individual wellbeing as a way of identifying, calibrating and correcting deviations from it, then it is normalising. This is surely evinced in the drive to take control of the 'genetic lottery' with the aim of producing 'normal competitors' in accordance with 'normal species functioning'.

Second, the primary role of norms in governing raises a question about the power of legal apparatuses, and the correlative normative function of

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[46]Ibid., 160–169; 180–184.

[47]Ibid., 169.

[48]Ibid.

[49]Foucault, *Abnormal,* 317. Also see, Foucault, Michel. 2003. *Society must be defended: Lectures at the College de France, 1975–1976*, eds. Mauro Bertani and Alessandro Fontana (trans: Macey, David), 254–263. London: Allen Lane.

[50]Ibid., 248.

laws.[51] Foucault maintains in his various discussions of normalisation and the emergence of a 'normalising society' that legal apparatuses are increasingly incorporated into a continuum of institutions, the function of which are 'for the most part' regulatory and which rely upon norms in their operation. One consequence of this is that the mode by which the law increasingly operates is that of the norm. This does not mean that law itself is superseded; quite evidently, that is not accurate. Rather, Foucault argues that as a regulatory apparatus, the law continues to operate within the regime of biopower, but in a different way than it previously had. As François Ewald outlines, norms are not strictly opposed to the law, though they may be opposed to the 'juridical' code that links law to sovereignty, in which the law is necessarily 'armed with the sword'.[52] In fact, not only are norms not opposed to the law, in a normalising society they become the means by which law operates. In a biopolitical society, norms allow the law to operate in conjunction with a series of increasingly regulatory apparatuses such as medicine. In doing so, norms permit the law unprecedented access to individual bodies, allowing it to act as a continuous regulatory force rather than an occasional, prohibitive instrument of sovereign right.

One implication of the interaction of law and norms is that the emphasis on value pluralism and state neutrality is less effective in differentiating liberal eugenics from its more interventionist counterpart than is often allowed. The power of normalisation means that legal restrictions or enforcements are not specifically required for the state to intervene in shaping conceptions of the good in regard to individual and population health and reproduction. As studies of liberal governmentality have shown, the tight integration and interaction of the law and norms in modern politics means that the state can effectively 'govern at a distance' through ostensibly non-state institutions.[53] This does not mean that the doctrine of value pluralism is simply false, since it has a discursive force that is not captured within the truth-falsity opposition. But it does suggest that recourse to and the enactment of value pluralism are more complicated than has been allowed in the liberal eugenics debate.

Further, as I suggested previously, what often falls out of the liberal eugenics view is the way that individual decision-making is normatively constrained even when the shape and scope of notions of human good are not explicitly enforced by the state. Foucault's account of the operation of norms in a biopolitical society brings into relief the condition of living in a normative universe, in which norms

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[51] Also see Waldschmidt, Anne. 2005. Who is normal? Who is deviant? 'Normality' and 'risk' in genetic diagnostics and counselling. In *Foucault and the government of disability*, ed. Shelley Tremain. Ann Arbor, MI: University of Michigan Press; especially the distinction she suggests between laws as 'normative norms' and 'normalistic norms', which require the comparison of people against each other and in relation to a standard such as statistical averages (193–194).

[52] Ewald, Francois. 1990. Norms, discipline and the law. *Representations* 30:138. For a recent discussion of the relationship of law and norms, see Golder, Ben and Peter FitzPatrick. 2009. *Foucault's law*. London: Routledge.

[53] See Burchell, Graham, Colin Gordon, and Peter Miller, eds. 1991. *The Foucault effect: Studies in governmentality*. London: Harvester Wheatsheaf.

operate to confer and shape our bodily, ethical, social and political realities through establishing, consolidating, and sustaining the strictures of 'right and wrong, of valid and void'.[54] This means that individual decisions will necessarily be made in a normative environment, in which norms delimit the boundaries of normal and abnormal bodies.[55] Individual reproductive choices do not escape the normative matrix that shapes perceptions and valuations of possible bodily lives. This entails that human bodies are valuated and regulated through the establishment and imposition of norms. Such norms shape the desirable possibilities for living through the delimitation of the normal and abnormal, with the subsequent risk that the abnormal will be subject to correction or elimination.

In a sense, the general point that I am making here is not especially original – for a number of commentators have used Foucault's account of normalisation to claim that genetics and biomedicine are, or risk being, normalising, because of the ways in which they are embedded within regimes of power and the control mechanisms of biopolitics. For instance, Karen-Sue Taussig et al. articulate this line of critique in their ethnographic reflections on achondroplasia. They argue that the tendency to see the human genome as the site at which 'the human future' can and must be negotiated indicates the persistence of eugenic thinking in the United States of America today. This is not simply the eugenics of old though, but a 'flexible eugenics' that combines individual choice understood as an obligation to be free with 'genetic normalisation'.[56] There is, they suggest:

> a convergence, or constitutive tension, between genetic normalization and an individualization that increasingly engages biotechnology – *biotechnological individualism*. From this tension, what we call *flexible eugenics* arises: long-standing biases against atypical bodies meet both the perils and possibilities that spring from genetic technologies.[57]

While Taussig et al. make no reference to the philosophical justifications for liberal eugenics, it is not hard to see that their critique bears upon this debate, particularly in the emphasis on individual choice.

As an expression of what I am calling the 'normalisation critique' of genetic medicine this perspective is tempting for its greater sensitivity to the normative context in which bodies appear as differentially livable. But this critique suffers from two problems. First, it misunderstands normalisation, in that it implies that normalisation refers to the standardisation of bodies according to a norm imposed upon the atypical or abnormal. It is in relation to such standardisation that the emphasis on individualisation appears as a 'constitutive tension'. But normalisation does not

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[54] Cover, Robert. 1992. Nomos and narrative. In *Narrative, violence and the law: The essays of Robert Cover*, eds. Martha Minow, Michael Ryan, and Austin Sarat, 95. Ann Arbor, MI: University of Michigan Press.

[55] See Butler, *Bodies that matter*; Butler, Judith. 2004. *Undoing gender*. New York, NY: Routledge, 40–56.

[56] Taussig, Karen-Sue, Rayna Rapp, and Deborah Heath. 2005. Flexible eugenics: Technologies of the self in the age of genetics. In *Anthropologies of modernity: Foucault, governmentality and life politics*, ed. Jonathon Xavier Inda. Malden, MA and Oxford: Blackwell.

[57] Ibid., 196.

strictly refer to or operate through the homogenisation of the population or erad-ication of difference at a biological or anatomical level. Rather, 'normalisation' refers to the way in which a standard is established as a norm or principle of com-parison and which subsequently allows for the identification of deviations through the designation of normal or abnormal. Foucault's comments in *Security, Territory, Population* are especially revealing of this logic when he suggests that the role of the norm in disciplinary power is better understood as 'normation' than 'normalisa-tion'.[58] By this he means that what is at issue is not standardisation per se, but the process by which norms are formulated and established at all. In this light, standard-isation is epiphenomenal in relation to normalisation understood as the constitution of norms.

The analytical consequence of this is that the formulation and imposition of the norm does not simply apply to but actually *precedes* the existential reality of the normal and abnormal. Foucault writes:

> it is not the normal and the abnormal that is fundamental and primary in disciplinary normal-isation, it is the norm. That is, there is an originally prescriptive character of the norm and the determination and the identification of the normal and the abnormal becomes possible in relation to this posited norm.[59]

This means that infractions of the norm are *produced* as an effect of the applica-tion of the norm, such that the phenomenal particularity of an individual is itself constituted and made evident through the operation of the norm. Because of this, Foucault argues that normalisation is simultaneously totalising and individualising in its operation: normalisation simultaneously establishes homogeneity *and* diver-sity. That is, the imposition of a norm establishes a common standard and forces those bodies placed in relation to it to reveal their specificity through the identifi-cation of divergences from that standard. In this sense, there is no tension between normalisation and individualisation; rather, the latter is inherent to the former.

The second problem with the normalisation critique relates to the way it treats the biological. Foucault's account of normalisation often emphasises the way that norms operate in relation to bodies. While much can and has been said about exactly what he means by 'the body', his account of disciplinary and biopolitical normali-sation is most often taken up as a portrayal of the social and political construction of the body through the operation of power. In general terms, this means that the application of social norms has a constitutive effect on the body through differential and evaluative categorisations of it. In short, norms shape the ways that bodies can be understood in the social field. In this vein, the normalisation critique is important

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[58]Foucault, Michel. 2007. *Security, territory, population: Lectures at the College de France, 1977–1978*, ed. Michel Senellart (trans: Burchell, Graham), New York, NY: Palgrave MacMillan, 57.

[59]Ibid. There is then an empirico-theoretical question about whether contemporary configurations of power, including biomedical power, can rightly be described as disciplinary and thus normal-ising. I do not take up this question here, but see Rose, Nikolas. 2007. *The politics of life itself: Biomedicine, power and subjectivity in the twenty-first century*. Princeton, NJ: Princeton University Press; and Diprose, Rosalyn et al. 2008. Governing the future: The paradigm of prudence in political technologies of risk management. *Security Dialogue* 39(2–3):267–288.

for its focus on the ways in which social norms operate within biomedicine to shape the ways bodies are perceived and understood as normal or abnormal, as desirable possibilities for living or as impossible forms, as impaired or diseased. In this, it provides an important corrective to the neglect in the literature on liberal eugenics and genetics of social norms and the ways they shape reproductive choices. However, in its almost singular focus on social norms, this view misses the opportunity for a more sophisticated account of the interaction of social and biological norms, since the latter are almost wholly obscured.

As Elizabeth Wilson points out, there is a widespread reluctance to discuss biology in contemporary feminist and critical theory, because of a perception that recourse to biological explanation is reductionist, if not necessarily determinist. This has, however, come at the cost of a more engaged understanding of 'the microstructure of the body' and the ways it may actively contribute to culture, signification and sociality.[60] I am not suggesting here that a 'pure', non-normative discourse of biology can resolve the complexity of questions of normality and abnormality. The significance of the normalisation critique is surely that it makes naïve recourse to biology and biomedical expertise in ethics unsustainable. Nor does greater focus on biology entail a return to an impoverished and by now almost entirely polemical debate about the degrees of influence of 'nature' and 'nurture': determining their causal influence for human identity is not what is at issue. Instead, what is required is a theorisation of norms and normativity that starts from the necessarily labile intersection and irreducibility of the social and biological in discussing human bodily variation in bioethics. I will begin to sketch such an approach in the following section.

2.4   The Vitality of Social Norms

Foucault's conception of the norm is social and political, such that he describes the historical regimes of power within which norms gain force. His concern was with examining the political fixation of the normal and abnormal through the operations of power, from his early analyses of the clinic and of madness through to the later genealogy of desiring man. His approach to norms and normalisation attempts

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[60]Wilson, Elizabeth A. 2004. *Psychosomatic: Feminism and the neurological body*. Durham and London: Duke University Press, 5. To be clear, I do not mean to imply that liberal bioethics does better in terms of talking about biology. In fact, correlative to the obfuscation of the operation of norms in this literature is a tendency toward genetic reductionism, in which a gene is isolated as the causal origin of complex traits such as intelligence. This is evident in the rhetoric that genetic therapy or enhancement simply requires the identification and modification of a 'gene for' a desirable or undesirable condition or trait. But this reductionism ignores the complexity of the interaction between biological (including genetic), environmental and other factors in human variation. Rich, non-reductionist approaches to molecular biology can and should be used to offset this tendency within bioethics. For a sophisticated critique of the 'gene for' rhetoric, see Oyama, Susan. 2000. *The ontogeny of information: Developmental systems and evolution*. 2nd edn. Durham, NC: Duke University Press.

to reveal the means by which power takes hold of bodies, calibrating and regularising their capacities. In developing this conception of norms and bodily life, Foucault draws substantially on the work of Georges Canguilhem, who in turn extends the work of the neuropsychologist, Kurt Goldstein, both of whom focus less on social norms than on the norms and normativity inherent to the living organism itself.[61] I want to suggest that Canguilhem's considerations of norms can help to redress the obfuscation of the interaction of biological and social norms in the approaches that I discussed above. In what follows, I briefly sketch the approach to norms proposed by Goldstein and Canguilhem, and I conclude this chapter with some comments on the implications of this for liberal eugenic approaches to genetic intervention.

In his 'holistic' approach to understanding conditions of health and pathology in the organism, Goldstein argues that neither statistical nor idealistic conceptions of the norm and normal are sufficient, since neither can do justice to the individual. Instead, he argues that only a norm that 'permits taking the entire concrete individuality into consideration, a norm that takes the individual himself [sic] as a measure'[62] can be adequate to understanding conditions of health, disease and abnormality. From the point of view of the whole individual organism, health amounts to a situation of 'ordered behaviour' which allows the organism to meet the demands made upon it by the environment in which it exists. Disease arises as a 'catastrophic reaction' to changes within an organism such that it is no longer able to meet the demands placed upon it in its 'proper, "normal" milieu',[63] and which thereby threatens the very existence of the organism itself. As this implies, Goldstein makes a distinction between disease and variation from the norm as abnormality: he writes, 'any disease is an abnormality but not every abnormality is a disease',[64] since not every deviation from the normal will threaten the organism in an existential way. Further, rehabilitation from disease is not simply the eradication of a catastrophe, but may come about through the development of a new state of health, understood as a previously non-existent set of ordered relations between the organism and its environment; that is, health is not an ideal condition to which the organism is restored, but an active interaction and 'negotiation' between the organism and its environment.

This insight that health describes functional relations between an individual and its environment is central to Canguilhem's extension of Goldstein's understanding of norms and health in his study of the concepts of the normal and the pathological in medicine. Canguilhem argues that life itself is inherently normative, insofar as

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[61] Goldstein, Kurt. 2000. *The organism: A holistic approach to biology derived from pathological data in man.* New York, NY: Zone Books.

[62] Ibid., 329.

[63] Ibid.

[64] Ibid., 326.

it aims at the restoration of functional or 'normal' relations between an individual organism and its environment. He writes:

> Taken separately, the living being and HIS [sic] environment are not normal: it is their relationship that makes them such. For any given form of life the environment is normal to the extent that it allows it fertility and a corresponding variety of forms such that, should changes in the environment occur, life will be able to find the solution to the problem of adaptation... in one of these forms. A living being is normal in any given environment insofar as it is the morphological and functional solution found by life as a response to the demands of the environment. Even if it is relatively rare, this living being is normal in terms of every other from which it diverges, because in terms of those other forms it is normative, that is, it devalues them before eliminating them.[65]

For Canguilhem, health amounts to a 'normal' situation, one in which the organism is normatively attuned to its environment and is thus able to meet the demands of it. Conversely, pathology or disease is the incapacity to meet those demands; but while it amounts to a deviation from the normal state, it is not strictly speaking, a situation of disorder or normlessness. Rather, 'the pathological is not the absence of a biological norm: it is another norm but one which is, comparatively speaking, pushed aside by life'.[66] Thus, norms are not only internally specific to the organism but vary across the conditions of its existence, either when its normal condition is disrupted by physiological changes or changes in the demands that an environment places upon it such that it can no longer meet those demands.

But while placing emphasis on the normal as the normative relation between an organism and its environment, this does not mean that Canguilhem privileges stasis or stability at the expense of diversity, divergence and mutation. In fact, he argues that life includes within itself a capacity for errancy that ensures that no state of being is ever entirely fixed. Moreover, for him, even if it is logically second, the abnormal is existentially prior to the norm. Related to this, Canguilhem is careful to distinguish the anomalous from the abnormal, suggesting that the former is a descriptive concept while the latter is evaluative and normative. That is, the anomalous refers to the statistically infrequent, but the abnormal refers to that which is against the normal. But for Canguilhem the relation of the abnormal and normal is not simply one of 'contradiction and externality'. It is instead one of 'inversion and polarity': the abnormal does not exist outside the extension of the norm as such, but indicates a less preferable possibility in relation to the norm.[67] That is, abnormality indicates that all possible modes of living are not normatively equivalent for an organism, since some (and only some) divergences from a norm will be experienced as an obstacle or hindrance in living. As Ewald writes, 'if all possible forms are

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[65]Canguilhem, Georges. 1991. *The normal and the pathological* (trans: Fawcett, Carolyn). New York, NY: Zone Books, 144.

[66]Ibid.

[67]Ibid., 239–240.

not normal, it is not because some forms are naturally impossible but because the various possible forms of existence are not all equivalent for those who must exist in them'.[68] Thus, the importance of the designation of the normal and abnormal is not that it indicates simple variation from an a priori model or type, but instead evaluates the ways that such divergences affect the modes of living of an organism in a specific environment.

My aim here is not to provide a full defence of Canguilhem's work as a philosophy of health and disease. Nor am I arguing that the focus on biological norms should simply replace the more socially oriented analyses of Foucaultian scholars. My point is rather that in conjunction with Foucault's conception of biopower and normalisation, this conception of health, norms and disease allows for a focus on the question of the interaction of social and biological norms. Goldstein and Canguilhem are centrally concerned with the relation of an individual organism and its environment in establishing and maintaining a normal or healthy state. However, Canguilhem also claims that, 'the form and functions of the human body are the expression not only of conditions imposed upon life by the environment but also of socially adopted modes of living in the environment'.[69] This suggests that biological and social norms are simultaneously inseparable and irreducible. That is, given that the environment or milieu of a human being is always already social, the idea of the normal must encompass the constitutive tensions engendered by our being in two worlds at one and the same time.

Interestingly, while physiological and social norms are empirically inseparable for Canguilhem, it is also important that they are analytically distinguishable. For instance, he argues that while physiological norms are immanent to the organism, social norms have no equivalent immanence. In a living organism, norms are 'presented without being represented, acting without deliberation or calculation', such that there is 'no divergence, no delay between rule and regulation'. In contrast, rules in a social organisation must be 'represented, learned, remembered, applied'.[70] Further, while biological norms are geared toward a functional end, social norms are not – speaking of the 'health' of a society is metaphoric in a way that speaking of the health of a living body is not. Canguilhem's attempt to distinguish between social and biological norms means that the former cannot simply be extrapolated from the latter, for that would risk collapsing different normative forms and yielding to a version of biological determinism. Nor, however, can assessments of health and disease be made in isolation from or without reference to either social or biological norms. It may be that Canguilhem overstates the analytic difference between social and biological norms; but in any case, what should be clear is that both are constitutively open to transformation.

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[68]Ewald. Norms, discipline and the law, 157.

[69]Canguilhem, *Normal and Pathological*, 269.

[70]Ibid., 250.

To return to the debate on liberal eugenics, this characterisation of norms and the conceptions of health, disease and diversity that it gives rise to may provide important leverage in discussions of therapy and enhancement. For one, this provides a way of differentiating between disease and divergence, abnormality and anomaly. In doing so, it may help to recuperate a sense of therapeutic practice aimed at the restoration of health from the potential overreach of the normalisation critique that sees such attempts as an imposition of sociopolitical standards of normality. Of prime importance for this view of health are not 'species-typical' characteristics or functions but the essentially normative relation between an individual organism and the environment in which it exists. Within this view, to attain a normal state for an individual is not to regularise that individual in relation to others or in reference to an abstract 'empirical ideal', but to attain a condition under which the individual itself can flourish, even if that condition appears as statistically anomalous or atypical. Perhaps one controversial example of such a therapeutic practice would be self-demand amputation for 'body integrity identity disorder', in which sufferers are psychologically debilitated by living with a body that is otherwise considered morphologically normal. Or, conversely, the provision of cochlear ear implants to restore hearing may be an important therapeutic practice for some individuals, and not simply a 'normalising' measure that destroys the distinctive identity of Deafness (though it may also be that for others).

This is not to say that the immanent approach to norms that Canguilhem proposes eliminates reference to species-typical traits altogether, but these traits are not the standard from which divergences are therapeutically assessed. In effect, the evaluation of the health of an individual in relation to species-typical functioning confuses statistical norms and therapeutic norms. That is, while the notion of species-typical functioning attempts to describe a non-normative statistical regularity across numerous individuals, the therapeutic question addresses variation in relation to the individual's own trajectory and existential milieu. In other words, while the statistical norm is synchronic insofar as it indicates divergences across individuals in space, therapeutic norms are diachronic in that they allow for the comparison of states within the lifespan of an individual and their assessment as more or less successful forms of living for that individual. Variation and disease, then, are normative in the sense that they require consideration of the value for the living organism of divergences from its normal state of health. No doubt, the opposition between statistical norms and therapeutic norms as synchronic or diachronic is too simplistic on its own, but the basic point is that 'diversity is not disease; the *anomalous* is not the pathological'.[71] The reduction of one of these categories to the other entails collapsing different conceptions of norms that should be kept analytically distinct.

The perspective that I propose also allows for a more differentiated approach to the question of human enhancement. As we saw in the first section of this chapter, the idea of the normal has been mobilised in various ways in debates on therapy

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[71]Ibid., 137.

and enhancement, often appearing as the point of descriptive and moral differentiation between them. In response to this, other commentators have rejected the notion altogether, claiming that it cannot do the work of distinguishing therapeutic interventions from enhancements. Indeed, they reason that as it is not possible to distinguish between therapy and enhancement, the latter must be as morally acceptable (if not obligatory) as the former. I argued, though, that even these theorists unwittingly rely upon an idea of the normal. The question, then, is whether the normal can be recuperated in such a way that it does not commit one to either a strong conception of human nature or of species-typical functioning and their attendant problems. I have argued that it can be; moreover, it can be in such a way that does not lead to an overly simplistic *tout court* rejection or endorsement of enhancement technologies. As Joanna Zylinska has argued, being 'for' or 'against' enhancement is an 'impossible position to sustain'; instead, the ethical task in relation to enhancement is '*knowing how to differentiate*' and '*how to use our prostheses well*'.[72] The kind of internally differentiated conception of the normal that I am proposing here, which focuses on the flourishing of an individual as a living being in its always already social environment, may be one of the tools we need in order to take up this task.

2.5 Conclusion

I began this chapter by examining three different approaches to the problem of the 'normal' and its use as a standard of moral differentiation between therapy and enhancement. This provided a way of considering the extent to which the idea of the normal undermines value pluralism, a key principle in establishing the liberality of liberal eugenics. I argued that defences of liberal eugenics fail to take adequate account of the force of social norms in shaping individual decisions. In the second section I elaborated on this through the 'normalisation critique' made by scholars who draw on the work of Foucault in their discussions of genetics and eugenics. Of the 'normalisation critique', I claimed that an over-zealous focus on social norms obscures the contributions that the immanent norms of the body may make to questions of health and normality. Finally, I provided a brief sketch of an alternative way of thinking about the idea of the normal human being that starts from the complex interaction of social and biological norms. This idea allows for an ethical recuperation of the normal, without relying on problematic conceptions of species-being, or externally applied idealising standards against which anomalous bodies are judged to be inadequate. In this, recognition of the constitutive tensions and transformability of the notion of the normal can allow us to more fully confront the ethical task of our own self-making.

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[72]Zylinska, Joanna. 2010. Playing God, playing Adam: The politics and ethics of enhancement. *Journal of Bioethical Inquiry* 7(2), 155, 158.

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Chapter 3
Reproductive Autonomy as Self-Making

> *Over himself, over his own body and mind, the individual is sovereign.*[1]

3.1 Introduction

I mentioned in the previous chapter that liberal eugenics relies on two principles to distinguish itself from previous historical manifestations of eugenics, the first of which is value pluralism and the second of which is individual liberty. These two principles are fundamentally interrelated: value pluralism presupposes and relies on the political liberty of individuals. It requires that individuals have the liberty to live in accordance with their own values and conceptions of the good. The protection of individual liberty also requires value pluralism; the principle of value pluralism helps to ensure a wide domain in which individuals can act without unjustified constraint on their liberty. In John Stuart Mill's words, 'the only freedom which deserves the name, is that of pursuing our own good in our own way'.[2] Further, in his classic formulation of the limits of freedom thus conceived he argues that the only justification for limiting freedom is in order to prevent harm to others. Thus, the principle of harm plays a key role in the negotiations of liberty and value pluralism. This also ensures a central role for the principle of harm in debates on reproduction. As I mentioned in the previous chapter, it may be that the principle of harm is the primary limitation on value pluralism in relation to individual parental decisions. It is to these negotiations of individual liberty and harm that I turn in this and the following chapters.

Arguments for the moral legitimacy of liberal eugenics rely centrally on the claim that this project is morally distinct from its totalitarian predecessor because it protects or enhances, rather than restricts, reproductive freedom. While earlier eugenic

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[1]Mill, John Stuart. 1989. *On liberty and other writings*. Cambridge: Cambridge University Press, 13.

[2]Ibid., 16.

programs emphasised state intervention in and control of reproduction within a population, the new, flexible eugenics places emphasis on the unrestricted decision-making of individual parents as the best defence against coercive reproductive policies and practices. As John Harris argues:

> 'the best way both to avoid totalitarianism, and to escape the possibility of … prejudice, either individual or social, dictating what sort of children people have, is to permit free parental choice in these matters … For such choices are for the most part likely to be as diverse as the people making them'.[3]

This strong emphasis on reproductive freedom means that two particular issues immediately present themselves for further reflection. First, what is reproductive freedom, or in other words, what kind of freedom is it? Second, what are the limits of reproductive freedom? Interestingly, while there has been much discussion of the second of these questions, particularly in terms of the principle of harm derived from Mill, there has been significantly less articulation of what 'reproductive freedom' actually amounts to. The conjecture upon which this chapter is based is that a fuller response to the first of these questions will help to address the second of them, though it will not wholly resolve it.

As the above quote from Harris suggests, much of the discussion around reproductive liberty emphasises the importance of defending the free choice of parents against state coercion. This emphasis construes reproductive liberty as a negative freedom, in that what is at issue is the non-impedance of parental choice. Of course, this approach has a strong heritage in liberal normative philosophy and I do not wish to entirely reject it here. However, I want to argue in this chapter that reproductive freedom can also be understood as a form of positive freedom – that is, as the freedom to make oneself according to various ethical and aesthetic principles or values. To make this argument, I draw on the work of Michel Foucault, and particularly his later conceptions of ethics as a practice of the self. Foucault's later work focuses on the ways in which ethical subjectivity emerges in practices that enact moral principles or codes, which he sees as being closely related to a 'practice of liberty'. Both adopting and adapting Foucault's notion of the practice of liberty, I argue that reproductive autonomy requires enactment to gain meaning within the life contexts of prospective parents. That is, it is not merely a principle of right but a practice that produces ethical subjects in its enactment. In short, human reproduction should be understood as a deeply personal project that integrates both negative and positive freedom and, moreover, produces ethical subjects.

3.2 The Presumptive Priority of Reproductive Liberty

In general terms, the principle of procreative or reproductive liberty has at its core Mill's conception of the extent and limits of freedom, and determines that a more or less broad domain of freedom should be protected from state intervention for

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[3]Harris, John. 1998. Rights and reproductive choice. In *The future of human reproduction: Ethics, choice and regulation*, eds. John Harris, and Soren Holm, 22. Oxford: Clarendon Press.

procreative decision-making. While elaborated in different ways, the principle of procreative liberty is often supposed to take presumptive priority, such that attempts to limit such liberty must meet a high standard in order to override the importance of liberty rights. A majority opinion regarding any particular reproductive technology, such as genetic enhancement or cloning, would not in itself be sufficient to meet that standard. Instead, it is argued that attempts to place limitations on procreative liberty have to establish that reproductive technologies would cause a sufficiently high degree of harm to warrant impinging on the rights of parents to choose according to their own interests and values. While I take up questions of harm in more detail in the following chapter, here I focus specifically on the conception of liberty in regards to reproduction to which this liberal tradition has given rise.

In this tradition, one of the staunchest advocates of new reproductive and genetic technologies, John Harris, argues in his recent book that the 'democratic presumption' in favour of individual liberty protects a wide freedom to access reproductive technologies, including those used for enhancement purposes. Further, the presumption in favour of the freedom of citizens to make their own choices without interference places the burden of proof on attempts to limit freedom. Specifically, Harris argues that such attempts at limitation must show that serious harms to individuals and society would result from the exercise of reproductive freedom, where that harm must also be 'real and present, not future and speculative'.[4] In this view, the right to reproductive liberty has a trumping power in debates on the restriction or extension of reproductive choice.

Importantly, Harris asserts that the right to reproductive liberty should be solely understood as a negative right of non-interference, such that it does not oblige others to participate in projects to exercise that freedom. For him, 'it should go without saying' that a right to reproductive liberty does not obligate others to cooperate in the realisation of procreative interests. Reproductive liberty only means that, 'neither the state nor professional organizations, nor advisory or regulatory bodies',[5] may legitimately prevent such cooperation. However, the requirement that reproductive liberty is a negative freedom that only requires the non-curtailment of reproductive choice may not be as easy to sustain as Harris supposes. This is because any effective capacity to exercise the right to access such technologies that reproductive liberty is supposed to protect will require the cooperation of medical experts and others to ensure the success of that reproductive project. This suggests that there may be a weak positive right which requires that reproductive liberty is not simply *honoured,* but *promoted.*[6] What is at stake in this distinction is whether the right course of action in a given situation simply respects important values or contributes to the

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[4]Harris, John. 2007. *Enhancing evolution: The ethical case for making better people*. Princeton and Oxford: Princeton University Press, 74.

[5]Harris. *Enhancing evolution*, 74.

[6]See Sparrow, Robert. 2008. Is it 'every man's right to have babies if he wants them'? Male pregnancy and the limits of reproductive liberty. *Kennedy Institute of Ethics Journal* 18(3):280–282. On the distinction between honouring and promoting, see Baron, Marcia, Phillip Pettit, and Michael Slote. 1997. *Three methods of ethics: A debate.* Malden: Blackwell; Pettit, Phillip. 1989. Consequentialism and respect for persons. *Ethics* 100(1):116–126.

overall realisation of them. Consequentialists, of which Harris is one, generally take the second view that actions should promote the overall realisation of important values. This would entail that others are obliged to assist in the overall realisation of the important value of reproductive liberty. To be clear, I am not arguing that there is such an obligation, but at the very least, it is not obvious that there is no such obligation.

Adding further weight to the claim that he is ultimately unable to maintain a strict distinction between negative and positive liberty rights in reproduction, Harris is not satisfied with the idea that reproductive liberty is simply a matter of the satisfaction of bare preferences 'like drinking coffee or playing tennis'. Instead, he argues that it is more fundamental, and in fact can be considered to be a 'basic human right' akin to rights for freedom of expression and freedom of religion. This means that claims against the presumption of freedom in reproductive choices must be 'proportionately stronger, and the harms that are claimed to result from its exercise must be proportionally greater'.[7] This view of reproductive liberty as a basic right gives it a trumping power in moral debates on reproduction. The uncontroversial interpretation of this would be that it establishes that the right to reproductive freedom overrides other non-rights claims. But it might also be argued that as a *basic* right, reproductive liberty also overrides other kinds of rights claims, such as, say, the right of a medical practitioner to not provide treatments that they personally find morally offensive. Whether Harris wants to make this stronger claim for reproductive liberty is unclear, as are a number of other possible implications of the view of reproductive liberty as a basic right. To draw out this claim further, then, I want to focus on two issues – first, the argument that reproductive liberty is a basic moral right, and second, the kind of freedom that Harris takes it to be.

In establishing the claim that reproductive liberty is a 'dimension of a fundamental human right', Harris draws extensively on the work of Ronald Dworkin. This is interesting since the text that Harris quotes in *Enhancing Evolution* to establish the claim is Dworkin's *Taking Rights Seriously*,[8] in which he develops what is perhaps one of the strongest rejections of the idea that there is an abstract right to liberty. Dworkin argues, 'there exists no general right to liberty at all',[9] and further, the claim to a right to liberty cannot be resuscitated through a distinction between liberty as licence and liberty as a basic right. Instead, he claims that if constraints on basic liberties harm us, it is not because of the constraint on liberty itself, but because of its impacts on something beyond liberty. Specifically, this means that 'what we have a right to is not liberty at all, but to the values or interests or standing that this particular constraint defeats'.[10] Ultimately, Dworkin argues that equality is more fundamental than liberty, and proposes a liberal conception of equality as centrally requiring a 'right to equal concern and respect'.[11]

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[7]Harris. *Enhancing evolution*, 76.

[8]Dworkin, Ronald. 1977. *Taking rights seriously*. 1st edn. London: Duckworth.

[9]Ibid., 269.

[10]Ibid., 271.

[11]Ibid., 273.

While this suggests some tension in Harris' claim for liberty as a democratic presumption, it does not show his construal of reproductive liberty to be inaccurate or misleading. Rather, it directs attention to the ways in which the *specific* right to procreative liberty might be defended. While Dworkin rejects the idea of an abstract right to liberty, he nevertheless maintains the possibility of rights to specific liberties, especially those that protect values of particular importance or moral and political significance. Such rights include those of freedom of religion and freedom of speech or expression. For Dworkin, the principle of procreative autonomy is guaranteed by the First Amendment of the United States of America's Constitution, which protects freedom of religion and expression.[12] While Dworkin's argument is more complicated than is discussed here, Harris' argument for reproductive freedom as a basic right similarly relies on the moral comparability between it and the right to freedom of expression, which is often considered fundamental in liberal democratic states. The comparability or analogy derives, he argues, from the fact that both have at their core the 'freedom to choose one's own way of life and live according to one's most deeply held beliefs'.[13] Compelling as this might initially sound, the analogy between reproductive liberty and freedom of expression is not convincing.

As Onora O'Neill argues, while reproduction matters to people and allows them to express or enact their deeply held beliefs, it does not follow that it should be seen as a matter of self-expression, or that a right to self-expression can establish a right to procreative liberty. Reproduction, she points out, 'aims to bring a third party – a child – into existence'; reproduction 'aims to produce a dependent being', such that the requirements of care often curtail rather than enhance individual autonomy.[14] While O'Neill's point suffers from presupposing an opposition between autonomy and dependency that may prove unsustainable, I want to push her point about the falseness of the analogy between reproductive liberty and freedom of expression further. For, in my view the fundamental problem with this analogy lies in the fact that the former aims to produce another rights-bearing individual while the latter does not. To neglect that point of difference or to subsume it under the claim to self-expression leads to a form of moral narcissism, understood as a failure to recognise the other as other and their consequent incorporation into one's own self-regard. I return to this point later in the book, but for now, let me say more about reproductive liberty.

We have seen that what is at issue in the defence of procreative liberty rights is not an abstract right to liberty per se; instead, the importance of such rights derives from the significance in people's lives of the values and beliefs of which liberty allows expression. Harris indicates that the importance of procreative liberty derives from respect for the values that underlie procreation, such that what this right protects

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[12]Dworkin, Ronald. 1993. *Life's dominion: An argument about abortion and euthanasia.* London: HarperCollins Publishers, 160–168.

[13]Harris. Rights and reproductive choice, 35; Harris. *Enhancing evolution*, 78.

[14]O'Neill, Onora. 2002. *Autonomy and trust in bioethics.* Cambridge: Cambridge University Press, 61–62, 66.

is the 'freedom to choose one's own lifestyle and express, through actions as well as through words, the deeply held beliefs and the morality which families share and seek to pass on to future generations'.[15] In formulating reproductive liberty in this way, Harris again draws substantially on Dworkin, specifically his construal of autonomy and its role in relation to procreation.

For Dworkin, the key point of reference for autonomy is not rationality; instead, autonomy centrally relates to conceptions of integrity and dignity. He argues that the right to autonomy, understood as the right to make important decisions for oneself, derives from the capacity that the right protects to shape our own lives according to the values, commitments, convictions and interests that are important to us. He writes, '[r]ecognizing an individual right to autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our own coherent or incoherent – but in any case, distinctive – personality'.[16] Further, 'freedom is the cardinal, absolute requirement of self-respect', since 'no-one treats his life as having any intrinsic, objective importance unless he insists on leading that life himself, not being ushered along it by others'.[17] Regardless of the merits or otherwise of Dworkin's account of autonomy, the important point here is that in drawing on this account, Harris' conception of reproductive liberty runs into considerable tensions.

For on the one hand, he insists that what is at issue in reproductive liberty is a right to a negative liberty that protects parents against the imposition of external constraint on reproductive choices. But on the other hand, he grounds this claim to negative liberty on a stronger conception of autonomous self-creation through living in accordance with one's deeply held values and beliefs. That is, the claim to a negative liberty rests on a more positive freedom, which Isaiah Berlin classically characterised as the wish to be one's own master, in the sense that one's decisions depend on oneself rather than on external forces.[18] While Harris may be loath to admit to a positive dimension to reproductive liberty, it nevertheless appears here as the foundation for his strong emphasis on unrestricted parental choice. While this might identify tensions in Harris' account of reproductive liberty, suggesting that he is unable to maintain a strong distinction between negative and positive liberty, I am not suggesting that this dependence is a problem in itself.

Rather, this close connection between negative freedom and the capacity to live a life in accordance with one's own values offers a potentially rich path for understanding the importance of autonomous decision-making in relation to technologies such as genetic enhancement. In particular, it allows for greater attention to the ways in which reproductive liberty is enacted and negotiated in everyday practice, not simply as a right to unimpeded action, but as a process of ethical self-formation.

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[15]Harris. *Enhancing evolution*, 76.

[16]Dworkin. *Life's dominion*, 224.

[17]Ibid., 238–239.

[18]Berlin, Isaiah. 2002. Two concepts of liberty. In *Liberty*, ed. Henry Harris. Oxford: Oxford University Press.

I take this up in the following section, but before turning to that, it is worth considering another formulation of reproductive or procreative liberty that does not rely on the problematic association between freedom of expression and reproductive liberty, and is more explicit about the role that values traditionally associated with procreation play in both grounding a right to reproductive liberty and placing limits on it.

John Robertson offers one of the more fully elaborated arguments for the presumptive priority of procreative liberty in his strong rights based approach to reproduction and the limits of freedom. In order to establish the presumptive priority of procreative liberty, Robertson similarly relies upon the intuition that reproduction is a core human activity and decisions about reproduction have a deep significance for personal identity and the meaning of one's life. He argues:

> Procreative liberty should enjoy presumptive primacy when conflicts about its exercise arise because control over whether one reproduces or not is central to personal identity, to dignity, and to the meaning of one's life ... Decisions to have or avoid having children are thus personal decisions of great import that determine the shape and meaning of one's life.[19]

In Robertson's terms, the 'existential' significance of procreation relates closely to a biological drive to reproduce that connects us with nature and future generations.[20] As such, reproduction can provide solace in the face of death, but its significance may also encompass the expression of love between couples, as well as a religious dimension for many persons. Whether or not one agrees with these formulations of why it is so, the intuition that reproductive decision-making is of deep significance for personal identity and the shape of one's life appears relatively uncontroversial. However, what is interesting is the kind of work that Robertson expects this intuition to do in terms of establishing both the presumptive priority and the limits of reproductive liberty.

At the most basic level, Robertson defines procreative liberty as the 'freedom to reproduce or not to reproduce in the genetic sense'.[21] In this, reproduction is restricted such that the act of reproducing may or may not entail subsequently engaging in the process of childrearing. Reproductive liberty, however, only protects activities directly related to the question of whether to reproduce or not to reproduce – it does not extend to practices of parenting. Further, Robertson's construal of reproduction also centrally entails a genetic relatedness between parent and offspring. This may seem overly restrictive in light of in vitro fertilisation processes that separate genetic and gestational reproduction, and to incorporate this, Robertson also extends procreative liberty to female gestation, with or without a genetic connection to the child that results. Thus, surrogacy may still be considered

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[19]Robertson, John A. 1994. *Children of choice: Freedom and the new reproductive technologies*. Princeton, NJ: Princeton University Press, 24.

[20]Also see his more elaborate discussion of the importance of biological connection in his defence of 'modern traditionalism' in Robertson, John A. 2003. Procreative liberty in the era of genomics. *American Journal of Law and Medicine* 29(4):450–452.

[21]Robertson. *Children of choice*, 22–23.

a form of reproduction. While the moral or ethical significance of genetic related-
ness is controversial, this is not my focus here. Instead, what is more interesting for
my argument is the way in which the perceived existential value of reproduction is
used to place limits on some reproductive practices.

Robertson's definition entails that procreative liberty has two strands in that it
covers both the freedom *to not reproduce* and the freedom *to reproduce*, each of
which involves different interests. In general terms, the first involves interests in
access to the means of preventing pregnancy, in the forms of refraining from sexual
intercourse, the use of contraception or access to abortion. The second primarily
entails 'the freedom to engage in a series of actions that result in reproduction'.[22]
However, it is more complex since it also involves potentially differing interests
relating to coital and non-coital reproduction. While the interests associated with
coital reproduction (such as freely choosing a partner, engaging in sexual intercourse
and gaining access to medical assistance to ensure birth) are relatively uncontrover-
sial in advanced liberal democratic societies, the technological advances that make
non-coital reproduction increasingly available raise substantial questions about the
limits of reproductive liberty.

For Robertson, it is self-evident that coital reproduction is protected by the prin-
ciple of procreative liberty. As he points out, parents do not require licences to
have children, nor are they required to provide justification for doing so. However,
technologies for non-coital reproduction test the limits of procreative liberty, and
Robertson proposes that the means for establishing whether such technologies fall
within its scope is the test of proximity. That is, whether new reproductive tech-
nologies and practices such as non-therapeutic genetic enhancement, reproductive
cloning and the intentional diminishment of offspring are protected rests on their
proximity to the core interests of reproduction, core interests that are exemplified in
the practice of old-fashioned coital reproduction. Applying this test, he concludes
that such practices 'would not fall within procreative liberty because they deviate
too far from the experiences that make reproduction a valued experience'.[23] This
somewhat infelicitous formulation is supposed to indicate that such practices do not
accord with the 'core interests' protected by procreative liberty.

Unfortunately, within the context of Robertson's argument in *Children of Choice*,
these 'core interests' remain somewhat obscure. It does, however, appear that one
of the, if not *the*, core interest of reproduction is the desire to bear 'normal healthy'
offspring.[24] In this view, it is the desire to have a normal healthy child that is genet-
ically related to at least one of his or her parents that ensures the significance of
reproduction as an activity that gives meaning to human lives. Further, the centrality
of this desire and its realisation establishes the presumptive priority of procreative
liberty while also setting out its limits. While this clarification seems essential to
establishing the limits of reproductive liberty, Robertson's attribution of substantive

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[22] Ibid., 30.

[23] Ibid., 167.

[24] Ibid., 149.

content to the core interests involved in reproduction also introduces complexities into his argument that are not fully acknowledged.[25]

For one, without explicit discussion, Robertson here takes recourse to notions of normality and health to distinguish between reproductive activities that fall within the scope of procreative liberty and those that do not. Given this, his argument should be subject to the analysis of the concept of normalcy that I proposed in the previous chapter. Moreover, Robertson goes on to restate the principle of procreative liberty in the claim that, 'procreative liberty would protect only actions designed to enable a couple to have normal, healthy offspring whom they intend to rear'.[26] He defends this approach as a form of 'modern traditionalism', by which he means an approach that, 'is modern in its acceptance of new technologies, but traditional in demanding that those techniques ordinarily serve traditional reproductive goals of having biologically related offspring to rear'.[27] This approach strives for a happy medium between the radical libertarian view that allows free access to all reproductive technologies and the traditionalist view that emphasises the perceived sacredness of human reproduction, and which tends to disallow technological interventions.

With this formulation of the principle of procreative liberty, though, we have moved some distance from the initially stringent formulation Robertson offered, whereby what was at issue was simply the liberty to decide for oneself whether to have children or to not have children. In this, reproduction was distinct from rearing, and the latter was not protected by procreative liberty. Now, modern traditionalism requires both *genetic connectedness* and the *intent to rear* offspring. This reformulation suggests that Robertson is unable to maintain the strict distinction between reproducing and rearing that he initially desired. But what, then, is the significance of this? As I have said, the presumptive priority of procreative liberty rests on the perceived existential value of reproduction in personal identity and in leading a meaningful life. But is it really credible that this existential significance rests on (biological) reproduction alone, or does it rather rely on the integration of reproduction and rearing? Contrary to Robertson, I suggest that reproduction *strictly defined* is neither necessary nor sufficient to establish the presumptive priority of procreative liberty. Instead, practices of childrearing and their ethical significance are built into Robertson's understanding of procreative liberty from the start. That is, it is not simply genetic inheritance that establishes the importance of reproduction in people's lives; rather, it is the bonds of familial attachments, and the vulnerability and responsibility that they entail, in the variety of forms they take, that ensure the existential and ethical significance of reproduction.

If this is right, then it suggests that the nature of procreative liberty is unlikely to be adequately understood if it is simply taken to be a negative liberty or a matter of unimpeded choice. Nevertheless, as with Harris, Robertson is explicit

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[25]Ibid., 150–172, passim.

[26]Ibid., 167.

[27]Robertson. Procreative liberty in the era of genomics, 446.

that procreative liberty must be understood as a negative right or right of non-interference. He states that reproductive liberty:

> means that a person violates no moral duty in making a procreative choice, and that other persons have a duty not to interfere with that choice . . . [it] does not imply the duty of others to provide the resources or services necessary to exercise one's procreative liberty.[28]

At a constitutional level, procreative liberty protects against the interference of the state in procreative choices, but it does not entail a positive right to assistance from the state or any other person in the realisation of one's procreative choice. This understanding of procreative liberty as a negative right delimits a sphere of non-interference and understands the freedom involved in procreative liberty as a negative freedom, that is, a freedom from external constraints on the realisation of one's interests. However, given the significance of reproductive decision-making and the ongoing project of childrearing in the lives of parents, the construal of procreative liberty as negative freedom does not do full justice to the nature of the freedom entailed in such choices and the life plans of which they form a part.

In this sense, Robertson is subject to the same critique as I made of Harris, that the delineation of procreative liberty as solely negative is unsustainable. Instead, procreative liberty can also be seen as a form of positive freedom, here understood as freedom based on a capacity to shape one's own goals and values and to adopt and practice subjective ways of being that accord with those. We have seen that the approaches of Harris and Robertson stress the moment of choice rather than the implications of self-making that the conceptions of autonomy and reproduction that they draw on suggest. However, their reliance on these ideas introduces a complexity into procreative liberty that they leave unaddressed. In particular, they underestimate the ethical implications of construing reproductive autonomy as an activity in which one gives shape to one's own life – and in doing so, also shapes the lives of others. Neither Robertson's nor Harris' understanding of reproductive liberty goes nearly far enough in elaborating the conditions of possibility for the enactment of reproductive freedom, or considering the implications of the self-creative dimension of such enactment.

In order to elucidate this self-creative dimension of reproductive liberty, I turn in the following section to the later work of Michel Foucault. In this work, Foucault examines the practices of the Ancient Greeks in relation to sexuality to highlight the way that freedom is itself a positive practice of self-formation, realised through the enactment of significant values in everyday life. In doing so, he initiates an approach to ethics that emphasises the constitutive relation of one's self to self in relation to norms and values. I draw on this work to argue that reproductive liberty is a form of positive freedom that consists in the capacity for self-formation. Further, I will argue that reproductive autonomy can be seen as both a practice and problematisation of freedom, for what current debates and disagreements on new reproductive technologies show is that the very limits of freedom are being negotiated in its enactment.

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[28]Robertson. *Children of choice*, 23.

3.3 Enacting Freedom: The Ethical Practice of Reproductive Autonomy

Throughout his work, Foucault was concerned with the historical and social production of forms of subjectivity, ranging from the madman, through the infamous characterisation of 'docile bodies' in *Discipline and Punish* to the 'confessing' and 'desiring subject' in the *History of Sexuality* series. But while his work up until the first volume of *History of Sexuality* focused on the production of subjects through technologies of power, Foucault claims that in the research he undertook for *The Use of Pleasure*, he became increasingly aware of a different aspect of the production of subjectivity. Of this, he comments that the task of providing a 'history of desiring man' required that he focus not only on the ways in which subjectivity is produced through the operations of regimes of power and knowledge, but also on 'the forms and modalities of the relation to self by which the individual constitutes and recognizes himself *qua* subject'.[29] On the basis of various discussions of different historical modes of acting upon oneself and techniques for doing so, he identifies this dimension of the production of subjectivity under the broad term of 'technologies of the self'.[30] By this, he indicates the practices and means by which individuals act upon themselves as *ethical* subjects, that is, the way in which individuals make themselves up as subjects by enacting particular moral codes, modes of being, or aesthetic or ethical criteria.[31]

In sketching the parameters of the way in which individuals make themselves up as ethical subjects, Foucault outlines four practically interrelated but analytically distinct aspects of this activity, which are worth repeating here for heuristic purposes. The first of these entails the identification of one or another part of oneself or of one's life as the object of moral conduct. The second, which he calls the 'mode of subjection' isolates 'the way in which an individual establishes his relation to the [moral] rule and recognizes himself as obliged to put it into practice'.[32] In other words, it isolates the way in which a rule comes to be seen as having a bearing on one's life and conduct. Third, ethical self-formation entails a more explicitly active and reflexive dimension in the 'ethical work' that one undertakes upon oneself, the kinds of practices, behaviours and techniques that one adopts in order to bring oneself into accord with a rule or value. And finally, it entails a '*telos*'. For an action is not simply moral in isolation but also 'by virtue of the place it occupies in a pattern of conduct', which commits an individual to a certain 'mode of being characteristic

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[29]Foucault, Michel. 1987. *The use of pleasure: The history of sexuality*. Vol. 2. (trans: Hurley, Robert). London: Penguin, 6.

[30]Foucault, Michel. 1993. About the beginnings of the hermeneutics of the self. *Political Theory* 21(2):203.

[31]It should be noted that Foucault distinguishes between ethics and morals, where the latter refers more directly to codes and rules, and the former refers to a way of being or *ethos*. See Foucault. *Use of pleasure*, 25.

[32]Ibid., 27.

of the ethical subject'.[33] By identifying an aspect of oneself for moral transformation, bringing that aspect into relation with a moral rule, enacting certain practices that allow for or bring about the desired transformation, and having a vision of the end or purpose of that transformation, one creates oneself as an ethical subject.

Summarising these four dimensions, Foucault writes that, 'self-formation as an "ethical subject" ' involves, 'a process in which the individual delimits that part of himself that will form the object of his moral practice, defines his position relative to the precept he will follow, and decides on a certain mode of being that will serve as his moral goal'.[34] This means that ethical self-formation involves much more than simply 'self-awareness'. The crucial dimension of technologies of the self is the relation that individuals establish with themselves, the nature of which is determined in relation to sets of values, principles and codes for living. This subsequently shapes the way in which individuals constitute themselves as subjects of their own actions through certain practices and associated matrices of knowledge. It is a matter of developing a reflexive relation to oneself that constitutes oneself as an ethical subject of one's own actions, through the selection of a certain action or form of being as the object of ethical concern and transformation according to more or less voluntarily applied criteria. Or in other words, it entails a transitive relation of auto-affection, whereby who one is comes into being through one's own relation to oneself and associated practices of self-formation.[35]

One centrally important aspect of Foucault's approach to ethical subjectivity is his opposition to the Cartesian and phenomenological conception of a psychologically substantive being that exists prior to the operations of power and technologies of the self. Instead, he emphasises the way in which subjectivity emerges from and is shaped by historical and culturally located experiences. Subjectivity is understood as an artefact of practices of self-formation, where that self-formation encompasses both the operations of power/knowledge and techniques of the self. This means that the ethics of the self does not presuppose a more or less voluntaristic subject that exists prior to its formation through acting upon itself. [36] Practices of self-formation are not simply expressions of choice, whether enacted in words or actions, of a preexisting individual; rather, the individual subject only emerges as an artefact of the enactment of those choices. Even so, the ethical subject that Foucault describes is not a heroic figure that creates itself ex nihilo. Foucault explains:

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[33] Ibid., 28.

[34] Ibid.

[35] See Han, Béatrice. 2002. *Foucault's critical project: Between the transcendental and the historical* (trans: Pile, Edward). Stanford: Stanford University Press, esp. 149–187; for further discussion of the conception of the relation of self to self that Foucault relies upon and the tensions that it introduces into his work.

[36] See, Macherey, Pierre. 1998. Foucault: Ethics and subjectivity. In *In a materialist way: Selected essays*, ed. Warren Montag, 96–107. London: Verso.

> [while] the subject constitutes itself in an active fashion through practices of the self, these practices are nevertheless not something invented by the individual himself. They are models that he finds in his culture and are proposed, suggested, imposed upon him by his culture, his society, his social group.[37]

Practices of the self are to a large extent given by the culture in which an individual lives, and in taking up such practices and putting them into effect in his or her own life, each individual actively constitutes his or her own identity and ethical capacity within the context of their own sociocultural location. Thus, it is through the adoption, enactment and alteration of norms and models that may already be found in a culture or society that the self emerges.

In light of this, it is a source of much confusion in secondary literature that Foucault goes on to associate the practice of ethical self-formation with what he calls a 'practice of liberty'. Much of the secondary literature emphasises the transgressive aspect of such a notion, whereby a practice of liberty is understood as roughly congruent with forms of political resistance. However, another inflection is also possible. In his characterisation of Ancient Greek practices, Foucault emphasises that the practice of ethical self-formation he describes delimits 'an ethics for men: an ethics thought, written and taught by men and addressed to men – *to free men* obviously'.[38] It may well be possible to criticise the theoretical extension of such a gender-specific model of ethical practice beyond its initial social and historical location. However, it is important that the ethical practices described by Foucault were not directed at men by virtue simply of their being male. They are, rather, directed at free men by virtue of their being *free*. The point of emphasising this is that those engaged in such a practice of liberty were not simply striving to become free, but were in fact already considered to *be free*. On the basis of this, Foucault argues that for the Ancient Greeks, an ethics of the self involved a self-reflexive relation to one's own freedom that made of that freedom an object of both ethical concern and a practical exercise. The *ethos* or aesthetics of existence that one develops is predicated on and directed toward the elaboration of one's liberty in relation to a particular domain of behaviour. A 'practice of liberty' entails that freedom is not given once and for all, but requires a practical exercise upon oneself to be delimited, maintained and elaborated.

Let me now return to the issue of reproductive liberty. Given his focus on a privileged political elite in Ancient Greece, it is pertinent to ask what validity Foucault's understanding of a practice of the self could possibly have to contemporary life, and particularly to the prospects of new reproductive practices such as genetic enhancement. It is altogether too obvious to point out that the general political development of the West has seen the extension of rights and the freedom they can entail to a much wider population than was the case in Ancient Athens. But in light of this,

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[37]Foucault, Michel. 1984. The ethics of concern for the self as a practice of freedom. In *Ethics: Subjectivity and truth, essential works of Michel Foucault, 1954–1984*, ed. Paul Rabinow, 291. London: Penguin.

[38]Foucault. *Use of pleasure*, 22; my emphasis.

by extrapolating the analytic principles that Foucault outlines from the model of an Ancient Greek practice of freedom to the context of advanced capitalist liberal democracies, it can be argued that liberty rights similarly entail the enactment and practice of freedom today. By this, I mean that it is precisely by virtue of being free – in the sense of being subjects of liberal democratic governance that presupposes the political value of liberty and extends liberty rights to all citizens – that we can engage in practices of freedom. Conversely, it is to the extent that citizens engage in practices of freedom that the liberal democratic principle of liberty rights for all citizens is enlivened and given a reality within the context of everyday life. In this sense, it is by virtue of engaging in practices of freedom that the free subject of liberalism has a reality.

It is not hard to subject the democratic presumption of reproductive liberty to the typology of an ethics of self-formation that Foucault suggests. In this light, the democratic presumption appears as a norm of individual freedom that is given in the culture of Western liberal democracies, a norm which may be contested in various ways, but which is also deeply embedded in the institutions, values and practices of such cultures. Through its enactment in quotidian practices, that norm produces free subjects as artefacts of its enactment. In terms of the four dimensions of self-formation as an ethical subject that Foucault picks out, it is possible to see that the *telos* of such a practice, whether explicitly or consciously recognised or not, is to become a free (reproductive) subject. The part of oneself that is isolated for transformation is the desire and capacity for reproduction and associated activities of childrearing, and the 'mode of subjection' is that of engaging a form of liberal democratic subjectivity predicated on principles of freedom, rationality and autonomous self-realisation. Finally, the practices of subjection entail taking responsibilities for decisional choices, along with the myriad practices that engage subjects as reproductive agents, from the use of contraception to prevent pregnancies, to the negotiations of medical procedures and technical expertise in more interventionist procedures to achieve conception, and the maintenance of a successful pregnancy that ideally gives rise to a 'normal healthy child'. Thus the free (reproductive) subject is born.

To be clear, this brief account of the birth of the free reproductive subject does not mean that reproductive liberty is simply illusory, that it is simply a matter of 'false consciousness' where deeper analysis reveals the thorough determination of subjectivity. That individual freedom is a cultural norm that relies on enactment for its reality does not mean it does not have a distinctive force as a moral idea or principle. It clearly does have such a force in Western liberal democracies and elsewhere, even if it is contested. The point is not that this is undermined by its being a norm of subjection, but that the force of individual freedom as a moral norm is inseparable from it being a norm of subjection. As Nikolas Rose has analysed, freedom, and especially freedom of choice, is increasingly the matrix through which individuals are expected to and do interpret themselves and their actions. He argues that individuals are expected to 'interpret their past and dream their future as outcomes of choices made or choices still to be made'. This ultimately means that 'modern

individuals are not merely "free to choose", but *obliged to be free*'.[39] In this light, the presumptive priority of reproductive liberty can be seen as one discursive mechanism by which the liberal obligation to be free is taken up and enacted in ethical self-formation.

It is worth noting here too, that the freedom of individuals that liberalism makes central is primarily seen as the mechanism by which the relationship between the governed and governing is negotiated. Or, more specifically, what is at stake in liberal formulations of negative freedom such as those discussed in the previous section is what can be called the 'independence of the governed with regard to government'.[40] But rather than being simply or strictly opposed to government, that freedom is itself produced by and through a liberal rationality of government, insofar as the central problematic of liberalism is the proper limitation of the scope of governance. In this sense, individual freedom is itself an artefact of liberal governance. But, if this is correct, then substantial questions arise about the interrelation of negative and positive freedom. We saw in the previous section that conceptions of reproductive liberty characterise it as a negative freedom that determines the proper scope of constraints by government on individual liberty, understood more specifically as a matter of choices about whether to reproduce or not reproduce. I have argued that reproductive liberty can alternatively be seen as a form of ethical self-formation, whereby the free reproductive subject comes into being through the enactment of the principle of individual freedom in everyday practices. This second formulation shifts focus from the absence or otherwise of external constraints on individual action to the capacities of individuals to adopt ways of life that accord with the reproductive choices and significant values that give meaning to their lives. This can be characterised as a form of positive freedom.

However, this may give the impression that I am urging a contrast – if not conflict – between two types of freedom, such as that outlined by Berlin. In his classic formulation, Berlin saw negative and positive freedom as opposed. He characterised positive freedom as a desire to be master of oneself, which involves an idea of the self split from itself, where one part is the 'transcendent, dominant controller', and the other the 'empirical bundle of desires and passions to be disciplined'.[41] Two major forms, namely, self-abnegation and self-realisation, historically typify positive freedom and Berlin suggests that both conflict with negative liberty. However, an account of positive freedom that draws on Foucault's conception of ethical self-formation, with the attendant theorisation of subjectivity as an artefact of relations of power and technologies of the self, does not necessarily lead to this opposition. Revising Berlin's distinction, Paul Patton has argued that the account of freedom

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[39] Rose, Nikolas. 1999. *Powers of freedom: Reframing political thought*. Cambridge: Cambridge University Press, 87.

[40] Foucault, Michel. 2008. *The birth of biopolitics: Lectures at the Collège de France 1978–1979* (trans: Burchell, Graham). Basingstoke: Palgrave MacMillan, 42.

[41] Berlin. Two concepts of liberty, 181.

that Foucault develops emphasises 'the importance of individual capacities as pre-conditions for the exercise of freedom',[42] and identifies two forms of constraint on those capacities. The first are external constraints and the second are internal, such as 'the psychological effects of insecurity, dependence or trauma'.[43] The first set of constraints follows a standard idea of negative freedom. The latter, however, allows for a revised notion of positive freedom: this is less a matter of a desire or will for self-government than it is of internal limitations on an individual's capacity to formulate and enact a course of action.

This characterisation of the freedom involved in self-formation helps to bring out that there are not different kinds of freedom per se, but that the realisation of capacities through either the absence of internal and external constraints is funda-mentally interrelated. Making use of one's negative freedom depends on the exercise of positive freedom in the sense that it requires the absence or overcoming of cer-tain internal limitations. Correlatively, the realisation or exercise of positive freedom also depends upon the existence of a degree of negative liberty. In other words, the freedom entailed in self-formation and the development of a subjective *ethos* nec-essarily requires the prior existence of an arena or area in which a person can act without interference and coercive limitation of the paths of action or modes of being available to them. The interrelation of negative and positive liberty might then be taken to inflect Foucault's suggestion that, 'freedom is an ontological condition of ethics. But ethics is the considered form that freedom takes when it is informed by reflection'.[44] The freedom that provides the ontological condition of ethics can be understood as negative liberty and the considered form that it takes as positive freedom, as self-formation or ethics understood as *ethos*, such that negative liberty appears as a precondition of positive liberty within Foucault's formulation of an ethics of the self. This means that negative liberty is dependent on its enactment in positive practices of freedom to gain reality and import in everyday life. In this way, negative and positive concepts of freedom do not necessarily conflict; instead, they appear as mutually reinforcing and constitute two necessary dimensions of eth-ical self-formation. If this is right, then attempts to limit reproductive liberty to a negative right of non-interference seem doomed to fail.

One significant caveat must be added at this point, which refers to the ques-tion of the obligations of others in promoting the exercise of freedom, or the extent to which reproductive liberty entails positive rights. The complexity of this issue exceeds the limits of this chapter, so suffice here to say that in arguing for recog-nition of a positive dimension to the freedom entailed in reproductive liberty, I am not making a claim for a corresponding positive right. Harris and Robertson both emphasise that reproductive freedom only entails a right of non-interference, and does not oblige anyone to assist in the realisation of another's reproductive project. Foucault's approach is less determinate. The conception of ethics and freedom that

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[42]Patton, Paul. 1989. Taylor and Foucault on power and freedom. *Political Studies* 37:262.

[43]Ibid.

[44]Foucault. The ethics of concern for the self as a practice of freedom, 285.

he offers does not posit an in principle connection between freedom and rights at all, least not legal rights, and Foucault was notoriously suspicious of rights discourse. At the same time, this approach does not reject all claims to rights. Indeed, rather than reject rights claims *tout court*, on more than one occasion Foucault identifies a need for a new conception of rights, one that is not tied to either sovereignty or disciplinary power. Building on this, Duncan Ivison has argued that Foucault allows for a naturalistic approach to rights that sees them as conduits within the operations of power and practices of freedom.[45] Rights are not simply bulwarks against power, but are historically contingent, mobile elements drawn upon in its exercise and its agonism. One implication of this is that this approach would not preclude claims to a positive right in reproductive autonomy, one that requires that reproductive projects are promoted rather than simply honoured for instance. But it does not require such a right as a necessary correlate of freedom. Construing the exercise of reproductive liberty as a practice of freedom allows consideration of the roles and responsibilities of others in the realisation of reproductive projects, but it does not stipulate in advance what those obligations might be.

Finally, if freedom is understood as enacted in self-formation, it is important to note that the entanglement of reproduction, technology, and moral choice leads not only to an extension of freedom, but to a *problematisation* of it. While central to Foucault's work, the notion of problematisation is much misunderstood and much abused. Viewed as the fulcrum of Foucault's approach to ethics in the second volume of *History of Sexuality*, the point of problematisation as a methodology and as a practice lies in the strategic identification of the 'local' contingencies of the present rather than the elaboration of moral universals. Problematisation, Foucault suggests, is a way to bring to the surface both the historical generality of a problem or set of problems within the conditions of our existence, as well as the historically specific mode of their expression. It is a mode of analysis that takes as its object the ways in which 'being offers itself to be, necessarily, thought'.[46] This means paying close attention to the ways in which generalised conditions of human existence such as sex and sexual behaviour have entered into a set of practices and discourses that gives them a historically specific form.

Recent changes in reproductive technologies and practices give rise to such a problematisation of liberty: as individuals strive to enact self-formative ethical practices by shaping their lives in accordance with closely held values and principles, they illuminate the ways in which this dimension of being has presented itself to be thought. Following Foucault, one might then seek to 'locate the areas of experience and the forms in which . . . [reproductive] behaviour . . . [has been] problematized, becoming an object of concern, an element for reflection, and a material for stylisation'.[47] Or more succinctly, we could ask 'how did reproductive behaviour come to be conceived as a domain of moral experience?' While my

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[45]Ivison, Duncan. 2007. *Rights*. Durham: Acumen, 186–196.

[46]Foucault. *Use of pleasure*, 11.

[47]Foucault. *Use of pleasure*, 23–24.

aim is not to respond to these philosophical-historical questions in detail here, this approach is nevertheless instructive. For what becomes apparent in the problematisation of human reproduction is that contemporary moral debates are themselves part of the ongoing negotiation and contestation of the nature and limits of reproductive freedom. Indeed, this contestation or agonism can be seen as an essential aspect of the realisation of reproductive liberty, as new practices such as the deliberate selection of deafness and disability in children test the limits of parental freedom and responsibility.

The deliberate selection by parents of traits for their children that are widely considered as disabilities provides one contemporary example of this negotiation and tests in a profound way traditional intuitions about reproductive ethics and parenting. Bioethical argumentation around these issues frequently relies on the related tropes that parents want the best possible lives for their children, and that the desire for healthy, normal children is overridingly strong and natural. Consequently, any deviation from the standards of health and normality constitute a breach of the underlying compact of reproduction, soliciting responses such as that of Harris, otherwise a libertarian, who suggests that the deliberate selection of disability is something that no 'decent person' would do.[48] Harris' response is related to his commitment to Mill's principle of harm as the only acceptable moral and political limit on individual freedom. At a rhetorical level, Harris' recourse to the principle amounts to an attempt to legislate the limits of freedom. But as such, it is simply another element within the problematisation of reproductive liberty. Despite its legislative rhetorical mode, it is another element within the ongoing agonism of reproductive freedom, even while it disclaims that very agonism.

3.4 Conclusion

I have argued that despite their political differences, both Robertson and Harris rest a case for reproductive freedom as negative liberty on a foundation of positive freedom. This is not problematic in itself – indeed, I suggest that an understanding of reproductive autonomy as positive freedom is vital to grasping in any real way the nature and significance of reproductive decisions and projects within our lives. What I have argued for, then, is a particular way of understanding that freedom, one that draws on Foucault's construal of ethics as a practice of self-formation. This emphasises the insight that historically contingent values and social norms are constitutive of ethical subjectivity, not in the sense that these factors *determine* subjectivity, but in the sense that ethical subjectivity is attained in practical relation to them. This means that reproductive freedom only gains meaning and reality through its enactment in everyday practices of ethical self-formation. The approach I propose allows for a richer account of the significance of reproduction in human life and

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[48] See Harris. *Enhancing evolution*, 89, 145, 189.

responds to intuitions about the deeply personal nature of reproductive decision-making. In addition, it highlights the transformative potential of the experience of reproduction, at both an individual and social level, through the problematisation of the limits of reproductive freedom in contested practices and technologies. Reproductive freedom thus appears as an ongoing, agonistic negotiation of the limits of the possible.

The point that new reproductive practices entail a problematisation of freedom and contestation of its limits implies that any more or less a priori formulation of the limits of individual freedom will necessarily also be part of that contestation. That said, some indication of how the moral and ethical limits of the practice of freedom could be established in Foucault's terms may still be warranted. Unfortunately, Foucault himself did not enter into a discussion of this, leading some interpreters to reject his account as a kind of narcissistic 'anything goes' philosophy. This impression is perhaps encouraged by Foucault's claims that a practice of freedom takes the relation that one maintains with oneself as ontologically and ethically primary. In countering this perceived tendency, a number of scholars have introduced a concern with alterity (which at a minimum requires that ethical practice respects the other *as other*) into projects of self-formation such as those involved in human reproduction.[49] This concern and potential limit on reproductive practices may prove important to prevent a Foucauldian reproductive ethics of self-formation from sliding into the moral narcissism that I suggested was a danger of seeing reproduction as analogous to self-expression. I take up this concern with alterity in a later chapter through a discussion of the concept of singularity formulated by French philosopher Jean-Luc Nancy and others. Prior to that, in the following chapter I explore in more detail the recourse that is made to the principle of harm as the limit on freedom, especially in response to the selection of traits that are typically considered to be disabilities.

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[49] See especially Oksala, Johanna. 2005. *Foucault on freedom*. Cambridge: Cambridge University Press; Ziarek, Ewa Plonowska. 2001. *An ethics of dissensus: Postmodernity, feminism and the politics of radical democracy*. Stanford: Stanford University Press.

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Chapter 4
The Limits of Reproductive Autonomy: Prenatal Testing, Harm and Disability

I argued in the previous chapter that Michel Foucault's account of the self-formative practice of ethics allows for a rich account of reproductive autonomy. His view of freedom as a practice of self-formation highlights the positive process of making oneself up in relation to norms and rules, and helps to bring out the significance that reproduction may have in human lives. It also highlights the way that the limits of reproductive autonomy are tested and established in practice. In this and the following chapters, I want to consider in more detail the ways that reproductive and genetic technologies problematise the limits of reproductive liberty, and in doing so, contribute to the constitution of the social world in which we must all live. In order to do this, I will examine the ways that the limits of reproductive liberty has typically been understood within bioethics, particularly through the lens of what has been one of the most controversial issues in reproductive ethics in recent years – the use of selection technologies that allow prospective parents to choose for or against children with traits that are typically considered disabilities.

While much of the bioethical and popular literature on human enhancement has focused on the possibilities for genetic modification to enhance certain traits, this technology is a long way from realisation. Instead, much 'enhancement' happens through the use of technologies that allow the selection of 'better' children prenatally. Two such technologies are preimplantation genetic diagnosis (PGD) and obstetric ultrasound. There have been specific debates around each of these technologies, and in the following chapters I will discuss each in turn. In this chapter, I will focus on the conceptual issues that arise around selecting for or against disability. While selection *against* disability is almost taken for granted as morally acceptable, disability critics have challenged this position and shown that it may well be founded on discriminatory attitudes that ultimately – if unintentionally – lead to a form of (morally unacceptable) eugenics. In contrast, selection for disability has often caused a kind of moral shockwave, so antithetical is it to most people's intuitions about what is 'good for the child' and thus the responsibility of parents to ensure wherever possible.

The debates over whether or not parents have the moral prerogative to choose children with or without disabilities trace, and establish, the outer limits of reproductive liberty, and at the same time challenge basic intuitions about the good life.

They also raise complex questions about moral harms. In this, they shine light on the central reliance on the principle of harm in the ethics of reproductive technologies. Especially within the utilitarian tradition, the principle of harm as articulated by John Stuart Mill provides a ready criteria for establishing the limits of reproductive freedom. Within this frame, prospective parents are free to pursue their reproductive projects to the extent that they do not cause (significant) harm to others. With regard to discussions about disability within reproductive ethics, one crucial corollary to the use of the principle of harm has been the non-identity problem outlined by Derek Parfit. According to this view, a child born with a disability is only harmed if the life he or she is likely to live is judged to be worse than the condition of not being born at all. Few lives fall into this category and as such, it seems that only rarely is harm done in choosing for a disability. This appears to point to the conclusion that parents ought to be able to choose children with disabilities if they so desire. This would seem to have radical implications – implications that disability theorists and activists might well favour; however, few commentators on selection technologies have embraced this conclusion.

Instead, consequentialist contributors to the debate are divided over the implications of the non-identity problem and the principle of harm, with many rejecting the conclusion above. In the first part of this chapter, I will canvas this problem and the ways that it has been addressed within reproductive ethics. I examine three different responses to the non-identity problem and its implications for reproductive ethics – namely, those of John Harris, Julian Savulescu and Jonathon Glover. Despite their differences, I will show that all three approaches construe disability as problematic; that is, for these prominent commentators, disability *problematises* the limits of reproductive autonomy and it does so because disability is thought of as a disvalue (though not necessarily a harm). In the second part of the chapter, I will turn to an alternative approach to disability that presupposes the value of lives of people with disabilities. I focus on the implications of the 'expressivist critique' of prenatal testing developed by disability theorists such as Adrienne Asch. This critique argues that the use of technologies to select against disability 'expresses' hurtful and/or discriminatory attitudes toward people who live with disabilities. James Lindemann Nelson has provided a notable critique of this view, claiming that the expressivist view is misplaced, since neither 'individual acts nor general practices' of prenatal screening 'necessarily express disrespectful messages'.[1] I will defend the expressivist critique against his argument, and show that plausible versions of its central claims can be developed through theoretical approaches that are little used in reproductive ethics.

4.1   Disability, Harm and the Non-identity Problem

One of the most controversial issues in reproductive ethics in recent years is that of whether parents should be permitted to deliberately choose children who will

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[1] Nelson, James Lindemann. 1998. The meaning of the act: Reflections on the expressivist force of reproductive decision making and policy. *Kennedy Institute of Ethics Journal* 8(2):165.

be born with conditions or characteristics that are typically considered disabilities. This issue has received extensive attention in reproductive ethics, much of which focuses on the decision of Sharon Duchesneau and partner Candy McCullough to select a sperm donor with a history of family deafness to increase the likelihood that they would have a deaf child. Since this would typically exclude a would-be donor from a sperm bank, the women made a private arrangement with a family friend with five generations of deafness in his family to provide sperm. Duchesneau was impregnated and subsequently gave birth to a son with only a small amount of hearing in one ear. Duchesneau is often quoted as saying, 'A hearing baby would be a blessing. A deaf baby would be a special blessing'.[2] The couple also indicated that when he is older, they would allow the child to make the decision about whether he wishes to wear a hearing aid or not.

One of the key issues in bioethical responses to Duchesneau and McCullough's decision has been whether deliberately increasing the likelihood of a child being born with a disability transgresses the harm principle, that is, whether deliberately selecting for disability constitutes causing harm to one's offspring.[3] Liberal political and moral philosophy relies on the principle of harm derived from John Stuart Mill to place limits upon individual freedom. This principle, simply stated, entails that one should be free to do as one chooses, up until the point at which one's actions cause harm to others. Part of the appeal of this principle is undoubtedly its apparent simplicity; but this simplicity is only apparent – for what counts as harm is not immediately clear from the principle itself. The everyday idea of harm is sufficiently vague that harms may not always constitute the kind of moral wrong that is to be prevented by the principle. Nor are harms and the extent of the wrong involved in a harm easily established empirically: harms can be subjective to a great degree. Further, the idea of harm is stretched to its limit in regard to cases involving future people.

In his classic essay, 'On Liberty', Mill argues – consistent with his claim that the individual maintains sovereignty over their own body and mind – that 'the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others'.[4] This harm principle denies that a person can be compelled to act or prevented from acting in accordance with the opinions of others as to their own good or best interest. It ensures that the only proper subject of constraint is the consequences of one's actions *for others*. Up until the point at which one's actions harm others, one is free to pursue one's own course without interference – even if that course might, from the point of view

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[2]See for instance, reportage of the story on BBC News Online: Anon. Couple 'choose' to have deaf baby. BBC News Online. Available at http://news.bbc.co.uk/2/hi/health/1916462.stm. For a more extensive coverage, see Mundy, Liza. 2002. A world of their own. *The Washington Post Weekly Magazine,* March 31.

[3]See Scully, Jackie Leach. 2008. *Disability bioethics: Moral bodies, moral difference*. Lanham, MD: Rowman and Littlefield, 61.

[4]Mill, John Stuart. 1989. *On liberty and other writings*. Cambridge: Cambridge University Press, 13.

of others, be opposed to one's own best interests. Mill's concern is primarily with limiting the effects of government and social regulation of the lives of individuals. The principle establishes a wide domain of negative liberty upon which the state and social regulations ought not impinge. This is a central platform of political liberalism (and libertarianism) and of moral utilitarianism. Despite its appeal, however, the principle of harm as stated by Mill is riven by ambiguity. One of these ambiguities is just what is meant by harm, and considerable philosophical attention has been paid to clarifying this.

One particularly influential effort is that of the American legal philosopher Joel Feinberg, who proposes a distinction between *harming* and *wronging* another.[5] In Feinberg's view, the principle of harm combines two understandings of harm – a *non-normative* notion of harm as setbacks to interest, and a *normative* notion of harm as a wrong. Of the first of these, he argues that interests in the important sense are distinguishable components of a person's wellbeing – and hence contribute to their flourishing or languishing – and a setback to those interests is a harm because it impacts upon wellbeing. The test for whether something constitutes a harm in this sense is whether the interest concerned is in a 'worse condition' than it would have been had the 'invasion not occurred at all'.[6] The second sense of a normative notion of harm is closely related to, but also distinct from this: '[o]ne person wrongs another when his indefensible (unjustifiable and inexcusable) conduct violates the others' right'.[7] In most cases, this will also entail invading the other's interests, and can therefore also be harmful in the non-normative sense. There are, however, some scenarios where this may not be the case, such that there can be wrongs which are not harms, just as there can be harms which are not wrongs. For Feinberg, the core of the principle of harm is the overlap of these two senses: 'only setbacks of interests that are wrongs, and wrongs that are setbacks to interest, are to count as harms in the appropriate sense'.[8] Thus he develops a counterfactual account of harm as setbacks to interest that also entail violations of rights.

John Harris points out that Feinberg's narrowing of the principle of harm in this way is related to his focus on criminal law.[9] Consequently, it is not clear whether such a conception of harm is appropriate to the application of the harm principle in ethics. However, Harris goes further than this to argue that Feinberg's way of drawing the distinction between a harm and a wrong, where the former is the proper object of law and the latter of morals, is fundamentally mistaken. He seeks to show that criminal law cannot plausibly be excluded from all cases where non-harmful wrongs have been committed, since there may be compelling social or political reasons to appeal to the law even when no-one can logically be said to be 'worse off'

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[5]Feinberg, Joel. 1987. *Harm to others*. Oxford: Oxford University Press.

[6]Ibid., 34.

[7]Ibid.

[8]Ibid., 36.

[9]Harris, John. 1998. *Clones, genes and immortality: Ethics and the genetic revolution.* Oxford: Oxford University Press, 106.

in Feinberg's sense.[10] From this, he concludes that the conception of harm provided by Feinberg is implausible and must be replaced.

As an alternative to the idea that harm entails being made worse off by the thwarting of one's interests and/or trespassing of one's rights, Harris then proposes the 'harmed condition' model of harm. He thinks it is both more economical and more plausible to say, 'to be harmed is to be put in a condition that is harmful', where a harmed condition 'obtains wherever someone is in a disabling or hurtful condition, even though that condition is only marginally disabling and even though it is not possible for that particular individual to avoid the condition in question', or more simply, 'a harmed condition is one in which an individual is harmed or suffering in some way'.[11] To harm someone, then, is to be responsible for causing that person to be in a harmed condition. As I discussed in Chapter Two, there appears to be a significant circularity in this conception of harm, and Harris attempts (unsuccessfully in my view) to avoid that circularity through the 'emergency room test' and the criterion of rational preferences.[12]

Apart from these problems, the breadth of Harris' notion of harm may well be surprising in itself, and Jonathon Glover, for instance, rejects it on the basis of it being overly broad.[13] The problem with this breadth is especially clear when we consider that Harris combines this conception of harm wherein even relatively minor disabilities count as being in a harmed condition, and the utilitarian dictum that it is as morally weighty to not prevent harm as it is to cause it. The conclusion that he draws, then, is, 'we ought not deliberately to produce a creature that will very probably suffer'.[14] Given the nature of most human lives, one might be forgiven for thinking that this would rule out a great many more reproductive projects than Harris actually has in mind.[15] Perhaps Harris' view could be rescued if the probability of suffering is comparative, that is, if suffering is *more likely* for an infant born with a disability than for others. But this is questionable, and moreover, would tend to lead Harris back to a conception of the average or the norm, which he is loath to allow. Without lingering on these potential difficulties in Harris' argument, the point to note is that Feinberg and Harris disagree over the breadth of the definition of harm, and what will therefore be limited by the application of the principle of harm.

But underlying this disagreement is another, more puzzling, ambiguity in the principle itself. In formulating the principle of harm as the key limitation of an

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[10]The thought experiment Harris uses to establish this point is that of selective termination in cases of multiple pregnancy (foetal reduction), in which the healthy embryos are aborted and the disabled retained. See Harris, *Clones, genes and immortality*, 107–108.

[11]Harris, *Clones, genes and immortality*, 109–110; Also see Harris, John. 1992. *Wonderwoman and superman: The ethics of biotechnology*, Oxford: Oxford University Press, 88.

[12]See Harris, John. 2007. *Enhancing evolution: The ethical case for making better people*. Princeton and Oxford: Princeton University Press, 91–92.

[13]Glover, Jonathan. 2006. *Choosing children: Genes, disability, and design*. Oxford: Oxford University Press, 13, 25.

[14]Harris. *Wonderwoman and superman*, 153.

[15]Indeed, a Schopenhauerian might conclude that it is best to cease reproducing altogether.

individual's actions insofar as they impact on others, Mill presupposed that the others in question were other already existing individuals. In reproductive ethics, however, some of the most difficult and puzzling questions arise in relation to the contingencies of who exists, that is, to future people. Parfit classically articulates the dilemmas that this provokes for the harm principle, under the name of the 'non-identity problem'.[16] The starting point for the non-identity problem is the existential fact that if an individual was not conceived in the month in which they were conceived, they would not exist – another, different, person would exist instead. The implications of this are clarified through an example. A woman who wishes to conceive is told that she has a medical condition that will ensure that if she conceives now, her child will be born with a disability. However, if she undertakes a short treatment and then conceives, her child will be born without the disability. While on the face of it, it appears that conceiving now would do harm to the child, this is not the case. For if the woman conceives later this child simply will not exist – it will be no worse off for being born with a disability, for otherwise it will not be born at all. The only point at which it can be said that the child has been harmed is if the disability is so severe as to make life not worth living, such that the child would have been better off not being born.

This problem has significant implications in bioethics, and has generated extensive discussion, including in relation to the notion of 'wrongful life'. This notion arises when the threshold of harm is set at the point where an individual is worse off simply by having been born. A life that is so devoid of quality as to fall below this threshold would be a life not worth living. This means that the very fact of having been born harms or wrongs the individual. Whether this notion of wrongful life is sustainable is highly contested and generates strong responses on both sides. There is no need to canvass this literature here, but one issue raised in it is particularly worth noting. This is whether the 'not worth living' criteria for harm is too high.[17] For if we accept this threshold, very few conditions will in fact constitute harms; that is, there will be very few cases where a child is in such a terrible condition that they can be considered as being worse off by having been born. Feinberg's narrow conception of harm is consistent with this threshold. If, however, a lower standard is set, then we can accept more occurrences of harm. Harris provides one example of setting a lower bar, where even a relatively minor disability can be understood as a harmed condition, such that a harm has been done to the child in having been born *even though* it cannot be said that its life is not worth living.

One question that arises here is how Harris reconciles this conception of harm with the strong emphasis he otherwise places on reproductive liberty. We saw in the previous chapter that Harris gives the right to reproductive liberty a trumping power in deliberations on reproductive technologies, insofar as it is bolstered by a 'democratic presumption' in its favour. When arguing for this democratic

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[16]Parfit, Derek. 1984. *Reasons and persons*. Oxford: Clarendon Press, 351–379.

[17]But see especially Archard, David. 2004. Wrongful life. *Philosophy* 79; Feinberg, Joel. 1986. Wrongful life and the counterfactual element in harming. *Social Philosophy and Policy* 4(1):145–178; Steinbock, Bonnie. 1986. The logical case for 'wrongful life'. *Hastings Center Report* 16(2):15–20.

presumption, Harris avers that reproductive liberty can only be limited on the basis of 'real and present, not future and speculative' serious harms.[18] We have to ask how Harris' understanding of disability coheres with the criteria of real and present serious harms. That is, if a relatively minor anomaly such as Harris' example of missing a little finger constitutes a harm, we still have to ask whether it constitutes a sufficiently serious harm so as to give grounds for limiting reproductive liberty. Unfortunately, Harris' formulation of the emergency room test gives no guidance on what might count as a sufficiently serious harm, or how that seriousness might be established, so as to limit reproductive liberty. It simply establishes that some conditions might be thought of as harmed conditions, and remains silent on the relative seriousness of them. This highlights an ambiguity in his understanding of reproductive liberty and the categorisation of some harms as serious and others as not; but we might also ponder the criteria for harms to be real and present rather than 'future and speculative'. Given that decisions about reproductive liberty and disability are decisions about future people, it is not obvious just what should be understood by the criteria of 'real and present' harm.

There is then, much ambiguity remaining in Harris' own formulation of harm, and its relative force in regard to reproductive liberty. However, what is clear is that Harris' formulation of harm is an attempt to resist the conclusion to which a strong emphasis on reproductive liberty, understood as the unrestrained exercise of parental choice in order to express deeply held values, would seem to lead. That is, parents should be free to have offspring with disabilities if that choice can reasonably be said to express deeply held values and ways of life. In relation to conditions such as deafness and achondroplasia, around which significant cultural communities have arisen, it could be argued that choices to reproduce and rear children with conditions of deafness or achondroplasia do in fact express the values and ways of life of parents who are part of those communities. Indeed, for such parents, deafness or achondroplasia is not a disability but an embodied condition of community belonging.[19] It would follow that such choices are protected by the democratic presumption in favour of reproductive freedom. That Harris resists this conclusion through an account of disability as an objective harm suggests tensions that are unlikely to be easily resolved.

While Harris redefines harm in relation to disability and reproductive liberty, Julian Savulescu proposes a different approach to the nexus of liberty, harm and disability. In an early commentary on the case of Duchesneau and McCullough, Savulescu argues that there is in fact no ethical issue involved, since 'the couple have the right to procreate with whomever they want'.[20] Transposing the central issue to parental choice about embryos – choices made possible by PGD for

[18]Harris, *Enhancing evolution*, 74.

[19]Contrary to Neil Levy (Levy, Neil. 2002. Deafness, culture and choice. *Journal of Medical Ethics* 28(5):284–285) deafness may well be a necessary condition for belonging to the Deaf community. See Preston, Paul M. 1994. *Mother father deaf: Living between sound and silence*. Cambridge, MA: Harvard University Press.

[20]Savulescu, Julian. 2002. Deaf lesbians, 'designer disability', and the future of medicine. *British Medical Journal* 325:771.

instance – Savulescu goes on to argue that reproductive liberty means that parents should be free to make these decisions for themselves, unless their decisions harm others. However, given that the non-identity problem means that a child is not harmed by being born deaf (since otherwise they would not have been born at all), it follows that parents should be permitted to choose children with deafness if they so wish. As he writes:

> [b]ecause reproductive choices to have a disabled child do not harm the child, couples who select disabled rather than non-disabled offspring should be allowed to make those choices, even though they may be having a child with worse life prospects.[21]

The final clause of this sentence points to a significant complication in Savulescu's otherwise apparently straightforward argument from reproductive liberty. For he also holds that prospective parents are under a moral obligation to choose children with the best life prospects – what he formulates as, 'the child – from the possible children they [the parents] could have – with the best opportunity of having the best life'.[22] He sees this as the goal of reproductive decision-making, as well as the underlying reason for why prenatal testing is offered to and sought by parents. Nevertheless, parents are best able to make decisions about such prospects for themselves; he writes, 'to discover what are the best prospects, we must give individual couples the freedom to act on their own value judgment of what constitutes a life of prospect'.[23]

   This combination of claims raises a number of questions about the strength of the obligation that Savulescu is proposing, as well as its relation to reproductive autonomy. For the perceived obligation to choose the child with the best prospects does not necessarily prevent parents from choosing a child with a disability when they themselves decide on what constitutes the best prospects. 'Best prospects' will generally be context dependent, as well as dependent on the values of the choosing parents. If one adopts a strong value pluralism, it may follow that parents with conditions such as deafness, who value inclusion within the Deaf community, would see deafness as a condition of their child having such context and value dependent best prospects. However, ultimately, Savulescu *does not* think that parents should be free to choose children with disabilities. Rather, as he later argues, he thinks that parents have an obligation to 'strive to have disability-free children' and that the actions of Duchesneau and McCullough were permissible, but wrong.[24] Like Harris, he is ultimately reluctant to accept the conclusion to which an argument from reproductive liberty would seem to lead. But the task of avoiding this conclusion is arguably more difficult for Savulescu because he accepts the implications of the non-identity problem. This means he cannot simply argue that having a disability does harm to

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[21] Ibid., 772.

[22] Ibid.

[23] Ibid.

[24] Savulescu, Julian, 2008. Procreative beneficence: Reasons not to have disabled children. In *The sorting society: The ethics of genetic screening and therapy*, eds. Loane Skene, and Janna Thompson, 51, 54. Cambridge: Cambridge University Press.

the individuals so affected. How, then, does he avoid the conclusion that parents should be free to select children with disabilities if they so wish?

The view that parents are morally required to select offspring with the best possible prospects has come to be known as the principle of procreative beneficence. In his initial explication of the principle, Savulescu argues that it entails that, 'couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant available information'.[25] The principle entails that parents have reason to use available technologies to gather information about the collection of foetuses among which they must choose, and further, that the information may provide good reason to choose one over another. The first consequence of the principle is that parents have good reason to select embryos without disease genes over those with disease genes. The example that Savulescu uses to make this point is the scenario of parents choosing between in vitro fertilisation embryos, where one appears to have a genetic predisposition to asthma. Since asthma reduces quality of life, the parents have good (prima facie) reason to select the embryo that does not have this predisposition. It will have the better prospects of having a good life. Savulescu also argues that the same reasoning applies to the selection of embryos on the basis of non-disease genes, since traits such as intelligence will themselves generally contribute to a higher quality of life.[26]

Three points should be made here about this account of procreative beneficence. First, this account relies on a kind of decision-theoretic consequentialism, such that the moral weight of the obligation to choose the best child is strictly related to having good reasons to choose one embryo over another. Savulescu clarifies at various points that 'should choose' simply means 'have good reasons to choose'. In the absence of other overriding reasons, one should – is morally required to – do what one has good reason to do. That is, choosing the child who is expected to have the best life prospects is morally required because it is rational; doing otherwise in the face of good reasons is wrong in the sense that it is irrational.[27] Thus, the principle of procreative beneficence does not justify coercion; at most, it would allow for attempts at persuasion. This is obviously one among many approaches to the question of moral obligation and the relationship between reasons and actions, and I do not wish to either defend or deny it here. For my purposes, it is enough to be clear on the specific strength and rationale for the obligation to choose one embryo over another.

The strength of the obligation entailed in the principle of procreative beneficence is closely related to the second point. One of the controversial aspects of procreative

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[25] Savulescu, Julian. 2001. Procreative beneficence: Why we should select the best children. *Bioethics* 15(5/6): 415.

[26] This, he argues, is true on a hedonic or a desire-satisfaction account of wellbeing, as well as an objective list theory. Note that Savulescu is not committed to saying that the more intelligent individual *will* have a better life – simply that it is rational to *expect* that they would.

[27] For a more extensive critique of Savulescu's conception of obligation, see Sparrow, Robert. 2007. Procreative beneficence, obligation and eugenics. *Genomics, Society and Policy* 3(3):43–59.

beneficence is the way that it relates to the requirements of procreative autonomy as a moral principle. This latter principle would allow that parents are free to choose any embryo, so long as the resultant child was not harmed. As we have seen, there are a number of ways in which limitations are placed on the principle by its main proponents. But in a general sense, this principle would at times conflict with procreative beneficence, since the latter requires parents to choose the embryo with the best life prospects *even where* the resultant child is not harmed if it has less than the best prospects. If reproductive autonomy takes precedence, there is no obligation on parents to select any particular child – the decision will be wholly theirs. But if procreative beneficence takes precedence, there is a moral constraint upon the kinds of decisions that parents may take. Savulescu's response to this conflict varies: in early formulations of procreative beneficence, he concedes that the principles will have to be weighed up against each other in personal decisions, although public policy should favour liberty rights.[28] In later defences of procreative beneficence, he rejects reproductive autonomy as an 'extremely implausible'[29] moral principle, since it provides no limits on what parents might choose. Nevertheless, it remains compatible with procreative beneficence at the legal level, where parents should be able to enjoy the legal 'right to make procreative choices which foreseeably and avoidably result in less than the best child'.[30] However, procreative beneficence is also 'compatible with setting legal constraints on parental autonomy – parents, for example, should be prevented by law from selecting children whose lives are expected not to be worth living'.[31]

While interesting in itself, this shifting response to the apparent conflict between reproductive autonomy and procreative beneficence also points to a deeper tension within Savulescu's account of procreative beneficence. Savulescu is explicitly committed to the account of liberty provided by Mill, which entails that parents should be free to pursue 'experiments in living' even where those experiments might be disagreeable to others. As we have seen, this means that parents should be free to make decisions about the expected life prospects of an array of embryos in accordance with their own values. We have also seen that the moral obligation to choose the embryo with the best prospects simply means choosing in accordance with what one has good reason to choose. The commitment to value pluralism entailed by Mill's conception of liberty means then, that parents may well have overriding reasons to choose an embryo with a condition that on an objective account might reduce its prospects of a good life. In other words, parents might have good reasons to choose an embryo that has a disease condition or disability, such as, say, deafness.

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[28] Savulescu. Procreative beneficence: why we should select the best children, 425.

[29] Savulescu, Julian and Guy Kahane. 2009. The moral obligation to create children with the best chance of the best life. *Bioethics* 23(5):279.

[30] Ibid., 278.

[31] Ibid., 279.

Indeed, it seems reasonable to suppose that at least some parents who are selecting for a characteristic such as deafness *do not* expect it to reduce wellbeing. In fact, they may reasonably suppose that a *hearing* child born to two deaf parents who are members of the Deaf community could be expected to be worse off, since this would set the child adrift between two cultures, belonging wholly to neither the Deaf community nor the broader hearing culture.[32] Thus, they may well think that the characteristic of deafness will actually enhance wellbeing, insofar as it is a necessary condition for inclusive participation in the Deaf community. If this is right, then it appears that there is no conflict between reproductive liberty and procreative beneficence. In fact, procreative beneficence risks appearing trivial, since it ends up adding little to what an account of reproductive liberty might already entail. While it may place limits on the nature of the justification that parents could give for actions protected by reproductive autonomy, it does not necessarily alter the substantive content of parental decisions and related courses of action. In short, parents would simply be required to make decisions in accordance with the reasons that they see as good according to their own sets of values. Given this, choosing an embryo with genetic deafness would not be wrong even in the minimal sense of being irrational.

How, then, does Savulescu reach the conclusion that such a choice would be wrong, even if permissible? He does this through developing an objectivist account of disability. In a later comment on the actions of Duchesneau and McCullough, Savulescu's position (elaborated in collaboration with Guy Kahane) shifts from denying that there is any morally significant issue since the decision should be left wholly to the couple, to the claim that procreative beneficence implies that, 'parents have reasons to select hearing children rather than deaf ones', unless it can be shown that deafness is *not expected to be a disability* that reduces wellbeing. This formulation highlights a subtlety in Savulescu's argument that must be fully recognised. Savulescu defines disability as something that will 'reduce the goodness (value) of a life (disability in the intrinsic sense) and/or reduces the chances of a person realizing a possible good life (disability in the instrumental sense)'.[33] Deafness fails both these tests in his view – it reduces the goodness of a life by limiting access to the world of sound, and, 'makes it harder to live, to achieve one's goals, to engage with others in a world which is based on the spoken word'.[34] On this view, deafness is expected to be an objective disability that reduces wellbeing. Anyone who takes this view could not have good reason to choose deafness; they

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[32] See Davis, Lennard J. 1995. *Enforcing normalcy: Disability, deafness and the body*. London: Verso, xvii–xviii, for a discussion of this 'biculturalism'. In this regard, it might be argued that the approaches I have discussed fail to take seriously the demands of cultural and value pluralism in relation to Deaf culture. On this issue, see Sparrow, Robert. 2005. Defending deaf culture: The case of cochlear implants. *The Journal of Political Philosophy* 13(2):135–152.

[33] Savulescu. Procreative beneficence: reasons not to have disabled children, 55. There is a kind of conceptual fiat at work here, wherein disability is by definition bad, since the prefix 'dis' expresses a negativity in relation to 'ability'. All that remains, then, is to show that a particular condition can be legitimately called a 'disability' for it to be negatively judged.

[34] Ibid.

should choose against deafness, and it would be wrong to do otherwise. This objective account of disability means that no-one could reasonably choose in favour of a condition such as deafness, no matter what their values or reasons for making such a choice.

However, when applied to reproductive choices between embryos this has implications that work against his apparent commitment to value pluralism in the determination of what counts as the best life prospects. As Rebecca Bennet has discussed, the moral force of the 'best chance at the best life' condition derives from a further implication of the non-identity problem outlined by Parfit, namely, the phenomenon of impersonal harm.[35] While no particular individual is harmed by being born with a disability (unless that disability is so bad as to make life not worth living), it is still the case that the world would be a better place if that child was not born, and a child without disability was born instead. This is because the *overall* quantification of wellbeing is less if the disabled child is born, even though that disability is not a harm to that child personally. The underlying idea is that it is possible for there to be wrongs that do not cause harm to any specific person, that there can be 'harmless wrongdoing'[36]. The implication of this argument in relation to disability is that disability is a wrong *even if* it cannot be said that any specific person is harmed by their having a disability. This means that the wrongness of choosing for a condition such as deafness is not simply a matter of irrationality, of failing to abide by the moral requirement entailed by good reasons. Instead, disability is itself a wrong, and a choice in favour of a condition that can be described as a disability is wrong in a stronger moral sense. Or as Bennet argues, the account of impersonal harm upon which the principle of procreative beneficence relies, in which wellbeing is maximised if a child without disabilities is born in the place of one with disabilities, entails that disabled bodies are *morally devalued*. This is because a life with disabilities is understood to contribute less to the overall quality of life than a life without disabilities.[37] A life with disability is less valuable than a life without disability.

Before turning to the disability rights critique of prenatal testing that challenges the apparent devaluation of disabled bodies, let me consider one further attempt to navigate the demands of liberty and harm in relation to disability. In his response to Duchesneau and McCullough's attempt to give birth to a deaf child, Glover is committed to some of the same theoretical precepts as commentators already discussed, though he rejects Harris' understanding of disability and harm. His own approach to disability combines aspects of both the functional (or medical) and social models to conclude that, 'disability involves a functional limitation, which (either on its own or – more usually – in combination with social disadvantage)

[35]Bennett, Rebecca. 2009. The fallacy of the principle of procreative beneficence. *Bioethics* 23(5):265–273.

[36]Savulescu. Procreative beneficence: why we should select the best children, 418.

[37]Bennett. The fallacy of the principle of procreative beneficence, 270.

impairs the capacity for human flourishing'.[38] In this definition, Glover retains the 'messy' concept of normality in the contrast between disability and normal species functioning, but argues that it is not morally important on its own; instead, what matters in considering the ethics of choosing disability is human flourishing. He states, '[m]ere normality or abnormality is unimportant. What matters is the contribution to whether or not a person flourishes'.[39] In regards to deafness, it is not the functional limitation of not being able to hear that matters – instead, primary importance goes to the capacities for human flourishing and the ways in which deafness may present an obstacle to human flourishing. It is clear to Glover that deafness does indeed limit capacities for human flourishing. As evidence for this conclusion, he suggests it 'impairs safe navigation through the world', since 'the deaf child will not hear the car coming'.[40] More generally, deafness entails 'the loss of a whole dimension of enriching experience', that is, sounds such as those of the natural world, of music and so on.

Assessing this conclusion requires a closer look at Glover's understanding of flourishing. The account of flourishing that he finds most compelling is the liberalised Aristotelian one provided by Martha Nussbaum. He describes her account as entailing goods such as,

> 'health, nourishment, shelter, sex, and mobility, as well as being able to use the senses and to imagine, think and reason ... family and other relationships, attachments and love ... living a life one has thought about and chosen, in one's own surroundings and context ... laughter, play and living in contact with the natural world'.[41]

In addition to this, Glover's idea of a good life includes some account of happiness, primarily a desire version that is liberalised to include some evaluation of the desires themselves.[42] In making use of these ideas, at one point in his discussion, he is careful to point out that what matters in his formulation is *capacities for* flourishing – that is, a condition should be understood as a disability if and only if it impairs the realisation of important preferences (while recognising the problem of adaptive preferences).[43] However, in relation to conditions such as blindness and deafness, Glover appears to abandon these nuances. He asks, '[d]o the senses of hearing and sight count as dimensions of human flourishing, such that deprivation of them is a disability?' and concludes that both conditions constitute generalised disabilities. In doing so, though, he moves away from the emphasis on capacities for flourishing, and places emphasis instead on *functioning*. This has the consequence that blindness or deafness cannot but appear as a deprivation in comparison to 'normal species functioning'. It also means that the lives of people with these characteristics are distinguished or marked by lack.

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[38]Glover. *Choosing children*, 9.

[39]Ibid., 14.

[40]Ibid., 23.

[41]Ibid., 89.

[42]Ibid., 91–93.

[43]Ibid., 9.

This is not strictly consistent with Nussbaum's list of capabilities and their relation to flourishing. Significantly, Nussbaum does not see her 'capabilities' approach to flourishing as providing a comprehensive moral doctrine: it is a political theory and the capabilities are 'specifically political goals ... free of any specific metaphysical grounding'.[44] While there is ambiguity in and contestation about the 'single list' of capabilities, Nussbaum is insistent that the list must be understood as a list of *core human entitlements* – not a list of core human characteristics.[45] Glover appears to instead read the capabilities she lists as human characteristics. This has important implications, for it shifts the weight of a concern with human flourishing away from ensuring social and political conditions under which all persons can live a life of dignity, to a more individualising assessment of the physical and or mental capacities of a person, especially in comparison to normal species functioning. When Nussbaum writes that the 'Central Human Capabilities' include, '[b]eing able to use the senses, to imagine, think and reason',[46] this should be understood as living in social and political conditions that encourage and foster 'the life of the mind' through education, freedom of expression and so on. In relation to deafness, rather than conclude that deafness is (necessarily?) an obstacle to flourishing, this would require that societies provide appropriate resources to ensure the flourishing of persons with the condition.

Finally, for Glover, deliberately seeking to bring into being a child with deafness may be a moral wrong, insofar as it transgresses the moral onus on parents to promote the flourishing of their offspring. However, being born deaf, even when one's parents have deliberately sought that condition, does not *harm* the child. As with Savulescu, Glover accepts the implications of the non-identity problem, which leads to the claim that the individual born deaf is not harmed, since otherwise, they would not have been born at all. Further, Glover accepts the claim of impersonal harm, wherein although no specific person is harmed, the world is made a worse place by a child being born deaf. In accepting this, Glover could also be accused of a moral devaluation of disability that Bennet identifies in Savulescu's thought. Glover also argues, though, that the concern with impersonal harm can only ever be a supplement to, not a replacement for, an account of what we owe to people, and more precisely, what parents owe to children. Specifically, he argues that what parents owe to children is that they have a 'decent chance of a happy [or good] life',[47] where the good life is understood as involving capacities for flourishing and the satisfaction of significant desires. We have seen that Glover places emphasis on functional characteristics in his approach to flourishing, such that deafness cannot but appear as a disability and an obstacle to flourishing. In conjunction, these strategies – the impersonal harm strategy and the flourishing strategy – allow Glover to

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[44]Nussbaum, Martha. 2006. *Frontiers of justice: Disability, nationality, species membership.* Cambridge: Harvard University Press, 70.

[45]Ibid.

[46]Ibid., 76.

[47]Glover. *Choosing children*, 58.

cast deafness as a morally significant harm, and choosing to give birth to a deaf child as a moral wrong.

My discussion in this section has focused on the various recourses to the principle of harm that some of the most high-profile commentators in contemporary bioethics make in relation to parental choices about disability. My aim here has been less about showing that the arguments made are wrong per se, than it has been to trace a certain tension in them concerning the moral and existential value of disability. For philosophers such as Harris and Savulescu, who usually so fearlessly follow an argument to its (often counterintuitive) conclusion, it is notable that they are so reluctant to embrace the conclusions of liberty arguments in relation to disability. While I do not espouse a psychoanalytic reading of the text, we might nevertheless ponder the affective undertone of this tension in their arguments. What seems to be at issue is the imaginary of embodiment that guides much thinking about human enhancement.

Too often, the vision of human embodiment and excellence at work in these debates bears little relation to the experiences of embodiment that make up most people's lives – experiences of vulnerability and dependency, of occasional strengths and frequent weaknesses, of infancy, ageing, illness, of pain and of ecstasy. In this regard, the cover images of recent books on human enhancement are revealing – the dust jacket of Harris' *Enhancing Evolution* is dominated by the image of a tensed muscular arm (presumably male) while that of Savulescu and Nick Bostrom's *Human Enhancement* has twenty-seven images of a bodybuilder in various poses that highlight the muscularity of the (again, male) body.[48] Given this vision of the body, it is perhaps not surprising that disability appears as a problem from the point of view of theorists of human enhancement. Despite the differences in the positions they take then the common feature of the approaches of Harris, Glover and Savulescu is that each of them, albeit in different ways, confronts disability as *a problem,* where this term can be understood in two ways. First, in an everyday sense of 'problem', disability is negatively valued, as, for instance, an obstacle to flourishing. In a second, more technical sense of 'problem', which I draw from Foucault, disability 'offers itself to be thought', and, insofar as it is circumscribed by the parameters of harm, appears to establish the limits of freedom. Or, in other words, the conceptual nexus of disability and harm is one way in which human reproductive practices have been *problematised*.[49]

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[48]My point here goes to the semiotics of a text, which may or may not be intentional and only tenuously attach to the author. It is worth considering the way that the muscle-bound male body stands as the synecdoche of enhancement in these texts. This seems some distance from the social synecdoche involved in disability discrimination, whereby a disability stands in for the whole person, noted by Asch and others, which I discuss in the following section. See Harris, *Enhancing evolution*; Savulescu, Julian, and Nick Bostrom, eds. 2009. *Human enhancement*. Oxford: Oxford University Press.

[49]On forms of problematisation, see Foucault, Michel. 1987. *The use of pleasure: The history of sexuality*. Vol. 2 (trans: Hurley, Robert). London: Penguin, esp. 23–24. Also see my discussion in the previous chapter of the problematisation of reproduction.

4.2 The Expressivist Critique of Prenatal Testing: A Defense

In treating disability as a problem, one of the key presuppositions of the conse-
quentialist approach to disability, harm and reproductive freedom discussed in the
previous section is that a life with a disability is necessarily less desirable than a
life without a disability. On this approach, disability is by definition a constraint on
life possibilities, such that it can be said to constitute a harmed condition, or to limit
flourishing or diminish the value of a life. This approach tends to consider the value
or otherwise of a life with disability in comparison to a nominal (and idealised)
life without disabilities. In this section, I wish to consider a different approach to
disability and reproductive freedom that emphasises the value and possibilities of a
life with disability on its own terms. The disability rights critique of prenatal testing
starts from the presupposition that 'life with disability can be valuable and valued'.[50]
This shift in perspective underpins a critique of prenatal testing in which the point
of contention is less that of parents choosing *for* disability as choosing *against* it.
While the disability rights approach to prenatal testing has a number of strands –
and disability activists and scholars by no means form a consensus in relation to the
use of such technologies – for the sake of clarity and brevity, I want to focus on one
aspect of this approach here.[51] This is the claim that the widespread use of prenatal
testing technologies, and subsequent selective abortion, express a negative message
about disability, and in doing so, perpetuate disrespectful or disparaging attitudes
toward existing people with disabilities.

Identified as the 'expressivist critique', forms of this argument have been pro-
posed by a number of disability activists and theorists, including Sue Wendell,
Marsha Saxton, Nancy Press and perhaps most notably, Adrienne Asch. As Erik
Parens and Asch outline, these various versions of the expressivist critique centre on
the claim that prenatal testing to select against traits usually considered disabilities
'express a hurtful attitude about and send a hurtful message to people who live with
those same traits',[52] namely that, 'we don't want any more like you'.[53] Prenatal
testing isolates a particular trait that then 'stands in' for the whole person and, in
combination with termination of pregnancy, provides the basis for the elimination
of that life. In this synechdochic tendency, prenatal testing for disability repeats a
central characteristic of discrimination more generally, where one trait stands in for
the whole person, and works to obliterate the rest of the person. Or, in other words,
the social synechdoche of discrimination entails that a particular trait is linked to
a set of norms and assumptions that effectively foreclose recognition of the per-
son of whom the trait is but one characteristic. While the expressivist critique does

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[50]Asch, Adrienne. 1988. Reproductive technology and disability. In *Reproductive laws for the
1990s*, eds. Sherrill Cohen, and Nadine Taub, 70. Clifton, NJ: Humana Press.

[51]For a more extensive discussion of the strands of the disability rights critique of prenatal testing,
see Parens, Erik, and Adrienne, Asch. 1999. Special supplement: The disability rights critique of
prenatal testing reflections and recommendations. *The Hastings Center Report* 29(5):S1–S22.

[52]Ibid., S2.

[53]Wendell, Sue. 1996. *The rejected body*. New York, NY: Routledge, 153.

important work in bringing to the fore the social context in which prenatal testing takes place, a context marked by discrimination against persons with disabilities, it has also been the subject of substantial disputation.

James Lindemann Nelson draws on Ludwig Wittgenstein's philosophy of language to provide a particularly notable argument against the central aspect of the critique, namely, the *expressive* character of practices of prenatal testing and termination of pregnancy. He argues that practices such as prenatal testing and abortion are not 'semantically well-behaved enough' to be construed as sending a determinate message since they 'do not function as signs in a rule-governed symbolic system'.[54] In addition, Nelson rejects the claim implied in the expressivist critique that termination of pregnancy on the basis of disability is significantly different from termination for other reasons *because* it sends a hurtful message. If abortion on the basis of disability sends a hurtful message, then presumably, so do abortions on the basis of other foetal characteristics such as being the 'fourth-born'. This line of argument targets a distinction made by Asch between the rejection of *any* foetus versus the rejection of a *particular* foetus in an otherwise planned pregnancy. Finally, Nelson strives to show that therapeutic measures to prevent disability, and termination of pregnancy that prevents disability through eliminating the individual, are expressively similar. However, a plausible version of the expressivist argument must be able to distinguish between these cases, unless it is to become an argument against abortion in general. For pro-choice proponents of the expressivist critique, this is an especially important and difficult task.

From this, Nelson ultimately concludes that the expressivist critique is a 'distraction for sophisticated disabilities theorists and activists',[55] though it does have the virtue of forcing recognition of philosophical resources that are not usually mobilised within the field of bioethics. In what follows in this section, I will defend the expressivist critique against each of Nelson's objections in turn, though my purpose in doing so is less to show that the expressivist critique is right than it is to widen the scope of the philosophical resources at its disposal. While this strategy will not show that current formulations of the expressivist critique are defensible, it will, I hope, provide some reprieve for what I take to be the important elements of the critique. Specifically, it will push toward a more socially cognisant understanding of the place of prenatal testing in reproduction, as well as a phenomenology of disability that takes embodiment seriously as a condition of subjectivity and social recognition.

The central focus of Nelson's rejection of the expressivist critique is the idea that prenatal tests that allow parents to choose against a foetus with disabilities by terminating the pregnancy express a hurtful message to already existing persons with disabilities. This claim, he points out, requires careful elaboration of the conditions that must be fulfilled in order for non-linguistic behaviour to express a message.

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[54]Nelson, James Lindemann. 2000. Prenatal diagnosis, personal identity and disability. *Kennedy Institute of Ethics Journal* 10(3):213.

[55]Ibid., 226.

While proponents of the expressivist critique have largely failed to provide this, others such as Allan Buchanan and (building on his work) Nelson, have striven to clarify the conditions of non-linguistic expression. In doing so, they conclude that the central claim of the expressivist critique is implausible. Buchanan argues that the idea that making a decision expresses a judgement presupposes one of two things.[56] It may presuppose that a person cannot *rationally* make a decision unless they believe the judgement that the decision appears to affirm. That is, a decision to select against disability would require that one believe that a life with disabilities would not be worth living. Or, the idea might entail that one could be *motivated* to make a decision to terminate a pregnancy on the basis of foetal disability only if one holds to the belief that a life with disabilities would not be worth living. Buchanan holds both of these ideas to be implausible.

Extending on this view, Nelson rightly points out that Buchanan places too much emphasis on the belief structures of the person choosing to terminate, and in doing so, presupposes a higher degree of intentionality than is required for the recipient of a message to interpret a decision in a particular way. The claim of the expressivist critique does not require that a woman or a couple deciding to terminate a pregnancy on the basis of disability *consciously* hold a disrespectful attitude toward disability or *intend* to send that message to people with disabilities.[57] Nelson's own approach, then, is to consider whether the practices of prenatal testing and selective termination send messages at all. Citing Wittgenstein, Nelson wonders whether such practices are sufficiently embedded or coded within systems of symbolic rules to effectively yield a coherent message or meaning. He writes, 'for some piece of behaviour to have semantic significance, it must have a rule-governed role in a publicly sharable system of symbols',[58] and concludes that prenatal testing and abortion do not have this status.

Nelson is not unjustifiably pushed toward this concern with semantic significance because the expressivist critique is couched in terms of 'sending a message' and 'expressing an attitude'. However, it is worth asking whether this is in fact the appropriate register for the broader idea that the expressivist critique seems to be grasping at, that is, that the social significance of prenatal testing is inseparable from apparatuses of discrimination against people with disabilities. It would be possible to describe these apparatuses as discursive only if that is understood in a Foucauldian sense that incorporates more than simply semantic utterances and the rules that govern their significance. Foucault's understanding of discourse is complex, with considerable shifts between the so-called 'archaeological' and 'genealogical' phases of his work, and a full articulation of it is beyond the scope of this chapter. What is important about it for my purposes here, is that it concentrates on the conditions

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[56]Buchanan, Allen. 1996. Choosing who will be disabled: Genetic intervention and the morality of inclusion. *Social Philosophy and Policy* 13:30.

[57]Nelson. Prenatal diagnosis, personal identity and disability, 216; Nelson. Meaning of the act, 175–176.

[58]Nelson. Prenatal diagnosis, personal identity and disability, 217.

of power and knowledge that underpin the production of truth. That is, it seeks to illuminate the background conditions that establish the intelligibility and indeed, reasonableness, of statements of truth, as well as of individual actions and beliefs. While in the earlier phase of Foucault's work, he understood such conditions in terms of autonomous rules for the production of statements, in the later phase, he shifted focus to the socially and historically continent 'regimes of truth' that produce and constrain what is possible to know, to believe and to do.

In relation to disability, this would mean that discrimination is not simply a matter of individual beliefs about people with disabilities, but is instead a matter of the conditions of truth production that have underpinned and given social legitimacy to those individual beliefs. As disability theorists have shown, modern Western culture is characterised by a pervasive derogation of disability, which takes cultural and political forms such as an obfuscation of the everyday reality of the lives of people with disabilities, a hyperattentiveness to the disabling trait that reduces the person to the disability, or, at the extreme, policies and practices that seek to eliminate people with disabilities. It is against this backdrop of pervasive derogation that prenatal testing and selective termination take on a social significance that is irreducible to the beliefs, motives or intentions of individuals choosing to terminate a pregnancy on the basis of foetal abnormality. Such individual decisions are never made in isolation, but are given a certain coherence and reasonableness through the operation of background conditions of ableism. This is not to say that individual decisions are simply reducible to these background conditions, or to suggest that such conditions wholly *determine* the morality of possible courses of action. It is to say that such individual decisions are only possible within a context, and further, that these decisions always carry a trace of their background conditions of possibility.[59] It is perhaps this trace that is central to the idea that prenatal testing and termination sends a hurtful message to people with disabilities.

Recognition of these background conditions also has implications for responding to the further points of disagreement that Nelson raises. The second point in his objections relates to the necessity of distinguishing morally between abortion on the basis of disability and abortion on the basis of other reasons. The question he asks is, 'can objectors show in any convincing way that abortions (or other ways of avoiding birth) that have an objectionable expressive character are distinguishable than those that do not?'[60] In his view, attempts to do so, such as Asch's 'any-particular' distinction, fail to establish a moral disparity between abortions for disability as opposed to other reasons, a failure that is especially vexing for disability activists and theorists who otherwise adopt a pro-choice position. For the objection to abortion on the basis of disability seems to presuppose a moral disvalue in abortion per se, not simply those based on likely disability. But Nelson's objection to the 'any-particular'

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[59]On the idea of the 'trace', see Derrida, Jacques. 1997. *Of grammatology* (trans: Spivak, Gayatri Chakravorty). Baltimore: Johns Hopkins University Press. I use the term in a less technical sense here.

[60]Nelson. Meaning of the act, 169.

distinction and the moral disparity it seeks to establish warrants closer attention for it contains its own peculiarities, which mean that it is ultimately unsuccessful as an objection to the expressivist critique.

Asch argues that the ethical distinctiveness of abortion on the basis of foetal disability arises because it involves terminating a pregnancy that is *otherwise wanted* on the basis of a *particular* characteristic of a foetus. Abortion more generally entails that the pregnancy itself is not wanted, and nor is *any* foetus or child that might result. Nelson counters by arguing that this distinction is unsustainable, since properties such as being 'fourth-born' will cut across it: the property of being fourth-born is both particular to a foetus and a property of any foetus in a pregnancy following the birth of three children, suggesting that abortions on the basis of '$n + 1$' [where $n = 3$] also express hurtful attitudes toward fourth-born children. The obvious response to this, made by Asch, is that there are no equivalent background conditions of discrimination in relation to being fourth-born as there are in relation to disability.[61] Consequently, such decisions against further children beyond one's preferred number of them do not express hurtful attitudes toward the additional children of other families. But it is not clear that this response is also adequate to the second example of such an ambiguating property that Nelson provides, which is indigency. For it is arguable that classism is an equivalent system of discrimination, whereupon children of poor families have been treated in invidious ways because of their poverty. This would suggest that abortions on the basis of economic circumstance may well be equivalent in their capacity to express hurtful attitudes as abortions on the basis of disability.

Asch and Nancy Press[62] have both claimed that disability is intrinsic in a way that being fourth-born or indigent is not, and it may be that this provides a more interesting – if more difficult – strategy for responding to the apparent breakdown of the any-particular distinction. Their idea seems to be that disability is a characteristic that carries across social circumstances – it inheres in the person – whereas being fourth-born is entirely contingent on circumstance. Nelson has of course reacted to this claim, suggesting that this would entail that disability is, 'a property [that] makes whatever impacts it does independently of its social context'.[63] This would, he avers, contradict the strong tendency toward the social model of disability within contemporary disability studies. But this idiosyncratic understanding of 'intrinsic' is unsustainable, for I can understand gender as intrinsic to who I am – I would not be who I am without being a woman – and still also understand 'my' gender as a performative effect of social norms that I embody in various ways. This is possible

[61] Asch, Adrienne. 2000. Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements. In *Prenatal diagnosis and disability rights*, eds. Erik Parens, and Adrienne Asch, 237. Washington, DC: Georgetown University Press.

[62] Asch. Why I haven't changed my mind about prenatal diagnosis, 237; Press, Nancy. 2000. Assessing the expressive character of prenatal testing: The choices made or the choices made available? In *Prenatal diagnosis and disability rights*, eds. Erik Parens, and Adrienne Asch, 215. Washington, DC: Georgetown University Press.

[63] Nelson. Prenatal diagnosis, personal identity and disability, 219.

because I do not exist independently of my social context – who I am or can be is productively constrained by that context and therefore inextricable from it. I am not proposing a homology between gender and disability in identity formation here, but merely pointing out that 'intrinsic' and 'relational' are not necessarily opposed. Understanding the way in which a property such as gender or disability may be simultaneously intrinsic and relational requires a turn toward a richer understanding of *embodiment* as a condition of subjectivity.[64]

Recent interventions in disability studies that question the distinction between impairment as the biological reality and disability as the social response to that impairment, shift the terrain of theorising disability toward new conceptions of embodiment that do not presuppose a natural substrate overwritten by cultural forces. Instead, they allow a more sophisticated understanding of embodiment as always already cultural or social and nevertheless intrinsic to subject-formation. For instance, in her analysis of the impairment/disability distinction, Shelley Tremain argues that rather than the precultural condition for disability, impairments are an effect of historically specific relations of power, such that impairments are, 'materialized as universal attributes (properties) of subjects through the iteration and reiteration'[65] of norms of human function, morphology and abilities. This allows impairments to be, 'naturalized as an interior identity or essence *on which* culture acts . . . In short, impairment has been disability all along'.[66] The strength of this approach, which draws on the work of Foucault as well as Judith Butler (work I also draw on throughout this book), is the way in which it understands bodies as trenchantly embedded within relations of power, which not only shape interpretations and representations of bodies, but also shape the very possibility of what appears as a natural, normal and desirable body. Nevertheless, as I argued in an earlier chapter, this perspective can be limiting insofar as it eschews discussion of bodily norms that are distinct from but entwined with social norms in complex ways. I have argued that a bioethics that takes embodiment as a starting point should be attuned to that complex intertwining; indeed, one may go so far as to say that embodiment is the experience of the enmeshment of biological and social norms.

It may be that discussions of the phenomenology of disability better attest to embodiment understood as an experience of the interaction of biological and social norms, especially from a first-person or internal perspective. Within the tradition of phenomenology, Maurice Merleau-Ponty's work, beginning from the supposition that embodiment is the mode of our 'being-in-the-world' and our perception and cognition of the world is grounded in our corporeality, has been most useful for

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[64]There are of course various philosophical models of embodiment available, and I am not going to make a strong case for adopting any particular one of those here. Rather, I want merely to point toward the role of embodiment in the experience of disability, and indicate the importance of taking this into account in reproductive ethics.

[65]Tremain, Shelley. 2001. On the government of disability. *Social Theory and Practice* 27:632.

[66]Ibid.

conceptions of disabled embodiment.[67] One important aspect of Merleau-Ponty's account of embodiment is that for the most part, embodiment falls below the horizon of our conscious awareness, and it is only in moments of disease or discomfort that our bodies become evident to us as bodies. Drew Leder describes this coming to awareness of the body as a matter of 'dys-appearance', or what he understands as an intentional awareness of the body whereupon the body is sundered from or falls away from the self. Importantly, he argues such alienation from one's body can be both subjective and intersubjective: awareness of one's body might arise from a disruption in the quiet operations of the body itself, or from the objectifying gaze of another.[68] This latter *social dys-appearance* has been extended to disability, to suggest that the 'impaired body dys-appears as a consequence of the profound oppressions of everyday life',[69] that is, when the impaired body is revealed as impaired in relation to social norms. This points toward a view of the phenomenology of disability that does not presuppose a natural body untouched by social norms. Instead, embodiment is understood as necessarily relational and social, but as also constitutive of and intrinsic to our differential being-in-the-world.

This focus on embodiment is important for reproductive ethics for several reasons. For one, in relation to this discussion of the expressivist critique, it helps to make it clear that indigence and disability are not analogous properties as Nelson supposes. Some of their difference may be intuited in the popular formulations that one is 'born with' Trisomy 21, but 'born into' poverty. This suggests that the former is a characteristic of a specific form of embodied subjectivity, whereas the latter is a context or condition that an embodied subject emerges from within. This is not to say that class is not reflected in bodies in various ways. As Pierre Bourdieu analysed, bodily *habitus* is inextricable from class, evident in the ways that socioeconomic status is reflected in various more or less subtle bodily mannerisms and gestures for instance.[70] Nevertheless, these are styles of comportment or habits. Disabilities of various kinds may support or produce particular styles of comportment or habits, but are not strictly identical to these.

More generally, phenomenological accounts of disabled embodiment can help to address the paucity of much bioethical thinking about disability, which often disregards the experiences of people with disabilities in favour of abstract

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[67]This is despite the fact that Merleau-Ponty himself had little to say about corporeal variability (beyond the use of pathological cases to illustrate normality) and has been substantially criticised by feminist and disability theorists for his reliance upon the male body as his normative model. See in particular Scully. *Disability bioethics*, 83–105; Diprose, Rosalyn. 1994. *The bodies of women: Ethics, embodiment and sexual difference*. New York and London: Routledge, 102–130; Grosz, Elizabeth. 1994. *Volatile bodies: Toward a corporeal feminism*. St Leonards: Allen and Unwin, 107–111; Young, Iris Marion. 2005. Pregnant embodiment: Subjectivity and alienation. In *On female body experience*. Oxford: Oxford University Press.

[68]Leder, Drew. 1990. *The absent body*. Chicago, IL: University of Chicago Press, 83–97.

[69]Paterson, Kevin, and Bill, Hughes. 1999. Disability studies and phenomenology: The carnal politics of everyday life. *Disability and Society* 14(5):603.

[70]See, for instance, Bourdieu, Pierre. 1991. *Language and symbolic power*, ed. John B. Thompson (trans: Raymond, Gino, and Adamson, Matthew). Cambridge: Polity Press.

pronouncements on harm and quality of life. However, accounts of such experiences are crucial, since while making an understanding of the world possible at all, embodiment may also limit our capacities to imagine the lives of others. As Jackie Leach Scully argues, phenomenology recognises not only that one's sense of self is indissociable from one's body and environment, but also that moral understanding may rest upon this experience of oneself in the world.[71] This has the implication that any construal of the effects on quality of life or flourishing of a disability may be more or less tightly bound to one's own embodied experience. If our horizon of understanding is developed in relation to our own embodied being, not only is it important to take embodiment into account in explicating those views, but it may also be important to consider first-person narratives about the experience of differential forms of embodiment as a starting point for ethical engagement with others. This is not to say that such accounts must necessarily be accepted uncritically, but *engagement* with narratives of embodied experiences unlike our own (whatever those are) may nevertheless contribute to expanding our moral imagination.[72]

To summarise, Nelson interprets the distinction between abortion in general and abortion on the basis of disability to mean that genetically based disabilities are understood as, 'monadic properties, ones that inhere in the foetus itself, depending on no consideration of context, and which, moreover, are essential to the foetus's basic identity as the thing that it is'.[73] But this speculative interpretation is wrong on at least two counts. First, in relation to social context, it heads in exactly the wrong direction; it is precisely the social and historical context of discrimination against people with disabilities that makes selective abortions morally distinctive from abortions on the basis of other foetal characteristics. Further, the experience of disability cannot be extracted from this context – social context cannot be eliminated from what it means to be disabled or to have a disability. Second, in targeting the idea that disabilities can be understood as inherent properties that are 'essential' to identity, Nelson exaggerates the opposition between disability as an inherent property and 'relational' properties such as being fourth-born or being poor. He ends up in this position by ignoring the *embodied* nature of identity, where embodiment is intrinsic to one's being-in-the-world, while nevertheless always already relational and contextually bound. The problem as he sees it is that the idea of disability as an inherent property would contradict the social model of disability favoured by many disability activists and theorists. But this contradiction is only apparent. For a sufficiently sophisticated account of embodiment can show that a characteristic can be simultaneously essential to who I am *and* social or relational. Disability may be one of those embodied characteristics.

To briefly address Nelson's third point of objection against the expressivist critique, then, he claims that the expressivist critique is unable to distinguish morally between the objectionable nature of abortion for foetal disability as opposed to

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[71] Scully. *Disability bioethics*, 12.

[72] Ibid., 154, 173.

[73] Nelson. Meaning of the act, 173.

therapeutic measures such as foetal surgery, or even maternal supplements such as folate, which also have the effect of reducing the number of people with disabilities in the world. The supposed moral equivalence of these different practices derives from an exclusive focus on the outcomes of them: each contributes to fewer people with disabilities coming into the world; therefore, are all morally equivalent, and all should be subject to the expressivist critique. Nelson suggests on this basis that the underlying attitude that does the work of differentiation is actually a moral opposition to abortion. He writes, 'without attributing some particular disvalue to abortion, it is hard to understand the difference on expressivist grounds between eliminating the dysfunction and eliminating the dysfunctional individual'.[74] However, the concern with moral imagination and our capacities to engage ethically with alterity that I mentioned previously help to point to an important point of differentiation that does not rely upon a disguised objection to abortion.

As I argued in the previous chapter, decisions about reproduction entail a practice of ethical self-formation, one in which the limits of reproductive freedom are limned and tested in various ways. Such practices of self-formation are constitutive of ethical subjectivity, in the process binding us to important personal values and giving form to those in our lives. But they also necessarily entail forming ourselves in relation with others, and, in this aspect of self-formation, such practices shape the kinds of relationships that we bear to others. Feminist scholars have long argued that pregnancy itself involves a relationship between the pregnant woman and the foetus or baby that she carries within her, and, moreover, that this relationship may be ethically significant in ways that are rarely recognised.[75] Considered in this light, abortion and foetal therapy come apart: they are different practices of self-formation, which may express and realise different significant values. They also indicate and enact a different relationship between the woman and the other being inside of her. It would be too hasty to say that one of these relationships is morally permissible while the other is not. The point is simply that preventing disability through foetal therapy and maternal supplements is not obviously ethically commensurate with preventing the birth of a baby with a disability through termination when the emphasis is placed on the ethical practices of self-formation rather than the consequences of each.

4.3 Conclusion

In this chapter I considered the way that the principle of harm has been mobilised within debates in reproductive ethics as a way of placing a limit on reproductive freedom. I focused on concerns about parents selecting or deliberately striving to make children with conditions that are typically considered to be disabilities. In the first section of the chapter, I examined arguments from high profile consequentialists, namely Harris, Savulescu and Glover, who take the view that parents are

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[74]Nelson. Prenatal diagnosis, personal identity and disability, 220.

[75]Indeed, the scientific language of 'the foetus' itself abstracts from that relationship and may seem quite inapt for a woman as her pregnancy progresses.

certainly free and perhaps obliged to choose the child with the best expected life prospects. In tracing the tensions in their arguments about harm and disability, I argued that this approach necessarily treats disability as a problem – it construes disability as a harm that limits reproductive freedom, often in ways that are in tension with the stated arguments about that freedom. In the second half of the chapter, I turned to the expressivist critique of prenatal testing. While this line of argument has been strongly criticised by Nelson, I showed that theoretical resources are available to think differently about disability and its place in arguments about reproductive freedom. In particular, I argued that greater attention to embodiment as an unavoidable condition of ethical subjectivity provides promising avenues for defending and extending the expressivist critique.

In the course of this discussion, I raised two issues that require further attention, and which form the basis of the following two chapters. The first of these, which I hinted at in the discussion of prenatal testing and discrimination, is the idea of social appearance. By this I mean the ways that bodies appear within regulatory schemas of norms that productively constrain what is recognised as a valuable life. I discuss this idea further in the final chapter, which considers the impact of ultrasound images on ethical intuitions about the human foetus. The second idea that needs to be pursued further is the question of the ethical significance of our relations to others. This relationship of alterity has been seen as ethically primary by a number of scholars in recent years, and I draw on some of this work in the following chapter on PGD. Both these chapters take embodiment as a necessary condition of ethical subjectivity, and try to think through the implications of this in relation to technology. The underlying questions are: How do new technologies impact upon our experience of ourselves as embodied beings? What possibilities do they open up for imagining ourselves otherwise? Might the alterity that is internal to ourselves motivate us to attend with more sensitivity to the ethical demands of others?

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Chapter 5
Reproducing Alterity:
Ethical Subjectivity and Genetic Screening

5.1 Introduction

To a large extent, reproductive decisions are decisions about *who* comes into the world. As the non-identity problem discussed in the previous chapter makes clear, this is true of more traditional forms of decision-making and contingencies such as when conception occurs. It is also true, and increasingly obvious, with decisions about preimplantation and prenatal screening. Rather than address issues of the obligations that parents may have to give birth to specific children – such as those with the best chance of the best life – in this chapter, I want to ask what the fundamental stakes are of decisions about who comes into the world, and how screening technologies may impact upon this decision. In order to do this, I will first address and critique two kinds of arguments that have been provided that address this question: first, the defence of an ethics of the gift suggested by Michael Sandel; and second, the defence of a moral conception of human nature outlined by Jürgen Habermas. Both Sandel's and Habermas' recent interventions in reproductive ethics can be seen as responses to the perceived dangers of liberal eugenics, especially in terms of ethical self-perception and the relations that hold between ethical agents. The shared virtue of these approaches is that rather than focusing on the question of harm, they attempt to formulate critiques of genetic selection that highlight the nature of the ethical *relationships* that hold between parents and their children. They start from a more explicit recognition of the relational basis of ethics, though this is theorised in somewhat inchoate ways.

This relational focus is strongest in Sandel's communitarian critique of the genetic selection of the attributes of one's offspring. He argues that such selection undermines an 'ethics of the gift', which demands that one accept 'whoever comes'. Sandel's tack is promising, but ultimately unsatisfactory for several reasons. Primary among these is that in the absence of an alternative theorisation of the gift relation, Sandel's argument remains heavily theological. In response to this, I develop a non-theological approach to the ethical demand to accept 'who comes'. Habermas proposes that recent developments in genetic technologies, such as reproductive cloning and pre-implantation gentic diagnosis (PGD), threaten to transform the 'ethical self-understanding of the species', especially in the context of

projects of liberal eugenics. I suggest that while Habermas' broad thesis on ethical self-understanding has some appeal, the dual arguments that he provides to elaborate the implications of the perceived transformation of ethical self-understanding inaccurately describe the effects of PGD. The affectivity of Habermas' argument is to shore up the moral import of the principles of liberalism – such as individual autonomy – in the face of a perceived threat, in this case wrought by technological change. Shifting affective modes, I want to suggest that while new reproductive and genetic technologies may well be changing our conception of ourselves as ethical agents, this is not reason in itself to resist such change. Rather, I will suggest that the 'epistemic' shift wrought by new technologies can be seen as an opportunity and invitation to re-imagine our ontologies of ourselves as ethical agents in such a way that rational individuality is no longer seen as the primary modality of being ethical.

In this spirit, I argue in this chapter that a richer conception of corporeal life and its role in establishing ethical responsiveness allows a more accurate depiction of the impacts of new genetic technologies on ethical self-understanding. To draw this out, I turn to the concept of singularity developed by theorists such as Jean-Luc Nancy and Adriana Cavarero through the distinction made by Hannah Arendt between 'who' and 'what' a person is. Nancy and Cavarero both posit the singularity of embodied beings as central to ethical relationality and freedom, and I take up these conceptions to help articulate the ethical implications of using PGD to select children with a particular genetic profile. Interestingly, focusing on the concept of singularities helps bring into focus the 'obscure relation' between ethical freedom and the contingency of one's origin that Habermas admits he finds himself unable to sufficiently elaborate.[1] Both following and diverging from Habermas and Sandel, then, I suggest that if anything is at stake in genetic selection it is the contingency that underpins the singularity and unpredictability of who someone is. That is to say, persons are increasingly born for 'what' they are, that is, for determinate qualities and characteristics, and not for the unexpected singularity of 'who' they are. I suggest that the concept of singularity helps to elucidate the condition of ethical agents in the midst of being with others. Moreover, this revised ontology of ethical subjectivity allows greater insight into the actual effects of PGD than the precepts of autonomous individuality permits. Even so, it should be noted at the outset that I refrain from developing prescriptive claims in relation to PGD on the basis of the insights that this revised ontology allows. This is because to do so would require further argumentation about the ethical significance of singularity than I will be able to provide here; more importantly, the framework I am suggesting challenges the move to prescription as the primary aim and end of ethical thinking in the first place.

5.2   Genetic Selection and Ethical Self-Understanding

The possibilities for ensuring offspring with specific genetic traits – such as through using PGD to select for or against characteristics, or more interventionist technologies that may allow for the modification of genomes – are at the heart of debates

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[1] Habermas, Jürgen. 2003. *The future of human nature*. Cambridge and Malden, MA: Polity, 75.

on genetic enhancement and procreative beneficence. The decisions that these technologies provoke about *which* child parents should seek to give birth to appear to many as novel, and moreover, as indicative of an overreaching of parental and medical power. To be sure, parents have previously had some control over the genetic characteristics of their children, through the choices that are made about reproductive partners for instance. But new technologies allow far greater control and require more fine-grained decisions, decisions that are often made between an array of already existing embryos. Whether or not decisions about who is born are in principle novel, then, the technological developments of the past decade or so certainly suggest that they are different in scope than has been the case previously. Liberal eugenicists have denied that this extension of parental choice introduces unprecedented moral questions – since these choices are not morally distinct from decisions about education, specialised training and so on. On the other hand, critics of liberal eugenics have sought to emphasise a disparity in these kinds of parental decisions, suggesting that new levels of genetic control or mastery introduce damaging aspects into the relationships that ought to hold between parents and their children.

Two such critical approaches have been especially influential within the literature on the selection of future children using technologies such as PGD. While promising in their shift of focus to the relational aspect of ethics, both these approaches are ultimately uncompelling and I discuss each in turn here. The first of these is Michael Sandel's communitarian critique of the drive to genetic perfectionism, which he argues, undermines our sense of an ethics of the gift. Sandel argues that an ethics of the gift is enlivened by the 'openness to the unbidden' outlined by theologian, William F. May. He writes, '[t]o appreciate children as gifts is to accept them as they come, not as objects of our design, or products of our will, or instruments of our ambition'.[2] The problem with a drive to master the genetic features of children, then, is the 'human disposition it expresses and promotes', a disposition which transforms three key characteristics of our moral landscape: humility, responsibility and solidarity. While undermining humility and a solidarity based on the shared human characteristic of being subject to the 'genetic lottery', genetic mastery actually increases a sense of responsibility. That is, it makes parents responsible 'for choosing, or failing to choose, the right traits for their children'[3] in a way that they are not responsible when such traits are considered as matters of chance, nature or the actions of God.

While the theological connotations of Sandel's approach are reasonably clear, especially in the idea that a gift presupposes a giver – in this case, God – Sandel argues that an ethics of the gift can also be based on secular grounds. The secular idea of the gift that he wishes to mobilise, he suggests, is the same as the sense of a gift that is invoked in the common idea that a special talent is spoken of as a 'gift'. However, this is an uncompelling argument for a secular ethics of the gift, not least because it is not clear that this idea of the gift is necessarily secular. The claim that a rare musical talent is a 'gift' may well be meant in a theological way – that

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[2]Sandel, Michael. 2007. *The case against perfection*. Cambridge, Mass and London: Belknap Press of Harvard University Press, 45.

[3]Ibid., 87.

is, in the sense that the talent is a gift from God. Moreover, if the meaning is simply secular, then the notion of the gift invoked is simply metaphoric – there is no actual gift, but we think of it *as if* there were. But a metaphor on its own does not seem a solid foundation upon which to build an ethics. What is required here is a much more substantial analysis and reworking of the gift relation, such that it does not presuppose a theologically inspired metaphysics that will be uncompelling for many. This reworking will also have to be able to extract the notion of the gift from the relationship of giver and receiver, and hence of reciprocity, that it usually presupposes. Such an ethics has been suggested by a number of philosophers, primarily Emmanuel Levinas and Jacques Derrida, and scholars who draw on their groundbreaking work. Such an ethics might be thought of as an ethics of the 'gift of the other',[4] that is, in terms that emphasise the ethical importance of alterity and the incommensurate hold the other has upon each of us. In the section that follows, I draw upon one such account, which focuses most specifically on the ethical significance of birth.

Before this, though, the second critique I wish to discuss is that of Jürgen Habermas, which is based on a postmetaphysical account of human nature and the role this plays in modern ethical self-understanding. Habermas has argued against the project of a liberal eugenics, particularly focusing on the ethical implications of PGD in relation to 'saviour siblings' and genetic modification. He attempts to rest his opposition to the perceived threat of liberal eugenics on liberal grounds, and develops two arguments to this end. The first of these is that, far from enhancing individual autonomy, genetic intervention has the capacity to undermine the individual's capacity to 'be oneself' in the strong ethical sense of living one's own freely chosen life. Shifting focus from the liberty enacted in parental choice to the ethical freedom of the resultant child, he argues that genetic selection and modification threaten one's sense of oneself as an autonomous person, since they involve being treated as an object, and the mode of action taken toward the embryo is one of instrumentalisation. Habermas claims that the 'primary mode of experience, and also the one 'by' which the subjectivity of the human person lives, is that of being a body'.[5] Consequently, to the extent that one recognises one's body as being made by another, one's sense of oneself 'collides with the reifying perspective of a producer or bricoleur'.[6] His second point of opposition targets the claim that the principles of justice as fairness not only permit but require genetic selection and modification. He argues that rather than fulfilling the principle of universal egalitarianism, these practices undermine it by establishing an unprecedented interpersonal relation in which the programmed subject of genetic intervention never has the opportunity to reverse the relation that obtains between themselves and their designer. As Habermas writes, 'eugenic programming establishes a permanent dependence between persons who

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[4]Guenther, Lisa. 2006. *The gift of the other: Lévinas and the politics of reproduction.* Albany, NY: SUNY Press.

[5]Habermas. *The future of human nature*, 50.

[6]Ibid., 51. Emphasis in original.

know that one of them is principally barred from changing *social* places with the other', since 'the product cannot . . . draw up a design for its designer'.[7] Such relations, he argues, are 'foreign to the reciprocal and symmetrical relations of mutual recognition' otherwise established in the liberal social world of 'free and equal persons'.[8]

There are a number of ways in which the arguments presented by Habermas remain unconvincing. For one, his rhetoric of 'programming' and 'design' radically overestimates both the efficacy and extent of the kinds of interventions currently permitted by PGD. Selecting embryos on the basis of having or not having a particular genetic trait does not amount to the thoroughgoing intervention that Habermas seems to have in mind. Even in the more speculative realm of genetic enhancement, or modification for non-therapeutic reasons, the kinds of interventions that may be possible are not in the realm of a genetic 'bricolage'.[9] More specifically, Habermas' claim for the uniqueness of the irreversibility of the relation established between the 'designer' and the 'designed' requires some explanation of the incommensurable moral significance of genetic intervention. It is hard to see, for instance, how this relation is different from and more morally problematic than other non-reversible relations such as the genealogical irreversibility necessarily entailed in parent-child relations. Habermas does attempt an explanation of this, saying that the dependence entailed in normal parent-child relations 'only engages the child's existence . . . not their essence' and entails 'no qualitative determination of any kind of their future life'.[10] However, this explanation is notably opaque and dissatisfying.

Much could be said about Habermas' specific figuration of genetics, existence and essence at this point, but let me focus instead on the broader issue at stake. What underpins Habermas' arguments against liberal eugenics and PGD is a particular philosophical approach to the moral status of nature, or what some have called a return to the 'moralisation of human nature'.[11] For Habermas, the stakes of new genetic technologies are not simply the principles of individual autonomy and universal egalitarianism as cornerstone principles of liberal democracy, but rather, our *understanding of ourselves* as a species capable of moral action and freedom upon which those principles are built. Habermas argues that our ethical self-understanding is built upon an Aristotelian undertow in our lifeworld. Because of this, we readily distinguish between the organic and inorganic, the natural and the social, even if these categorical distinctions are no longer founded on

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[7] Ibid., 65.

[8] Ibid.

[9] While there is much fantastic and philosophical speculation about enhancing desirable traits such as intelligence, memory and physical agility and endurance, at least for now, genetic modification is technically more in the realm of gene replacement therapy and epigenetics, which permits the regulation of gene expression. Even these fields are proving more difficult than was initially supposed.

[10] Habermas. *The future of human nature*, 64.

[11] Ibid., 23; also see Fukuyama, Francis. 2003. *Our posthuman future: Consequences of the biotechnology revolution*. London: Profile Books.

ontological claims. The difficulty that biotechnological intervention creates in this context is that of the 'dedifferentiation' of these categories. This means those things that are 'given' or 'come to be by nature', are increasingly treated in accordance with the same objectifying mode of action that we take to those things that are manufactured or 'made'. According to Habermas, the problem is that the intuitive distinction between the given and the made is 'constitutive of our self-understanding as species members' and hence, the dedifferentiation of these categories threatens that self-understanding.

We can see at this point that much of the weight of his argument rests on the distinction between the given and the made. Biological life, he suggests, is given in the sense that it is not subject to the determination and control of other humans. Interventions into life at the level of the genotype threatens this status, such that biological life is increasingly open to choice rather than necessity, or 'chance' as other prominent figures in the liberal eugenics debate have put it.[12] It is tempting at this point to criticise Habermas' characterisation of the effect of biotechnological intervention on the basis that it is simply not the case that such interventions entail an unprecedented dedifferentiation of the given and the made. Rather, in accordance with Bruno Latour for instance, one might suggest that these categories have never been pure, that the modernist project of categorical purification has never been much of a success. Thus we have always been confronted with the 'quasi-objects' that emerge from the indistinction and intermixing of the given and the made, of the free subject and the reified object.[13]

Some care is required, however, since Habermas' use of these categories simply identifies the distinction as part of our 'lifeworld' and does not require that they have any ontological status. That is, it is not a matter of whether biological life is actually given rather than made; what is important is how we typically think of the status of the natural or biological and the way in which this provides foundation for our ethical self-understanding. It is at this level of the lifeworld that, he argues, our self-understanding is being transformed. Hence, his claim is not about the actual state of 'the given' and 'the made' – as if these were, in fact, once distinct but are now increasingly less so – but is rather directed toward the operation of this distinction in establishing the epistemic or discursive statuses of objectivity and subjectivity and the ethical consequences of this.[14] A related caveat to note here is that his normative opposition to genetic interventions proposed by liberal eugenics does not follow directly from perceived transformations in ethical self-understanding. This opposition is only justified on the basis of an already established commitment to the principles of liberalism and egalitarianism. Thus, genetic intervention is not a problem per se; it only becomes a problem to the extent that it collides with the principles of political liberalism, and especially the values of individual autonomy

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[12]Buchanan, Allen et al. 2000. *From chance to choice: Genetics and justice*. Cambridge: Cambridge University Press.

[13]Latour, Bruno. 1993. *We have never been modern*. Cambridge, MA: Harvard University Press, 60.

[14]There is, however, a considerable amount of slippage throughout Habermas' essay and he does not always remain within the limits of this epistemic approach.

and universal egalitarianism. That is to say, genetic intervention is problematic to the extent that it conflicts with the central principles of political liberalism, which it does by virtue of the transformation it brings about in the epistemic regime of ethical subjectivity that supports these principles.[15]

Despite the central role that the distinction between 'the given' and 'the made' takes for Habermas, the way it operates within his argument is decidedly ambiguous: the givenness of biological life all too quickly blends into the notion that *persons* are born not made, and further, that it is only now that 'made' persons participate in social relations. Thus, he writes that, 'up to now, only persons born, not persons made, have participated in social interactions'.[16] The notion that *persons* are simply born not made is one that feminists have long contested; it is also one which a number of other moral philosophers would reject on the basis that the status of personhood does not necessarily equate to biologically belonging to the species homo sapiens, or indeed any naturally given biological status. In fact, for some, it is entirely plausible that an intelligent machine has the moral status of personhood if it fulfils criteria such as rationality and self-consciousness for instance. The relation between biological 'givenness' – in the sense of not being determined or under the control of an intentional agent – and personhood is thus not straightforward. Yet it is precisely this relation that is at stake in Habermas' argument. Even so, Habermas does little to explicate the relation that he sees between biological givenness and moral status, and especially the status of being an ethically free agent. In fact, in the postscript to the main essay in *The Future of Human Nature*, Habermas admits that the philosophical depths of the debate on the 'natural foundations for the self-understanding of responsibly acting persons' remain unplumbed. He concludes that further analysis of 'the connection between the contingency of a life's beginning that is not at our disposal and the freedom to give one's life an ethical shape',[17] is required. In the spirit of this insight, in the following discussion, I sketch an outline of an alternative way of articulating the effects of genetic interventions on that connection, one that avoids the problematic distinction between the given and made that Habermas relies upon. In particular, I want to illustrate the potential importance of the concept of singularity for comprehending the effects of genetic intervention on embodiment and ethical self-understanding.

5.3   Natality, Corporeality, Singularity

It is interesting that Habermas himself notes an alternative way of articulating the implications of PGD, though it is not one he takes up in detail. In a brief discussion of Hannah Arendt's theorisation of natality and the link she makes between the surprise of the newborn and the capacity for free action, Habermas asks whether

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[15]It should be noted that I use the term 'epistemic regimes' in reference to Michel Foucault's analysis of the modern 'episteme' in books such as *The Order of Things* (1970), though I am not suggesting that the details of his analysis need be adopted.

[16]Habermas. *The future of human nature*, 65.

[17]Ibid., 75.

'a discernable intrusion of the intentions of third persons upon a genetic program [means] that birth no longer constitutes a beginning that could give the acting subject an awareness of being able to make a new beginning, any time'.[18] Withdrawing from the strength of this supposition, he suggests that Arendt's account of natality does not provide any necessary reason as to why a body loses its worth as the basis upon which to be oneself in the strong ethical sense. In this construal of Arendt's account of natality, in which he sees birth as 'a divide between nature and culture', Habermas ties the question of natality to that of autonomy very quickly; consequently, he may well be right to eschew the conclusion her account of natality appears to produce. I want to suggest, however, that more can be gained from Arendt and recent reformulations of some of her ideas than this correlation between natality and autonomy allows. In *The Human Condition*, Arendt writes:

> [i]t is the nature of the beginning that something new is started which cannot be expected from whatever may have happened before. This character of startling unexpectedness is inherent in all beginnings and in all origins ... The new always happens against the overwhelming odds of statistical laws and their probability, which for all practical, everyday purposes amounts to certainty; the new therefore always appears in the guise of a miracle. The fact that man is capable of action means that the unexpected can be expected from him, that he is able to perform what is infinitely improbable. And this again is possible only because each man is unique, so that with each birth something uniquely new comes into the world. With respect to this somebody who is unique it can truly be said that nobody was there before.[19]

This long quotation clearly evinces the ready connection that Arendt makes between the unexpected and action, and thus political appearance and freedom, for which Habermas discounts her characterisation of natality as a means of articulating the implications of genetic interventions. While this link is crucial for Arendt's formulation of the political, it need not be the central focus here. Instead, this paragraph also highlights the importance of the unexpected appearance of the existent in its unique identity, a uniqueness that is grasped at in the distinction between 'who' and 'what' someone is.

Arendt's formulation of a distinction between who and what someone is takes off from Heidegger's analysis of *Dasein* and is central to her conception of political action and the appearance of one among others in the public realm. She argues that the unique personal identity of who someone is, is actively revealed in all speech and action, and passively so in the idiosyncratic physical presentation of the body and sound of voice. Significantly, this personal identity may not be evident to the person herself, but is disclosed to others in the condition of human plurality. Indeed, the coherence of a unique personal identity may only be visible upon death. The life story of who someone is begins with birth and ends with death, but requires others for its manifestation at all, such that it is intrinsically tied to the public sphere. Interestingly, 'who' someone is cannot be elaborated easily within language; Arendt writes, 'though it is plainly visible, [it] retains a curious intangibility that confounds

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[18]Ibid., 60.

[19]Arendt, Hannah. 1998. *The human condition*. 2nd edn. Chicago, IL: University of Chicago Press, 177–178.

all efforts toward unequivocal expression'.[20] This is because the attempt to render this unique personal identity in language necessarily falls into a delimitation of 'what' someone is, that is, into the identification of the determinate characteristics that they share with others.

Not dissimilarly, the position of the body in this account of 'what' and 'who' is equivocal, since the shared materiality and needs of the body appear to relegate it to the privative realm of labour and the necessary reproduction of natural life processes, As Julia Kristeva writes:

> [e]nsuring the metabolism of nature, the body accomplishes both the reproduction of the species and the satisfaction of its needs. Women and slaves personify this body in labor, which is the zero degree of the human and is the primary expression of biological life or *zoe*.[21]

The body is both apolitical and 'generic' and is thus more closely associated with 'what' someone is. As such, it appears to work in opposition to the revelation of who someone is.[22] This would seem to make Arendt an unlikely figure to turn to for an account of the interrelation of embodiment and ethical freedom. However, recent formulations of the notion of 'who', and of the concept of singularity it references, that extend upon Arendt's analysis are of help here.

In her account of the narrativity of self-formation, Adriana Cavarero helps to illuminate the role of embodiment in the exposure of who someone is and the ethical importance of this. Beginning from the ostensibly innocent question of 'who are you?', Cavarero offers an account of self-formation in narrative founded on an embodied ethical altruism, which she develops from the distinction between the generality and singularity of an existent exposed in its relation to others.[23] Cavarero highlights the ethical importance of this distinction. She argues that focusing on the question of 'who' yields a 'relational ethics of contingency' that avoids the exclusions effected in the focus of philosophical discourse on 'what' one is.[24] She begins her analysis from the corporeal vulnerability and exposure of the one to another, and makes this exposure central to an ethics of relational contingency, such that what is at stake in ethics is the unique life that constitutes the self of the phenomenal individual. This understanding of selfhood works with a conception of the person as fundamentally intertwined with others in their constitutive co-appearance. One is never simply oneself, but always appears as oneself in relation with others, and part of that relation with others entails dependence and a necessary incompletion of the self. Hence, one might say that the self is never fully constituted in its

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[20] Arendt, *The Human Condition*, 181.

[21] Kristeva, Julia. 2001. *Hannah Arendt* (trans: Guberman, Ross). New York, NY: Columbia University Press, 177.

[22] Ibid., 178.

[23] See Nancy, Jean-Luc. 1991. Introduction. In *Who comes after the subject*? eds. Eduardo Cadava, Peter Connor, and Jean-Luc Nancy. New York and London: Routledge.

[24] Cavarero, Adriana. 2000. *Relating narratives: Storytelling and selfhood* (trans: Kottman, Paul A.). London and New York: Random House, 87.

appearance, but is always in the process of constitution. The appearance of oneself is both founded and founders on a dependency on others, for this dependency generates a necessary failure or incompletion in the self's appearance at the same time as it makes that appearance and exposition possible.

In contrast to Arendt's focus on the heroic aspects of the revelatory character of speech and action, for Cavarero, the paradigmatic figure of mutual co-appearance is the vulnerability and exposure of the newborn, who, she argues, appears in the full unity of the self without qualities, such that he or she is simply a '*who*'. The newborn is characterised by both absolute exposure and a unity of the self that is not yet fractured by the passing of time. As she writes:

> the baby who is born is always unique and one. Within the scene of birth, the unity of the newborn is materially visible and incontrovertible through its glaring appearance. The newborn – unique and immediately expressive in the fragile totality of her exposure – has her unity precisely in this totally nude self-exposure. The unity is already a physical identity, visibly sexed, and even more perfect insofar as she is not yet qualifiable.[25]

Without taking up all the implications of this characterisation, for Cavarero this means that embodiment and self-appearance are intimately intertwined and, further, that our having been born establishes an ethical reciprocity between existents insofar as the exposure of ourselves is always dependent on others, not simply in action, but from the moment of having been born. In this conception of selfhood Cavarero provides a way of parsing an account of natality from Arendt's emphasis on action and tying the notion of 'who' one is more tightly to the constitutive condition of embodiment. That the uniqueness of a 'who' is manifest most clearly in the total exposure and 'unity' of the newborn requires that the existent is not only necessarily embodied, but that the condition of embodiment is expressive of a unique personal identity. This account of natality means that the newborn appears without qualities: while embodied and therefore sexed, for Cavarero, 'the one who is born does not yet have any qualities',[26] such that they are absolutely irreducible to the determinate characteristics of what they are or will become.

As Cavarero's emphasis on 'uniqueness' suggests, one of the ways that the distinction between 'who' and 'what' someone is can be further articulated is through the idea of singularity and its differentiation from generality, or general characteristics that find expression in particular beings. While the notion of singularity has been especially popular in contemporary French philosophy, perhaps no other theorist has gone as far to develop an ontology and ethics of singularity as Jean-Luc Nancy in his radical extension of Arendt's framework.[27] As he explains of the notion, singularity 'is that which occurs only once at a single point . . . Not a particular, which

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[25] Ibid., 38.

[26] Ibid.

[27] Although Nancy references Arendt infrequently, he does acknowledge the significance of her reflections on 'human plurality', especially in relation to Heidegger. Related to this, his emphasis on the notion of 'who' and on birth draws on Arendt, as do his reflections on spacing in the book *The Experience of Freedom* (1995). It should be noted that Nancy's reflections on ontology and

comes to belong to a genre, but a unique property that escapes appropriation'.[28] For Nancy, singularity is distinct from particularity, in that the latter is equivalent to the manifestation of general characteristics in a thing. For instance, a red ball might be understood as a 'particular' manifestation of the general characteristic – or 'genre' in Nancy's formulation – of redness. Or, with regard to genetics, an individual body could be understood as particular insofar as it is seen as an individual manifestation of a more general genotypic (or phenotypic) trait, for example, of the existence of the defective gene called 'Huntingtin' involved in Huntington's disease.

Understood as a singularity, however, the individual body exceeds the correlations of generality and particularity: it is someone that occurs only once, here and now. In this way, Nancy suggests, singularity is not opposed to the general or the particular, but includes them within itself, since singularity is simply the 'distancing, spacing and division of presence' in coexistence.[29] Crucially, Nancy also argues that such an understanding of singularity is intimately tied to the question of birth, and as such, to the question of freedom, since, 'it is each time freedom that is singularly born. (And it is birth that frees)'.[30] Clearly, by the term 'freedom', Nancy does not mean the autonomy (self-rule) of the subject. Instead, his conception of freedom refers to the ontological spacing of being itself, a spacing that is necessary for singularities to co-appear at all (since otherwise there would only be the unity of being itself).

Much more could be said about Nancy's formulation of singularity and its importance for an understanding of ethical freedom, but I will only briefly make two specific points here. Firstly, as with Cavarero, Nancy posits a close relation between singularity and embodiment, writing that, '[a] singularity is always a body, and all bodies are singularities . . . the bodies, their states, their movements, their transformations'.[31] However, whereas Cavarero avoids questions of technology and tends toward a romanticisation of the natural in her account of the uniqueness of the newborn, Nancy resists making a clear distinction between nature and technology. He argues that 'nature' and 'technology' indicate different 'modes of accomplishment' or 'execution' that co-exist in a relation of mimicry (which is not simply a matter of copying).[32] Secondly, the notion of singularity allows a reformulation of

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ethics constitute an extremely complex and often allusive engagement with the Western philosophical tradition, and especially with Kant, Hegel and Heidegger. My comments on his work are brief and necessarily leave much to be explained further.

[28]Nancy, Jean-Luc. 2004. Banks, edges, limits (of singularity). (trans: Anidjar, Gil) *Angelaki: Journal of the Theoretical Humanities* 9:41.

[29]Nancy, Jean-Luc. 2000. *Being singular plural* (trans: Richardson, Robert D., and Anne E. O'Byrne). Stanford: Stanford University Press, 2; also see his further explication of the notion of singularity and its necessary relation to co-presence or 'being-with', itself a central idea in his extension of Arendt.

[30]Nancy, Jean-Luc. 1995. *The experience of freedom* (trans: Macdonald, Bridget). Stanford: Stanford University Press, 66.

[31]Nancy. *Being singular plural*, 18.

[32]Ibid., 101–114, 17–19; Nancy. Banks, edges, limits (of singularity), 42–43.

our understanding of subjectivity and, at least for Nancy, is posed as a 'critique or deconstruction' of the philosophical emphasis on the subject as a rationalistic, interiorised and monadic individual. Understood as a way of approaching the question of who someone is, Nancy's conception of singularity actively evades the attribution of properties to an interiorised self or subject, and insists on the necessity of 'being-with-others' in order to be at all. In short, being *is* 'being-with'. Importantly, to the extent that this approach gives rise to a 'critique or deconstruction' of the subject, it undoes the distinction between the subjective and objective that has such a profound hold on conceptions of ethical freedom.[33] One implication of this is that the distinction between 'the given' and 'the made', or the subjective and objective, that structures Habermas' understanding of the impact of PGD on ethical self-understanding need no longer govern the way in which we imagine or understand ethical subjectivity. Further, this means that the Kantian arguments against instrumentalisation or objectification no longer provide the ground for normative opposition to technologies such as PGD. Given this, the question that arises is how the concept of singularity might help understand the ethical transformations effected by such technologies.

5.4 Screening Singularity

The focus on singularity elaborated by Cavarero and Nancy suggests that the predetermination of the *qualities* of the newborn indicates a transformation in our mode of relating, which has the effect of forestalling or eroding the immediate recognition of who they are. That is to say, the transformation effected by genetic intervention and selection is that the newborn is born for *what* they are, that is, for their determinate qualities and characteristics, and not for the unexpected appearance of *who* they are. This amounts to the reduction of the singularity of the newborn to its particularity, that is, to the manifestation of certain desirable general characteristics that are determined in advance and are ineluctably manifest in the body of the newborn. To be clear, the reduction of the singular to the particular does not mean that the unique identity of who someone is is therefore eradicated or undermined per se. Rather, it is a matter of the failure of recognition of that singularity, such that while that unique identity may well come to incorporate its own beginning in the 'technical creation of the singular-plural',[34] its appearance as such goes unnoticed in its arrival.

Further, it is not individuality in the sense of the phenomenal appearance of the newborn that is under threat in genetic interventions made possible by PGD. Rather, what is potentially eroded is the unexpectedness that Arendt makes so central to

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[33]On the issue of how the notion of singularity relates to conceptions of the subject, see especially Nancy. Introduction. In *Who comes after the subject?* And, in the same volume, see Jean-Luc Nancy's interview with Jacques Derrida. 'Eating well', or the calculation of the subject, 96–119. Also see Nancy. *The experience of freedom.*

[34]Nancy. Banks, edges, limits (of singularity), 43.

the appearance of a unique identity. Cavarero is not explicit about this, but, returning to Arendt, one might emphasise that what is fundamental to the uniqueness of the self is the fact that the qualities of who someone is are not determined before their arrival. Or, as Nancy puts it, 'some *one* comes ('one' because it 'comes' not because of its substantial unity: the she, he, or it that comes can be one and unique in its coming but multiple and repeated 'in itself')'.[35] As the arrivant, the newborn defies expectation and determination. With PGD, that unexpectedness is diminished by the choice already made in advance that the child be born with a particular characteristic. Of course, the technical limitations on genetic screening as well as genetic expression ensure that the child born of PGD will exceed the expectations of parents and others in various tangible and intangible ways; but the child is also born immediately and ineradicably fulfilling a parental desire for a particularity rather than a singularity.

In order to make my point clear, let me quickly distinguish this position from the more standard approaches to PGD that are currently in circulation. First, it is true that the notion of genetic technologies undermining singularity or unexpectedness have been expressed previously, often to bolster conservative critiques of new technologies. For example, in reference to reproductive cloning, Hilary Putnam has expressed the view that genetic technologies may undermine 'the "right" of all children to be a complete surprise to their parents'.[36] The position I have elaborated differs from this in significant ways. For one, it does not require recourse to the attribution of a suspect right to unexpectedness. More importantly, it generates a new description of ethical subjectivity that takes seriously the connection between embodiment, contingency and ethical freedom, without positing a problematic distinction between the 'given' and the 'made' and the 'moralisation of (human) nature' that has gone along with this. This also means that my point is not simply that the child that results from PGD is a 'composite' of the given and the made: that may well be true, but it is also true that one would be hard pressed to find a baby that was not such a composite.[37] As such, this view does not help clarify what is ethically distinctive about the selection of embryos for certain genetic traits.

Nor is the point simply that PGD is a form of instrumentalisation in which a *child* comes to be treated as a (more or less fungible) object in the manner that Habermas and others claim.[38] As a number of commentators have pointed out, parents often have instrumental reasons for having a child, and PGD is not unique in that regard. That said, what I have suggested is specific to PGD and the genetic selection that it allows, is the immediate realisation of the choice for or against a particular characteristic in the body of the resultant child; that is, the desire for a

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[35]Nancy. Introduction. In *Who comes after the subject?* 7.

[36]Putnam, Hilary. 1999. Cloning humans. In *The genetic revolution and human rights: The Oxford Amnesty Lectures 1998*, ed. Justine Burley, 13. Oxford: Oxford University Press.

[37]This depends in part on the breadth of one's definition of the 'technological'.

[38]I emphasise 'child' here because, on the face of it, PGD does allow that embryos – or rather, pre-embryos – be treated as fungible.

child with a particular genetic profile is realised in the choice itself of which embryo to implant, or of which gene to modify and how.[39] This sets PGD apart from other ways in which parents may desire a child for the fulfilment of a particular life plan, for example, to inherit the family business or carry on the family tradition of medical practice. In cases such as this, the child can – and often does – come to reject that life plan for him or herself. In fact, the key difference here is that one of these cases entails a desire for the fulfilment of a particular life plan, the other a desire for a particular genetic profile or characteristic. It is not at all clear that there is an empirical or ethical alignment between those desires and attempts at their realisation. Relatedly, I am not suggesting that PGD operates to determine the life plan of the resultant child; their chosen characteristic may impact upon their life plan in significant ways, but it does not determine it. Instead, the view that I am suggesting does not require speculation about life plans. It simply is the case that the particular child is born for its manifestation of a general genetic characteristic and we can, at least temporarily, set aside discussion of what may result from that.

5.5 Conclusion

The intuition I explore in this chapter is that PGD (and, by extension, other technologies of genetic selection and intervention) is contributing to a transformation in ethical self-understanding. This is because it allows a shift in focus from the unexpected singularity of the newborn to the determination in advance of a particular characteristic that is immediately embodied in their being born. That is, it is the capacity to choose a *particular* characteristic that is immediately embodied in the newborn's corporeality that is distinctive about PGD, and which indicates its capacity to impact upon our ways of seeing ourselves and others as ethical agents. More needs to be said of this than I have been able to here, especially in relation to the ethical or moral significance of the reduction of the singular to the particular and the normative implications to draw from this. Even so, it should be clear that neither celebration nor resistance to technological change on the basis of its capacity to transform our ethical self-understanding alone is sufficient.

It is surely truistic that new genetic and reproductive technologies present both dangers and promises. At the level of a theorisation of subjectivity and attendant conceptions of ethics, the promise is that new technologies can contribute to an 'epistemic shift' in understanding the human as ethical agent. That is, they may open opportunities for reconceiving ourselves and our relations with others in ways that do not presuppose a more or less atomistic, autonomous individual as the primary datum of ethics. The danger is that this epistemic shift generates a kind of melancholic hypostatisation of individualistic ethical self-understandings, such that

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[39] I am presupposing the success of PGD and IVF processes to make my point here, which in practice is far from guaranteed. For an insightful empirical study of the use of PGD in the United Kingdom, see Franklin, Sarah, and Celia Roberts. 2006. *Born and made: An ethnology of preimplantation genetic diagnosis*. Princeton, NJ: Princeton University Press.

we not only miss the opportunity to re-imagine being ethical, but also misdiagnose the effects of such technologies. To make good on the promise of technological change requires that considerations of the implications of new genetic technologies extend beyond the current emphasis on autonomous individuality and reproductive freedom in terms of choice. For, ultimately, what is at stake in such technologies is a possible parsing of ethical freedom and the politics of choice. The conceptual break produced by this allows us to re-imagine ethical subjectivity and freedom in a way that emphasises contingency over choice, the unexpected over the autonomous and our shared or common coexistence over the determinations of individual will.

One implication of the argument that I have made in this chapter is that in opening up the question of who is born to fine-grained decisions, reproductive technologies such as PGD contribute in powerful ways to regulating the social appearance of bodies. If this is so, then two problems, which I have touched on without exploring in depth in this chapter, require further discussion. First, I mentioned in this chapter that Cavarero tends to romanticise the body, without acknowledging the fundamental role that technology plays in the constitution of corporeality. Technologies such as PGD make necessary a different approach that recognises the way that medical technologies are embedded in agential processes of the materialisation of bodies. In addition to this, and this is the second problem, practices of medicine and the processes of materialisation to which they contribute take place within complex contexts of social norms. Some of those norms will impact on what appears as a normal body, underpinning and shaping decisions on what counts as viable life. Nuancing the emphasis on singularity, the ineluctability of norms in social life means that the ethical force of the question, 'who are you?' will be circumscribed in various ways. In the following chapter, I trace one example of the interplay between reproductive technology, embodiment and social norms through a discussion of obstetric ultrasound.

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Chapter 6
Ultrasound, Embodiment and Abortion

6.1 Introduction

In her controversial documentary on abortion, *My Foetus*, British filmmaker Julia Black[1] asks the question of whether one could 'look at the facts' of abortion and still be pro-choice. The film did not provide a definitive answer to this question: Black herself stated her pro-choice stance, but in the film adopted a number of strategies used by anti-abortion campaigners to probe the ethical issues raised by abortion. Primarily, Black's focus lay on the imagery of the foetus, a powerful tool in anti-abortion campaigns, and in particular, on the effect of ultrasound technologies that allow three dimensional (3D) imaging of the foetus on our intuitions about the ethics of abortion. Black suggests at one point that if anything is to lead her to take an anti-abortion position, it is this capacity to 'see the foetus', particularly as it is performing activities normally associated with babies such as thumb-sucking. Black's sentiments seemed to find corroboration in more recent debates about legislation on late term abortions in the United Kingdom, sparked in large part by Stuart Campbell, who pioneered the technique of four dimensional (4D) scanning in Britain. Campbell controversially argued that 3D and 4D scanning reveal that a foetus shows 'signs of humanity' such as smiling, crying, and frowning from as early as eighteen weeks, or taking steps even earlier. He also writes, 'there is something deeply moving about the image of a baby cocooned inside the womb ... [I've] sat with parents who trembled at the sight of their soon-to-be newborn'.[2] These two instances provoke questions about the specific emotive and, I will argue, *ethical*, force of seeing the foetus and further, how the visualisation of the foetus may impact upon intuitions about abortion.

Feminist theorists have long been interested in the ways that foetal images have been mobilised within debates on abortion as well as the way they operate more

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[1]Black, Julie, Dir. 2004. *My foetus*. Bivouac Productions. Screened on British Broadcasting Commission (BBC Channel 4), 20 April 2004 and Australian Broadcasting Commission (ABC TV) 8 August, 2004.

[2]Campbell, Stuart. 2006. Don't tear a smiling foetus from the womb. *The Telegraph*, 4 October. http://www.telegraph.co.uk/comment/personal-view/3632855/Dont-tear-a-smiling-foetus-from-the-womb.html

broadly to provoke an understanding of the foetus as an autonomous subject in conflict with the woman who carries it. While this work has been fundamental in establishing the cultural and political significance of foetal images, it has not had a great degree of impact within discussions of the ethics of abortion in bioethics. For the most part, the ethical debates have remained immune to the insights of feminist cultural analysis. Indeed, the focus in standard accounts of the ethics of abortion on conflicts of rights appears to unwittingly mimic the problem that the analyses of Rosalind Petchesky, Carole Stabile, Valerie Hartouni and others diagnosed over a decade ago.[3] That is, they unwittingly repeat the occlusion of the embodied being of the pregnant woman and construe the foetus as somehow independent of and in conflict with her. To be fair, this is not the case with all interventions in the ethics of abortion, a few of which do attempt to take women's embodiment as a starting point.[4] These, however, are in the minority.

Additionally, there have been recent calls for a bioethics more attentive to the moral force of foetal images. For instance, Paul Lauritzen argues that bioethics ignores the role that foetal images play in moral debates on abortion at its peril.[5] Nevertheless, these accounts remain limited insofar as they fall short of an engagement with the specific impact of obstetric ultrasound, and the images thereby produced, on moral intuitions about abortion. While I commend Lauritzen's call for greater recognition of the visual within bioethics, I will argue in this chapter that his analysis again fails to grasp the specific moral force of the image. Rather than occlude this force by attempting to see images as just another form of argument, I show that taking the possibility of a 'visual bioethics' seriously requires that more attention be paid to the specifically emotive or affective impact of images on ethical intuitions.

In this chapter, I develop an outline of the ways in which obstetric ultrasound impacts upon the embodied experience of pregnancy. In doing this, I also point toward the ethical implications of foetal imaging, since I start from a position that emphasises the centrality of embodiment in ethics. I suggest that the impact of ultrasound images on ethical intuitions derives in part from the way in which such images work upon and through the sympathetic imagination. In this, ultrasound images hail or call the foetus into being as a subject toward which we bear a social relationship and by virtue of that, such images also work to establish a particularly ethical relationship. Ultrasound does not simply *represent* an already existing body, but

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[3]Petchesky, Rosalind Pollack. 1987. Fetal images: the power of visual culture in the politics of reproduction. *Feminist Studies* 13(2):263–292; Stabile, Carol. 1998. Shooting the mother: Fetal photography and the politics of disappearance. In *The visible woman: Imaging technologies, gender and science*, eds. Paula A. Treichler, Lisa Cartwright, and Constance Penley. New York and London: New York University Press; Hartouni, Valerie. 1998. Abortion politics and the optics of allusion. In *The visible woman: Imaging technologies, gender and science*, eds. Paula A. Treichler, Lisa Cartwright, and Constance Penley. New York and London: New York University Press.

[4]For example see, Mackenzie, Catriona. 1992. Abortion and embodiment. *Australasian Journal of Philosophy* 70(2):136–155.

[5]Lauritzen, Paul. 2008. Visual bioethics. *The American Journal of Bioethics* 8(12):50–56.

actually constitutes the foetus as an embodied, social being. With ultrasound, the foetus is made present as a being toward which we bear a particular ethical relationship, a relationship that I argue is established not only through the moral attribution of 'personhood' but by virtue of the (technologically mediated) embodied appearance of the foetus. To be clear, this ethical relationship does not necessarily lead to the conclusion that abortion is immoral. The point is simply that ultrasound images put us in relation to a being that we do not otherwise have such a relationship with. In itself, that does not yield normative conclusions about abortion. But it does help to understand why it is that ultrasound images apparently have (or are at least perceived to have) a profound impact on intuitions about the ethical status of the human foetus. This chapter progresses in three parts: in the first of these, I discuss the call for a visual bioethics and argue that such a project must take account of the sympathetic imagination if it is to grasp the moral import of foetal images. From this, I consider two implications. First, I examine the way in which the sympathetic imagination is productively constrained by social norms; this allows for an analysis of the biopolitics of reproduction. Second, I consider the impact of ultrasound on the embodied experience of pregnancy, with particular focus on the ethical implications of this.

6.2   Ultrasound Images and the Sympathetic Imagination

As a quick scan of anti-abortion sites on the internet will show, ultrasound images have held a privileged position within debates on abortion for some time, and this is all the more so with the advent of 3D and 4D ultrasound. In response to this, in his 2008 article, Lauritzen argues that bioethics ignores at this peril the role that images play in moral debates, a claim he makes by focusing on the ways that images have been mobilised in contestations of the moral status of the human foetus. Arguing for greater recognition of the 'complex interplay of words and images' that goes beyond claims about 'emotional manipulation', Lauritzen claims that images can be understood as visually mediated arguments.[6] As such, they can be assessed and rebutted on the basis of criteria that are similar to those deployed in regard to linguistic arguments, namely, factual accuracy and consistency. These argumentative criteria indicate that he remains caught within the allure of language in attempting to address the role of images in ethics. Consequently, the particular ethical force of the image is again occluded.

   While Lauritzen places emphasis on the interrelation of words and images, wherein texts and images can enliven each other, his analysis is ultimately unable to resist the pull of language. This is evident in the fact that much of the article does not actually discuss the force of images so much as the rhetorical force of the narratives that frame them, whether it be the narrative of the classic anti-abortion

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[6]Ibid., 50.

film *The Silent Scream*,[7] or the captions of the Gary Trudeau cartoons that respond to it.[8] But, even at its most interesting in terms of its treatment of the interplay of words and images, Lauritzen's analysis occludes the specific force of images by reducing them to – or substituting them with – characteristics more readily associated with rationalistic argumentation. Thus, he claims that images can be read as peculiar kinds of arguments, susceptible to the criteria of accuracy and consistency. Visually based or mediated arguments, he argues, can be 'checked against the facts', by which he means they can be tested for representational accuracy just as the narrative that frames them can be tested for veracity. Further, while his point here is less clear, he suggests that consistency might be a useful test, when, for instance, claims for a continuous moral status as persons are made about embryos and foetuses at very different stages of development, such as in embryo adoption debates. But surely one point to be made here is that hyperbolic claims to personhood can and often do operate in the absence of images of the early embryo – indeed, one might speculate that this hyperbole is exactly a response to the difficulty of imaging or imagining the early embryo. This points to a more complex relation between images and words than Lauritzen allows. More importantly, however, the criteria of consistency and representational accuracy are insufficient for understanding the force of images in ethical debates.

This point is made well by Petchesky, who argued in her analysis of *The Silent Scream* that a literal rebuttal of the inconsistencies and falsehoods of the narrative, or revelation of the 'camera tricks' used in the making of the film, are not especially efficacious in helping to understand or combat the 'ideological' force of the film.[9] It is also reinforced by the recent controversy in the United Kingdom over the legal limit for late term abortions. Stuart Campbell in large part provoked this controversy by calling for a reduction of the legal limit currently set at twenty-four weeks – an argument that he based on the emotive force of the images produced by ultrasound. In an opinion piece he writes:

> [n]o one seriously disputes that the earlier a termination is carried out the better and safer it is. My own conviction about this has been influenced by my technique for producing detailed 3D images of the developing foetus that show it smiling, yawning, rubbing its eyes and apparently 'walking' in the womb. Though I perform these scans every day, I am still overcome by the excitement and the wonder of the foetus that is learning to be a baby. By twenty weeks it smiles, makes crying expressions and sucks its thumb. At twenty-three weeks, it begins to open its eyes and develops quite complex patterns of behaviour.[10]

He defied anyone who disagreed with his proposal to reduce the upper limit for so-called 'social' abortions to eighteen weeks, 'to see these pictures and not pause

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[7]Nathanson, Bernard. 1984. *The silent scream*. USA: American Portrait Films.

[8]Trudeau, Gary. 1985. Silent scream II: The prequel. *The New Republic*. June 10, 8–9; cited in Lauritzen. Visual bioethics, 54.

[9]Petchesky. Fetal images, 267.

[10]Campbell, Stuart. 2008. Is it time to rethink the abortion law? *The Telegraph*, 1 May. http://www.telegraph.co.uk/news/features/3636464/Professor-Stuart-Campbell-is-it-time-to-rethink-the-abortion-law.html

to wonder if they [the critics] might be wrong'.[11] Campbell's critics argued that rather than meaningful emotional expressions, the apparent smiles and frowns are nothing other than developmental reflexes. Further, they argue that these images actually reveal nothing scientifically new about foetal life.[12] While this contests the interpretive framework that should be given to an ultrasound image – although it does not contest its representational accuracy per se – this argument does not get to the real force of the images themselves.

We might speculate that rationalistic rebuttals of the 'arguments' made by foetal images fail because the force of the image is not in itself straightforwardly rational. Instead, foetal images operate most effectively at the level of emotion or affect, or what might more specifically be called the 'sympathetic imagination' – a characteristic that by no means diminishes their importance or philosophical interest. The role of the imagination in morality has long been contested in Western philosophy, but in recent decades it is increasingly recognised as an indispensable aspect of the capacity for moral reflection. In particular, the capacity to imagine ourselves 'in the place of another' has been cast as requisite for moral engagement, though at the same time, this formulation of the scope of the imagination has been critically scrutinised and the limits of the imagination tested in various ways.[13] What is generally accepted, though, is that the imagination allows for significant affective dimensions of moral relationships, especially affects such as sympathy and compassion, to be brought into play and perhaps even fostered and enhanced. It is this capacity of the imagination to foster ethically oriented affects such as sympathy and compassion that I am especially interested in, as my sense is that it is in this realm of imagination and affect that the force of ultrasound images of the human foetus lies. However, while the force of foetal images relies upon the irreducibility of the sympathetic imagination, such images also help to articulate some of the ambivalences of it. Foetal images problematise the sympathetic imagination and reveal something of the political and moral danger of valorising affective bonds as *the* condition of ethical engagement.

The idea of the 'sympathetic imagination' has been used in recent years in a number of ways, and has particularly been taken up in animal studies as a means of articulating the ethical relationship between humans and animals. Nevertheless, finding a clear definition of the sympathetic imagination is far from easy. One useful account of the moral importance of sympathy is that of Peter Goldie, who distinguishes sympathy from other imaginative projects such as empathy and what he

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[11]Campbell. Don't tear a smiling foetus from the womb.

[12]Hall, Sarah. 2006. Foetus scans fuel abortion debate. *The Guardian*, 3 October. http://www.guardian.co.uk/uk/2006/oct/03/health.healthandwellbeing For further discussion of Campbell's role in the United Kingdom abortion debates, as well as of Black's documentary, *My foetus*, see Palmer, Julie. 2009. Seeing and knowing: Ultrasound images in the contemporary abortion debate. *Feminist Theory* 10(2):173–189.

[13]Especially pertinent to bioethics is Mackenzie, Catriona, and Jackie Leach Scully. 2007. Moral imagination, disability and embodiment. *Journal of Applied Philosophy* 24(4):335–351.

calls 'in-his-shoes' imagining.[14] Sympathy, he argues, is different from these imaginative projects as it does not require that we feel the pain or suffering of the other *as if* it were our own. Instead, it involves thoughts and feelings *about* the difficulties that another may be suffering. Or as he puts it, 'your feelings involve *caring* about the other's suffering, not *sharing* them'.[15] Sympathy is also different from empathy and 'in-his-shoes' imagining because it is specifically normative: sympathy entails a moral compulsion to alleviate the suffering of the other.[16] Empathy, by contrast, may simply entail us sharing in the imagined experience but caring little about whether that condition continues or not for the other person. Empathy says nothing about how we feel *about* the suffering of another and only requires that we experience it as our own. Further, as an ethical emotion, sympathy is inherently partial.[17] Sympathy helps to explain, and perhaps justify, the intuition that we may care more, morally speaking, for those close to us than those who are far away in both the spatial and emotive sense. This does not give credence to a false belief that the suffering of those close to us is more significant or poignant, but recognises that *we feel* differently about the suffering in each case and that this differential feeling is ethically significant.

Goldie's account of sympathy provides some useful points for articulating the ways that the sympathetic imagination contributes to ethical relatedness. But, in relation to foetal images, we may also wish to nuance this account a little more. For one, Goldie appears at times to be suggesting that imagination plays no role in sympathy – that while important to empathy and 'in-his-shoes' imagining, the capacity to imagine the suffering of another is alien to the emotional response of sympathy. This would seem to be overstating the difference between sympathy and empathy, since even the former requires that we understand the other as a being that suffers. This understanding of the other may itself be an imaginative project. Arguably, because we do not have immediate access to the experiences of another, ethics necessarily involves an aspect of fantasy and imagination. This reinstitution of imagination in sympathy is significant for an understanding of the ethical force of foetal images. It is commonly understood that a foetus is not cognitively capable of the complex emotions that may underlie experiences of suffering, and there is considerable disagreement over the gestational age at which the foetus can feel physical pain. To date, the general consensus has been that foetal pain is unlikely before the third trimester, and impossible before about twenty-four weeks.[18] This is well after the dates at which most abortions are performed. But regardless of the scientific

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[14]Goldie, Peter. 2000. *The emotions: A philosophical investigation*. Oxford: Oxford University Press.

[15]Ibid., 214.

[16]Ibid., 215; also see Nussbaum, Martha Craven. 2001. *Upheavals of thought: The intelligence of emotions*. Cambridge: Cambridge University Press, 302.

[17]Ibid., 216.

[18]For recent media discussions of reviews by the United Kingdom's Royal College of Obstetricians and Gynaecologist of evidence for foetal pain, see http://news.bbc.co.uk/2/hi/health/10403496.stm. However, it is worth noting that some researchers on foetal neurobiology are attempting to push the likely date for foetal pain back to about eighteen weeks.

outcome of the issue of foetal pain, we should note the additional complexity that physical pain may not in itself be sufficient to establish an experience of *suffering*, since pain and suffering are not conceptually equivalent.

Despite this, ultrasound images ask us to feel sympathy toward the foetus and this entails that we imagine that the foetus is a being that is capable of suffering. I might venture that this imaginative act is possible because, however alien it may seem to us, the foetal life exposed in the ultrasound image is one that we have all lived through. Each of us has already been a foetus, and we come to understand that a foetus 'is' a being capable of suffering because we are capable of suffering. This also points toward another important clarification, for it is not simply suffering that induces sympathy, but the capacity for it – or in other words, sympathy may be more attuned to *vulnerability* than suffering per se. In his classic discussion of photography, Roland Barthes claims that photography bears an intrinsic relationship to the 'catastrophe' of death, that each photograph prompts the recognition of the *punctum* of time – that a death is yet to come, that it has already passed.[19] Perhaps something similar can be suggested about ultrasound images, in the way that they can provoke a sense of the tremulous beginnings of a human life. For every foetus captured in an ultrasound image carries a trace of its own contingent survival and the immanence of death – each carries a trace of the ontological fact that it could have been otherwise. To quote Susan Sontag out of context, to look at an ultrasound image is, 'to participate in another person's (or thing's) mortality, vulnerability, mutability'.[20]

I will return to the ethical importance of vulnerability later in the chapter, but for now, we should note another implication of Goldie's account of sympathy. For the presupposition of this account is that imaginative projects such as sympathy or empathy allow us to understand the suffering and the reasoning of others. And these others are beings with a cognitive capacity that at least bears some similarity to our own as imagining persons. Or, more pithily, he assumes that the imaginative projects that he discusses occur primarily between *persons*. There is an increasingly sophisticated and substantial literature on the anthropocentrism of this view, which is challenged by insisting upon the capacity to imaginatively understand and share the suffering of other non-human animals. This is not the line of argument that I am interested in following here though. Instead, the assumption that imaginative projects occur between persons is significant because it directs us toward the way that ultrasound works to constitute the foetus *as a person*.

In a classic essay, Louis Althusser argued that ideologies work to 'interpellate' individuals into particular social positionings, where the process of interpellation entails being called or 'hailed' into being.[21] Althusser's understanding of interpellation can help illuminate the effect of ultrasound technology, which does not simply represent the foetus, but has the effect of hailing the developing foetus into being as

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[19]Barthes, Roland. 2000. *Camera lucida: Reflections on photography* (trans: Howard, Richard). London: Vintage Books, 96.

[20]Sontag, Susan. 2008. *On photography*. London: Penguin, 15.

[21]Althusser, Louis. 1971. Ideology and ideological state apparatuses (notes toward an investigation). In *Lenin and philosophy and other essays*, 170–177. (trans: Brewster, Ben) New York, NY: Monthly Review Press.

a baby and as a son or daughter. Certainly, the interpellation of the foetus as social subject occurs through linguistic framing, for instance in terms of foetuses being identified as 'babies' and 'unborn children'.[22] But I would venture that the efficacy of this narrative dimension relies upon the illusion of immediacy that the images generate, along with the apparent developmental continuity they invoke. The illusion of immediacy established by the technology – the idea that it provides the first view of 'your baby', one that is unencumbered by the body of the pregnant woman – along with the vision it provides of an apparent continuity in activities between the foetus and the newborn operates to establish the status of the foetus as person. In doing so, ultrasound instigates and establishes an emotive and social relation to the foetus that is qualitatively different from that in effect without such access to the intrauterine life of the foetus.

One important aspect of this interpellative process is that ultrasound imaging allows the bodily or corporeal life of the foetus to appear to us in a way that was previously unavailable. In making available images of the foetus in utero, sonography does not simply *re-present* an already existent body, since that body does not present itself to us in the first place without the technology. Without the technology, we see only the effects of its manifestation, in for instance, the swelling belly of a pregnant woman. Nor does it, strictly speaking, create or constitute that body, since the foetus is prosaically in existence prior to its appearance in or as an ultrasonographic image. Yet ultrasound reveals a bodily existence that simply could not be present to a viewer without the technology. That is, the process of interpellation effected by ultrasonographic imaging makes apparent a corporeal life that is distinct from that of both the woman carrying the foetus (though interdependent with her) and of other viewers of the image. Importantly, this corporeality only appears in relation to others, such as the prospective parents, the sonographer and the medical experts who provide interpretation. This establishes the foetus as a being toward which we bear a social relation that differs substantially from that possible without ultrasonography.

Moreover, in making possible the social appearance of the corporeal life of the foetus, ultrasound also establishes a demand for ethical response. As a number of philosophers have argued, the appearance of the embodied existent to and with others both makes possible and demands an ethical responsiveness. While few theorists take up the issue of the kind of response demanded in a mediated presentation or appearance of the body such as occurs in ultrasonography, the relation between embodiment and ethical responsiveness provides a good starting point for articulating the impact of ultrasound images upon our ethical intuitions about the acceptability or otherwise of abortion.[23] In an attempt to develop such an

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[22]For example, see Urban, Rebecca, and James Meikle. 2003. Womb 'smile' fires abortion row. *The Age*, 14 September. http://theage.com.au/articles/2003/09/13/1063341814497.html

[23]This raises a broader question about the ethical significance of images. Interestingly, while the affective impact of images is often deployed to great effect, not only in campaigns against abortion, but also, for instance, in campaigns to enhance funding for aid and development agencies, little has been said to explain why images have such an effect on our ethical intuitions and responses. While

understanding, in the final section of this chapter, I argue that the force of the ultrasound image is to produce a particular ethical demand, one that is intimately related to the capacity to constitute the foetus as an *embodied subject*.

Before that, though, the general point that I have been making here is that the imagination is crucial to understanding the particular ethical and political force of foetal images. But I do not want to leave the impression that the imagination is simply a cognitive capacity that works in abstraction of the context in which people find themselves and live out their ethical and social relationships. Instead, I think it important to recognise the way that the imagination is itself embedded within, and no doubt shaped by, social norms that precede and exceed any individual life. Let me clarify through an example. In recent years, a number of states in the United States of America have introduced legislation that requires women seeking terminations of pregnancy to undergo an ultrasound and be given the option of viewing the images. Oklahoma's 2008 law went so far as to make it mandatory that a woman be shown the images of the foetus and have them explained to her, before the law was overturned in 2009 on technical grounds. One has to ask why there has been such a trend toward this kind of 'ultrasound legislation' in the political struggles around abortion.

While it might be that specific arguments against abortion inform these legislative interventions, and those arguments can and should be tested against criteria of coherence and veracity, I want to suggest that this is not all there is to the issue. For the motivating idea of this legislation appears to be that there is something in the process or act of seeing the foetus that impacts on a woman's response to, and emotional and ethical relationship with, the foetus. This is understood to be the case regardless of the specific textual or linguistic arguments that might interpret and frame reception of the image at the time, since there are no specifications in the legislation about the particular narrative framing that ought to be offered to the woman beyond explaining the anatomy of the foetus. In other words, ultrasound images of a woman's foetus are thought to have a moral force, regardless of the specific narrative frame that is given to them. Consequently, the anti-abortion lobby that promotes this legislation sees ultrasound itself as an important tool in dissuading women from undergoing abortions.

There is a great deal at stake in the practice of requiring women to undergo an ultrasound and view the images prior to terminating a pregnancy, not least ideas about reproductive freedom and its moral value. Interestingly, the banner under which this legislation has been promoted is that of informed consent – it is argued that the provision of information about the foetus through ultrasound enhances a woman's capacity to make a suitably informed choice, and in the absence of that information the decision is not properly informed. Opponents of the legislation

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much attention has focused on establishing whether particular images are morally good or bad, for instance in relation to pornography, less has been said of the effect of images on our ethical responsiveness and the responsibilities that take hold from that. Recent work in film theory promises to remedy this. For example, see Cartwright, Lisa. 2008. *Moral spectatorship: Technologies of voice and affect in postwar representations of the child*. Durham, NC: Duke University Press.

rightly counter that the information provided is medically irrelevant to the procedure that the woman is about to undergo and to which she apparently consents. The abortion is the procedure to which she must consent and it is a matter of her autonomy and free choice to be able to do so. Even given this though, it could be said that the practice of showing ultrasound images prior to termination does not in itself restrict women's choice in relation to abortion – a woman can still choose to abort or not following the ultrasound, even if the choice is made more emotionally difficult. This suggests that a politics of choice is not wholly adequate to the task of ensuring women's reproductive rights.

Instead, what can be argued is that the requirement to undergo an ultrasound and have the resulting images explained is a political attempt to enforce a particular moral and reproductive imaginary. It is effectively an attempt to limit the imaginative project of deciding on the possible. As Drucilla Cornell and others have argued, the capacity to imagine one's life for oneself is a fundamental aspect of autonomy, including reproductive autonomy.[24] The ultrasound legislation degrades a woman's legitimate imaginative projection of herself into the future and in doing so, restricts her self-realisation as an autonomous person. But that imaginative project or capacity can itself only be exercised in social and political conditions that are not of one's own making. While this point is banal and commonplace, it has implications for considering the ethical imbrication of ultrasound technology, since it prompts us to ask after the norms that inflect and regulate the reproductive lives of women. It is to this that I turn in the following section.

6.3 The Social Production of Sympathy: Biopolitical Reproduction

In order to understand the ethical force of ultrasound images, it is first necessary to understand how the technology operates in presenting a certain perspective on the real, as is the character of all image-making technologies. In this regard, theorisations of photography are of some value, though they do not wholly fit the technicalities of ultrasound. As Sontag argues, photographs frame the relation that the viewer has to the world, in doing so promoting a nominalist view that packages the world into atomised units of reality and 'denies interconnectedness, continuity, but which confers on each moment the character of a mystery'.[25] Despite the technology's inherent tendency to distortion, the authority of the photograph derives from its supposedly more accurate depiction of reality, such that photographs furnish evidence for the way the world is (or was).[26] In a similar vein, Petchesky argues of

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[24] See Cornell, Drucilla. 1995. *The imaginary domain: Abortion, pornography and sexual harassment*. New York, NY: Routledge; Cornell, Drucilla. 1998. *At the heart of freedom: Feminism, sex and equality*. Princeton, NJ: Princeton University Press.

[25] Sontag. *On photography*, 23.

[26] Ibid., 5.

foetal imagery that it 'epitomizes the distortion inherent in all photographic images: their tendency to slice up reality into tiny bits wrenched out of real space and time'.[27] At the same time, foetal images reiterate the 'central paradox of all photographs', that is, 'the *appearance* of objectivity, of capturing literal reality'.[28] This analysis is extremely valuable in its diagnosis of the technological conditions for the ideological separation and opposition of the foetus and the woman who carries it. Images such as those produced through ultrasound obliterate the body of the pregnant woman and show only the foetus abstracted from its biological environment, its conditions of existence: the ideal atomistic individual.[29] In this way, ultrasound obliterates the flesh in the very process of making it appear.

In addition to obliterating the condition of female embodiment, ultrasound images also obscure their own conditions of production, perhaps especially in their broader cultural mobilisations. Sonography was developed initially as a military technology for underwater navigation by submarines in World War I. In medicine, ultrasound was used therapeutically up until the about the 1940s, when its diagnostic capacities began to be explored – especially for the detection of gallstones and tumours. In 1959, Ian Donald, then Regius Chair of Midwifery at Glasgow University, found that ultrasound could be used to take measurements of foetal heads. It was only during the 1960s that Donald was able to more systematically use ultrasound to detect conditions such as multiple pregnancies, placenta praevia and foetal abnormalities. Since then, the use of ultrasound in pregnancy has become largely routine in the developed world, although its clinical value has sometimes been challenged.[30] Indeed, recent developments such as 3D and 4D ultrasound have provoked much discussion about whether these new techniques produce new clinical knowledge, or whether their value is primarily aesthetic and psychological, insofar as they enhance parental 'bonding' with the foetus. This alerts us to the 'prenatal paradox'[31] that emerges with the use of ultrasound. For while it may enhance parental bonding, the clinical use of ultrasound simultaneously increases the probability of abortion. As Barbara Duden notes, when the Federal Republic of Germany instituted national guidelines requiring two ultrasounds throughout a pregnancy in 1980 – the first country to do so – pro-life groups opposed the policy on the basis that it would lead to an increase in abortions.[32] Since then, there has been

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[27]Petchesky. Fetal images, 269.

[28]Ibid.; emphasis in original.

[29]See Duden, Barbara. 1993. *Disembodying women: Perspectives on pregnancy and the unborn* (trans: Hoinacki, Lee). Cambridge, MA: Harvard University Press; Petchesky. Fetal images; Stabile. Shooting the mother.

[30]See for example, Ewigman, B.G. et al. 1993. Effect of prenatal ultrasound screening on perinatal outcome. *New England Journal Medicine* 329(12):821–827.

[31]Taylor, Janelle S. 1997. Image of contradiction: Obstetrical ultrasound in American culture. In *Reproducing reproduction*, eds. Sarah Franklin, and Helene Ragone. Philadelphia, PA: University of Pennsylvania Press.

[32]Duden. *Disembodying women*, 76.

evidence to suggest that routine ultrasound screening has contributed to an increase in terminations, including in the later stages of pregnancy.[33]

This is some distance from articles in publications such as the *Christian Science Monitor*, which see ultrasound as the 'latest tool in the battle over abortion' and which promote the use of ultrasound in anti-abortion campaigns, including through the so-called 'witness to the womb' laws discussed above.[34] It suggests a deep tension between the clinical use of ultrasound and the cultural value of the images thus produced. For in its clinical use as a screening technology, ultrasound is inherently normalising. I do not simply mean that ultrasound eradicates difference through the imposition of a norm upon the deviant foetal body; rather, in the more accurate sense of normalisation, ultrasound allows for the identification and calibration of deviations from a set of quite flexible statistical norms. Ultrasound contributes to the 'normation' of gestational development, that is, it makes possible the formation and establishment of norms for judging the gestational development of a foetus, as well as its genetic character. Interestingly, while ultrasound was initially used primarily to track foetal growth rates and estimate gestational age, the routine screens throughout pregnancy today are geared primarily toward detecting foetal abnormalities. In conjunction with a maternal serum blood test, the first trimester ultrasound is used to screen for likely incidences of chromosomal abnormalities such as Trisomy 21, Trisomy 18 and Trisomy 13 (also known as Down's Syndrome, Edwards Syndrome and Patau Syndrome). Notably, ultrasound in itself does not *diagnose* these conditions, but merely contributes to providing a statistical risk factor for the likelihood of their occurrence by looking for various 'soft markers', key among which is the thickness of the nuchal fold at the back of the foetal neck. The second trimester screen, typically undertaken at eighteen to twenty weeks of gestation, is directed toward foetal anatomy, and can detect abnormalities such as cleft palate, missing limbs and congenital heart problems that may be otherwise unforeseeable.

Given this, the 'screening' aspect of ultrasound should perhaps be taken literally; the definition of screening provided by the *Oxford English Dictionary* includes, '[to] examine systematically in order to discover suitability for admission or acceptance', to select and separate, and even to protect (from hostility or danger).[35] Ultrasound screens for various kinds of disability and disease, helping to detect those that may pose a challenge to norms of ideal health and make them visible, a necessary condition, perhaps, for their elimination. Such mechanisms of population screening might be seen as characteristic of the immunitary paradigm of modern biopolitics identified and outlined by Roberto Esposito. He points out that the idea of immunity brings together the implications of a natural or induced 'refractoriness' on the part of the population with a temporary legal exemption from the responsibilities and

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[33] See Public Health Association of Australia. 2005. *Abortion in Australia: Public health perspectives.* 3rd edn., Canberra: Public Health Association of Australia 5.

[34] See Jonsson, Patrik. 2007. Ultrasound: latest tool in the battle over abortion. *Christian Science Monitor*, 15 May. http://www.csmonitor.com/2007/0515/p03s03-ussc.html.

[35] "screen, v.". *OED Online.* November 2010. Oxford University Press. http://www.oed.com. ezproxy2.library.usyd.edu.au/view/Entry/173441?rskey=w5nwQe&result=3&isAdvanced=false

obligations that bind individuals in a normal situation.[36] In keeping with this, one might consider that in many jurisdictions, including several states in Australia, abortion is illegal in the second and third trimester of pregnancy *except* when there is evidence of foetal abnormalities. Thus, the state legitimates abnormality as a basis for termination while simultaneously rejecting the permissibility of abortion in other circumstances. In other words, biological indicators of foetal abnormality and disability give immunity from laws otherwise condemning abortion. Where a life does not conform to the interests of a biopolitical state in the health of the whole population, that life 'must be available for termination'.[37] Of course, liberal states such as Australia do not require women to abort foetuses with abnormalities, nor do they recommend it as a matter of policy. In this, liberal states obviously differ from the version of biopolitics in force in Nazi Germany. Nevertheless, it appears that the 'suppression' or 'nullification' of life at birth that Esposito identifies as characteristic of Nazi biopolitics has at least some resonance within liberal biopolitics as well.

In response to this situation of the suppression of birth, Esposito urges a philosophical approach that resuscitates the role of birth in individuation as the key to shifting toward a more positive biopolitics. To do this, he draws on Gilles Deleuze's provocative essay on absolute immanence. Esposito postulates that the theoretical nucleus of this essay is the connection and divergence between '*the* life' and '*a* life', the latter of which is indicative of a singular life irreducible to the individual. He goes on to claim that this singular life identified by Deleuze is marked by an absolute uniqueness, like that of the newborn, 'who is similar to all the others, but different from each of them for the tonality of the voice, the intensity of a smile, the sparkle of a tear'.[38] Unlike the approach to singularity that I discussed in the previous chapter, which emphasises the relational dependency on the other and the role of narrative in the appearance of uniqueness, Esposito sees singularity as strictly *impersonal*.[39] In accordance with Deleuze, he relates singularity to the conceptual possibility of a life of pure immanence that is irreducible to an individual although it may be manifest in them. This approach is undoubtedly interesting, but considered in the context of ultrasound and abortion it takes on a connotation that one might be somewhat wary of.

Consider for a moment that what 3D ultrasound images of the foetus allow the anti-abortion movement to do is to claim just this singularity for a foetus. The ontic continuity that the ultrasound image constitutes between the foetus and the newborn pushes back the singularity of the newborn to the prenatal life of the foetus. What is apparent in much of the anti-abortion rhetoric is that one of the key strategies is to individuate each foetus as 'a unique human life'. What concerns the anti-abortion

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[36]Esposito, Roberto. 2008. *Bios: Biopolitics and philosophy* (trans: Campbell, Timothy). Minneapolis, MN: University of Minnesota Press, 45.

[37]Ibid., 133.

[38]Ibid., 193.

[39]Ibid., 194.

lobby is not life in general, but *a life, each life in its apparent singularity – a life* that is like all the others, but is also absolutely and irreducibly singular. To be clear, we should not for a moment think that this juxtaposition bankrupts the approach to a singular life proposed by Deleuze and others, for there are various ways in which the radical philosophy of singularity extends well beyond and clearly undermines the rhetorics of the anti-abortion lobby. Nevertheless, I think hesitation about the association that is sometimes made between a life of absolute immanence or absolute potentiality and the newborn infant may well be warranted when this argument is considered in context.

I should also note that the technology of ultrasound itself both reinforces this strategy of singularisation and undercuts it in the cultural deployment of ultrasound images, since such images do not so much distinguish as homogenise. Dislocated from space and time, the foetus appears as an icon of life in general, rather than individuated life. But this generalisation of the singular is itself important, for it is central to the normative production and distribution of sympathy that underlies the ethical force of the ultrasound image. Judith Butler has argued that what counts as human is constituted as such through a process of 'humanisation', whereby being human requires fulfilling a usually implicit set of normative criteria.[40] Butler argues that this regulation of the process of humanisation also generates a particular susceptibility or vulnerability to violence, particularly for those beings who do not wholly satisfy the criteria of regulation. This highlights the way that each foetus is vulnerable to criteria of humanisation, which allow for judgements on the normative and social value of different foetal lives. The effect of the anti-abortion lobby's generalisation of singularity through the mobilisation of 3D ultrasound images is that it also generalises this vulnerability, such that vulnerability to biopolitical dehumanisation is seen as the defining characteristic of all foetuses, insofar as they are (potentially) threatened by the practice of abortion.

In the context of these simultaneous processes of singularisation and homogenisation, it is also notable that the ultrasound images used by the anti-abortion movement are overwhelmingly close-up images of the foetal face. The importance of the face within ethics has been elaborated by Emmanuel Levinas, who claims that the face entails the imperative, 'thou shalt not kill'. He states that the face 'is the other before death, looking through and exposing death . . . the face is the other who asks me not to let him die alone, as if to do so were to become an accomplice in his death. Thus the face says to me: you shall not kill'.[41] The anti-abortion movement's mobilisation of the foetal face may grasp at this imperative encounter in an inchoate

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[40]Butler, Judith. 2004. *Precarious life: The powers of mourning and violence*. London: Verso; also see Butler, Judith. 1993. *Bodies that matter: On the discursive limits of 'sex'*. New York, NY: Routledge, 7; and Barad, Karen. 1998. Getting real: Technoscientific practices and the materialization of reality. *Differences* 10(2):87–128.

[41]Levinas, Emmanuel, and Richard Kearney. 1986. Dialogue with Emmanuel Levinas. In *Face to face with Levinas*, ed. Richard A. Cohen, 23. Albany, NY: State University of New York. Also cited in Butler, *Precarious life*, 131–132. Obviously, I am not implying that a Levinasian approach to ethics is implicated within the politics of abortion; I am simply suggesting that if Levinas is right,

and entirely unphilosophical way. In using images of the foetal face, it mobilises the imperative of non-violence for its own ends, simultaneously confirming the ethical importance of the face and undermining it. The foetal face addresses us, calling for a response, and perhaps especially one that resiles from a certain violence. As Butler points out, the face is intimately involved in normative processes of humanisation and the framing of what it is to be human, what it is to invoke and deserve sympathy.[42] Given this, it appears that just as images frame reality, the affect produced by images is also framed. Just as we need to be cognisant of the conditions of production of the image, so we must also be of the conditions of production of affect, where those conditions include the norms that cut across the bodies of individuals and populations, and allow for decisions on lives that matter and lives that do not. It is to this ethical force of the ultrasound image, including the sympathies it generates, that I now wish to turn more directly.

6.4 The Ethical Demand of Embodied Appearance: Relationality and Responsibility

I said earlier in the chapter that ultrasound makes apparent a corporeal life that is otherwise occluded, a corporeal life that is constituted in relation to others, including in its interdependence with the pregnant woman who carries the foetus within her own body. While the nature of pregnant embodiment and the constitutively interdependent relationship between the foetus and the pregnant woman have been discussed previously, what is less obvious is the ethical effect of the appearance of this otherwise occluded corporeal being. Ultrasound images prompt us to ask about the nature of foetal embodiment and its role in establishing ethical relationships. What kind of bodily imperative takes hold in the appearance of the foetus made possible through ultrasound? In this section of the chapter, I will consider influential accounts of pregnant embodiment as a starting point for an exploration of the notion of foetal embodiment. This exploration makes apparent the constitutive role of technology in embodiment. Further, it points toward important questions about the relationship between the unavoidability of responding when confronted with the bodily imperatives of the foetus, and the notion of ethical responsibility that we might wish to promote in order to short-circuit the anti-abortion stance to which recognition of such bodily imperatives seems to inevitably lead.

The obvious starting point for any discussion of pregnant embodiment is Iris Marion Young's classic essay, in which she explores the phenomenology of pregnancy to identify aspects of bodily existence unique to pregnancy. Young's central claim is that the subjectivity of pregnant women is 'decentred, split or doubled

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that the face entails an imperative encounter, then this may throw light on the impact of ultrasound images on intuitions about the ethical status of the foetus.

[42] Butler, *Precarious life*, 140–147. Also see Butler, Judith. 2009. *Frames of war: When is life grievable*? London: Verso, especially 1–23.

in several ways', since she 'experiences her body as herself and not herself', and because the temporality of pregnancy is such that, 'the woman can experience herself as split between past and future'.[43] Young's target in her argument for the split subject of pregnancy is the presupposition within existential phenomenology that subjectivity entails an intentional unity. Further, Young rejects the dualism between transcendentalism and immanence, wherein awareness of one's body is an 'alienating objectification' that impedes the realisation of one's goals. Contrarily, pregnancy provides a positive example of an awareness of one's body that does not impede the realisation of intentional goals and, 'pregnant consciousness is animated by a double intentionality: my subjectivity splits between awareness of myself and awareness of my aims and projects'.[44] As the pregnancy progresses, the weight and solid materiality of one's body makes the most ordinary tasks appear as the projects that they are, while also affording women a certain power and sense of respect.

Young's construal of pregnancy as a positive example of the splitting of the subject and the bodily possibilities that this may afford women opens up a rich terrain, but also has its limits. Gail Weiss, for instance, argues that Young's claim that pregnancy undermines the integrity of the body accepts that some subjectivities are not split, that some bodies are experienced as integrated and unified. Against this, Weiss urges that bodily integrity is not undermined by the experience of splitting, but is instead created through it and the recognition it brings of the continual flux of all bodies in daily life. For her pregnancy does not undermine so much as *resignify* bodily integrity.[45] Extending on this, one might also say that Young's account occludes the role that technology plays in the flux of the body. For Young, the splitting of the pregnant subject originates in part in the movements of the foetus. Of these, she writes:

> I feel a little tickle, a little gurgle in my belly. It is my feeling, my insides, and it feels somewhat like a gas bubble, but it is not; it is different, another place, belonging to another, another that is nevertheless my body. The foetus's movements are wholly mine, completely within me, conditioning my experience and space. Only I have access to these movements from their origin, as it were.[46]

Such movements of the foetus make the pregnant woman aware of the bodily differentiation between herself and the foetus she carries – her body is both her and not her, as are the movements of the foetus.

Young's essay, initially published in 1983, appeared at around the time when ultrasound was becoming routinised as a technology used in prenatal care. It is not surprising then that there is little comment on this technology and its effects on the

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[43]Young, Iris Marion. 2005. Pregnant embodiment: Subjectivity and alienation. In *On female bodily experience*, 46–47. Oxford: Oxford University Press.

[44]Ibid., 51.

[45]Weiss, Gail. 1999. *Body images: Embodiment as intercorporeality*. New York, NY: Routledge, 53. This claim it seems to me is important to make in the context of debates on abortion, where the right to bodily integrity is often integral to securing women's reproductive autonomy and consequent to that, access to abortion.

[46]Young. Pregnant embodiment, 49.

embodied experience of pregnancy in the essay. In a later postscript, though, Young does provide such comment and acknowledges that ultrasound may have altered the experience of pregnancy in significant ways. She concludes though, that if anything, the routine use of ultrasound reinforces her previous analysis of pregnant embodiment. The second part of the original essay focuses on the objectifying alienation experienced by pregnant women in the medical 'treatment' of pregnancy, whereby subjective experiences are rendered as phenomena that can be observed by anyone. Ultrasound is of a piece with this objectification, since it 'makes it possible for anyone to experience fetal movement by looking at the same projected image [of the foetus]. The pregnant woman's experience of that image is just the same as anyone else's who views it'.[47] The implication here is that the projection of the foetal image undermines the privileged relation of *feeling* that a pregnant woman bears to the foetus she carries, extracting it from her, and in doing so, restoring her to a kind of unified bodily integrity that is 'just the same as everyone else's'. This claim seems unlikely for a number of reasons.

For one, consider that one of the profound aspects of having an obstetric ultrasound is being able to see and hear the heartbeat of the foetus that you are carrying. The heart starts beating at about six weeks of gestation, well before foetal movements can be felt at about eighteen to twenty weeks gestation, and the regularity and pace of the heartbeat is one of the first things checked in both the first and second trimester ultrasound. The sometimes astonishing sight and sound of the foetus's heart beating at more than 130 beats per minute prompts the recognition that there is another heart beating inside me, one that is not mine. This heart that is beating regardless of my consciousness of it makes it clear to me that there is some one other than me in this body of mine. But it also makes me aware of the way in which this is always already the case; there is, by necessity, always already another in me – we can think genetically, or psychoanalytically, or even parasitically, to make this point. Jean-Luc Nancy's discussion of the intruder in relation to a heart transplant is not without relevance here, for as he indicates, the self is always stranger to itself. Or as Diane Perpich writes, '[o]ne is, as one already was (though perhaps without recognizing it), both strange and intimate to oneself, both self and intruder'.[48] This condition of strangeness to oneself is made manifest by technology, but is not strictly a consequence of it, especially if we consider that *techne* inheres in the human from the start. As a medical technology, ultrasound is not only objectively alienating (though at times it may be that too), but can instead induce an experience of the differential integrity of the body found in its flux, an integrity that paradoxically incorporates the body of another. Further, that technical possibility of hearing the heartbeat weeks before what is traditionally known as 'quickening', the first foetal movements, is itself constitutive of subjects, who are always already dependent on technology for their reality and form. The technology brings into being

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[47]Ibid., 61.

[48]Perpich, Diane. 2010. Vulnerability and the ethics of facial tissue transplantation. *Journal of Bioethical Inquiry* 7(2):180.

both potential mother and potential child. As Nancy writes, ' "I" always finds itself caught in the battlements and gaps of technical possibility'.[49]

In addition, the appearance of the foetus through ultrasound reveals its secret corporeal life, and in doing so, brings into effect a 'bodily imperative' that has significant implications for the *ethical* relationship that a woman bears to her foetus.[50] In *Body Images*, Weiss argues for an embodied ethics based upon dynamic imperatives that emerge from intercorporeal exchanges that transform our own body images and invest them with moral significance.[51] This moral significance, she argues, does not depend on universalistic or impartial detachment from others, but, 'can only arise in and through our relations with others'. As she writes, 'to be moral does not require ... separating my conscious "self" from my body and its desires; it involves developing a moral agency that can only be experienced and enacted through bodily practices, practices that both implicate and transform the bodies of others'.[52] Such bodily imperatives are not categorical, but are relationally bound and conditioned, and as such, they leave open a space between the imperative to respond and the shape that any given response takes in practice. For it is perhaps in the *phronesis* of reflection on the imperative to respond that a responsible response is most likely to emerge.

This points toward an important caveat for an embodied ethics, namely, that it must allow a break between the inescapability of response and the tenuous achievement (if that is what it is) of responsibility. As this suggests, the emotive response impelled by foetal images does not necessarily lead to an anti-abortion moral stance in itself, though it does raise important issues about the impact of images on our ethical intuitions. For while it might be that the corporeal appearance of the foetus establishes a demand for response, this demand itself only takes hold within preestablished social circumstances, such that the responsible action in regards to the decision to abort or not cannot be determined solely by the fact of the response impelled by those images. For one, any particular decision regarding abortion can only be made in the context of a life in situ, where that context may include significant inequalities in access to socioeconomic and other resources and mechanisms of support. The context in which such a decision must be made also includes the

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[49]Nancy, Jean-Luc. 2002. *L'intrus/The intruder* (trans: Hanson, Susan). *New Centennial Review* 2(3):3.

[50]I take the term 'bodily imperative' specifically from Gail Weiss, but the more general idea that embodiment entails an ethics is one that has been elaborated by a number of feminist theorists in recent years. Moreover, embodiment is often associated with moral affects. For instance, Adriana Cavarero identifies the responsiveness established by the appearance of an embodied existent to another as a form of ontological altruism, while Rosalyn Diprose eloquently argues that the necessary condition of corporeality gives rise to an ethics understood as generosity. Cavarero, Adriana. 2000. *Relating narratives: Storytelling and selfhood* (trans: Kottman, Paul A.). London and New York: Random House; Diprose, Rosalyn. 2002. *Corporeal generosity: On giving with Nietzsche, Merleau-Ponty and Levinas*. New York, NY: SUNY Press.

[51]Weiss. *Body images*, 158.

[52]Ibid.

life history of the woman carrying the foetus, such that the content of her own emo-
tive response to the bodily imperative presented by the corporeal life of a foetus
will be influenced by events, expectations, narratives and other elements that pre-
cede the pregnancy. For these reasons, an adequately internally differentiated notion
of responsibility is required if an embodied ethics can contribute positively to a
feminist ethics of abortion. Any such conception of responsibility must be able
to account for the social production and distribution of sympathies, and the ways
that our ethical practice is impelled by affects that are irreducible to, and some-
times irreconcilable with, the rationalistic tendencies of ethical reasoning, which
too often disavow our constitutive vulnerability and the corporeal interdependencies
that make us who we are.

6.5   Conclusion

In this chapter, I argued that obstetric ultrasound impacts upon ethical intuitions
about the status of the foetus, by interpellating the foetus as a social subject toward
whom we bear a specifically ethical relationship. I argued that focusing on the ways
that ultrasound images work in terms of the sympathetic imagination helps to artic-
ulate the impact that they have in abortion debates. However, it is important that the
sympathetic imagination is also productively constrained by social norms, which
instigate and shape decisions on what counts as a viable or livable life. As with other
imaging technologies, ultrasound 'frames' what it purports merely to represent. This
framing has a double effect in relation to the foetus. On the one hand, it contributes
to the 'normation' of the foetus, through the formulation and application of norms,
which forces a concern with the 'normal' and 'abnormal' foetus. This is the context
in which prospective parents are asked to make decisions about continuing or ter-
minating a pregnancy. On the other hand, the anti-abortion lobby has exploited the
framing capacity of obstetric ultrasound, especially to focus on the foetal face. The
facial emphasis is part of a logic that casts the foetus as necessarily vulnerable and
in need of protection. This logic works by simultaneously individuating each and
every foetus, and homogenising all foetuses in terms of vulnerability.

The attribution of vulnerability to the foetus as its defining characteristic has
important implications for a feminist ethics of abortion, especially one that starts
from the position that emphasises the centrality of embodiment in ethics. In this
view, the appearance of the foetus as an embodied being effected by ultrasound
imaging gives rise to bodily imperatives to respond. The ambit of the anti-abortion
lobby is that, given its constitutive vulnerability, the only appropriate response to
the foetus is one of protection. However, the recognition of vulnerability does not
in itself determine the shape of the *responsible response* in any given context.
A feminist ethics of abortion should be able to recognise vulnerability – not only
as a characteristic of foetuses, but as internal to subjectivity per se – while at the
same time allowing for an idea of responsibility that admits of other, sometimes
more pressing, concerns such as the freedom to make oneself according to one's
own deeply held ethical and aesthetic criteria. This is not simply a rewriting of the

'conflict of rights' problem, in which the woman's right to autonomy is said to conflict with a foetus's right to life. Instead, such an approach would begin from the embodied interdependency of a pregnant woman and the foetus she carries, as well as the differential vulnerabilities of each. It would see decisions about pregnancy and termination in the context of the social production and distribution of sympathies, and it would affirm the central role of the imagination in the determination of possible lives.

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Chapter 7
Final Remarks

As I near the end of writing this book, I also near the end of my first pregnancy. The experience of pregnancy has been instructive to say the very least, and no doubt informs the preceding pages in ways of which even I am not aware. What has perhaps been most instructive has been the tension – sometimes implicit, often explicit – between my own embodied experience of pregnancy on the one hand, and the medical apparatuses of control that attend pregnancy on the other. Or – since this risks overstating the opposition between the individual's experience of embodiment and social-institutional arrangements – what has been most instructive has been the routine interactions in pregnancy with the medical apparatuses as they interpret and shape my own embodied experience. As Annemarie Mol has argued,[1] bodies and medical institutions come together in various, more or less fractious, ways to provide a unified picture of a condition, in this case, of pregnancy.

A pregnant woman must run the gauntlet of a multitude of tests and measurements of risk factors in the course of 9 months of pregnancy. This often begins with a pregnancy test, purchased at any pharmacy or supermarket, the results of which will be confirmed by another pregnancy test at a medical clinic if it indicates a positive result. From then on, pregnancy involves an ongoing series of routine blood tests, urine tests and vaginal swabs. It typically also involves a first and second trimester ultrasound scan, which is supplemented throughout the pregnancy with routine Doppler tests of foetal heart rate, often each month or less. In addition, a woman may be required to have vaginal ultrasounds, cardiotocography, amniocentesis and chorionic villus sampling. She may be advised to take supplements for vitamin deficiencies, and her weight will be routinely noted as will her blood pressure. This is to say nothing of the additional interventions that may be required to address infertility or other reproductive hindrances, nor the various treatments that may be required for complications that arise throughout a pregnancy. All of these tests and measurements are geared toward establishing that her body and the foetus

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[1] Mol, Annemarie. 2002. *The body multiple: Ontology in medical practice.* Durham, NC: Duke University Press.

she carries fall within, and remain within, normal parameters – or, at the very least, within a manageable variation from normal parameters.

At the same time as negotiating these tests, the normal parameters of her body as she experiences them are being transformed from the inside. Her body is quite literally in flux as the pregnancy develops and transforms the very structure of her body, reshaping her breasts and belly, widening her hips, enlarging her feet. Her relationship to her own body is not immune to this transformation either, for her body is no longer simply hers (supposing for a moment that it ever was). Instead, her womb has become the home of another, and this presence becomes increasingly insistent and hard to ignore as the pregnancy progresses. Along with this presence, her sense of responsibility may also transform. What began as an abstract responsibility for decisions taken or not taken becomes increasingly concretised and focused upon the bodily imperatives that the ever-present baby confronts her with.

It is in the context of this multifaceted experience of transformation that I first read of the case of selective termination on the basis of the foetus missing a hand that I mentioned in the Introduction of this book. Reading the case notes at around the time of my second ultrasound scan, which tests for anomalies in foetal morphology, I was struck by the likely emotional difficulty of making such a decision to terminate after having carried a foetus for some months. In my experience, ultrasound testing produces at least as much anxiety as it allays. It is easy to forget that the anticipation of the test and the apparent legitimacy that it bestows upon a pregnancy – shifting it from the realm of the 'tentative' to the 'real'[2] – is an experience unknown to the generation of mothers previous to me. My mother would not have had the option of terminating a pregnancy on the basis of foetal abnormality, since at that time any such abnormality was only revealed at birth. I do not mean to valorise this state of relative ignorance, though it may well have had some benefits, as well as disadvantages. My point is simply that new technologies produce new desires and choices, and in doing that, they also produce new relationships and responsibilities.

Given the context in which I was reading these case notes, it is perhaps not surprising that I found the case troubling, but I do not believe that I did so only because of emotional identification. In Chapter-Two of this book, I examined recent arguments about genetic interventions in reproduction, especially in terms of their approaches to the concept of the normal. I argued for a view that allows a nuanced understanding of the concept that sees it primarily as a description of a relationship between a being and the world in which it lives (or an organism and its environment). This means that normality is not a stable characteristic or set of functions, but a way of assessing the capacities of a being to meet the challenges that it faces in its world. One advantage of this approach is that it allows for a differentiation between the anomalous as the statistically infrequent, and the abnormal. On this view, missing a hand does not on the face of it constitute a pathological abnormality, since its impact on the flourishing of an individual within their world may be

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[2]See Katz Rothman, Barbara. 1986. *The tentative pregnancy: Prenatal diagnosis and the future of motherhood*. New York, NY: Viking Penguin.

negligible. Instead, it is the interaction of this body with regulatory social norms that makes missing a hand appear as pathological, and the body that lacks in this way appear as an existential impossibility. I suggested that bioethics as a discourse must attend more seriously to the interaction of biological and social norms in the definition and identification of the normal body.

One significant implication of this is that reproductive decisions are never simply decisions of unbounded choice. They are always made in the context of the intersections of bodies and regulatory apparatuses, and are ineluctably set through with norms. But this does not mean that there are no choices to be made, or that reproduction is simply a matter of imposed control and false choice. Reproductive decisions undoubtedly involve deeply held values and beliefs about the good life, and they have a profound effect on the possibilities for living that are available to us. But they do not simply express these values; instead, as I argued in Chapter 3, the practice of reproductive liberty is part of our constitution of ourselves as ethical subjects. In deciding to reproduce or not, or to reproduce in this way and not that, we literally make ourselves who we are and who we can be. Commentators on the principle of reproductive autonomy often argue that it should take presumptive priority in controversies about reproductive technologies and practices. However, they also typically understand reproductive autonomy as a negative freedom, that is, as a matter of freedom from external constraints. I argued that reproductive autonomy is more adequately understood as a positive freedom, and I drew on the work of Michel Foucault on ethics as a practice of the self to make this argument. This approach responds to the intuition that reproduction is of deep significance in people's lives – it is not simply a matter of more or less free choices, but of a *practice of liberty* that fundamentally shapes our sense of ourselves and enlivens our deeply held values. This is also the case when one chooses not to reproduce. This approach also brings out the way in which new technologies contribute to a *problematisation* of reproductive liberty, of which contemporary moral debates are a part.

In Chapter 4, I explored one example of such a problematisation, which especially highlights the question of the limits of reproductive freedom. This is the controversial issue of the prerogative of parents to use reproductive technologies to select for or, more frequently, against characteristics that are typically considered disabilities. In the first half of that chapter, I considered responses to the case of Sharon Duchesneau and her partner Candy McCullough, who sought a sperm donor with a history of family deafness to increase the likelihood that their child would be born deaf. I did so particularly with an eye to the ways in which these responses drew upon John Stuart Mill's idea of the principle of harm, as well as Derek Parfit's formulation of the non-identity problem. I argued that commentators such as John Harris, Julian Savulescu and Jonathon Glover construe disability as a problem, in the sense that it is negatively valued and in the sense that it is used to circumscribe the limits of reproductive freedom. In the second half of the fourth chapter, I reversed directions to consider the expressivist critique of prenatal testing, which argues that, insofar as they are used to select *against* disabilities, such technologies express discriminatory attitudes toward people with disabilities. I defended the expressivist critique, showing that there are substantial – and, in

bioethics, underutilised – theoretical resources available to it that would allow a plausible critique of prenatal testing. One of these resources is the philosophy of phenomenology. As Jackie Leach Scully has argued, the value of phenomenological accounts of disabled embodiment is that they may extend moral understanding and the capacity to imagine the lives of others.

In Chapter 5 and Chapter 6, I addressed two problems raised in the course of the discussion of disability – the social appearance of the body and the ethical significance of our relationships with others. In Chapter 5, I addressed the second of these issues through the concept of singularity, especially as philosophers such as Adriana Cavarero and Jean-Luc Nancy have theorised it. They place emphasis on the question, 'who are you?' as a formula to encapsulate the constitutively relational basis of human uniqueness. They distinguish between the uniqueness of *who* someone is, and the determinate characteristics of *what* someone is. Applying this to 'PGD', I claimed that the predetermination of the *qualities* of the newborn indicates a transformation in our mode of relating, which has the effect of forestalling or eroding the immediate recognition of who they are. The newborn is born for *what* they are, and not for the unexpected appearance of *who* they are, the implication being that this evinces a failure to treat the other as other. But I also suggested that insofar as technologies such as PGD erode a certain kind of ethical self-understanding, as Jürgen Habermas has argued, they also open possibilities for new ways of thinking about ourselves as ethical subjects. Thus, I began to bring out the connections between technology and subjectivity.

In Chapter 6, I extended on this and took up the problem of the social appearance of the body, especially in regards to the routine use of ultrasound in obstetrics and its impacts on intuitions about the moral status of the foetus. Ultrasound plays a significant role in the circulation and realisation of norms in reproduction by establishing and shaping embodiment, and consequently, ethical and social relationships. Ultrasound helps to create the norms against which foetal bodies are assessed and calibrated, while also producing the desire for a 'normal, healthy' baby. Thus, the technology produces a desire for the norm, and in that, it establishes its own legitimacy and solidifies its role as a technology of normation. Moreover, it gives and takes moral status in its normation of the foetus. In this chapter, I argued that ultrasound images impact upon intuitions about the ethical status of the foetus because of the way they work on and through the sympathetic imagination. Ultrasound 'frames' what it purports to represent, and this framing contributes to the social production and distribution of sympathies. In this, it provides an example of the ways in which reproductive technologies very actively contribute to what will appear as a viable life or bodily form within the social sphere. These, it seems to me, are the issues most at stake in the case of the foetus missing a hand.

One characteristic of this book – for some undoubtedly its weakness, for others its strength – is that I do not make arguments about what people should or should not do in relation to reproduction. My interest lies elsewhere, namely in the ways that our current discourses and ways of thinking are shaping the possibilities for living. As I have argued in several ways throughout, norms constrain the imaginative possibilities for forms of bodily life in ways that preclude some from existence

itself. Norms shape the very space of appearance, simultaneously constituting and masking the conditions under which decisions to exclude or allow forms of bodily life are rendered intelligible. Fortunately, heavy burden as the process of ethical self-constitution may appear to be, it also means that we carry within ourselves the possibility of making ourselves differently as ethical subjects. An ethics of the self makes us constitutively open to transformation, thereby introducing an alterity into our selves that may allow us to respond to the unbidden alterity of the other with greater sensitivity and generosity. This opens hope for the futures of reproduction and of responsibility. Finally, then, there is no single future of reproduction. There is instead an ongoing, agonistic negotiation of a multiplicity of possible futures; this is how it should be.

Just as there are different futures available for reproduction, I also hope that this is true for bioethics. Paul Rabinow has argued that mainstream bioethics as it is practised today is a transnational apparatus for regulating medical practice, such that the ethical is now little more than the 'main mode of regulation'.[3] Further, he suggests that this regulation operates at the level of living beings, meaning that bioethics is a node within the operation of biopower and the management of life that it entails. I hope that I have demonstrated throughout this book that bioethics can be more, or at least something other, than a handmaiden of the state and bioscientific and medical apparatuses. In turning to a sense of ethics as *ethos*, which entails a practice of self-formation constitutively open to alterity, bioethics as a critical discourse is fostered. This turn, I hope, contributes to a different bioethics that is not about regulating life, but about allowing possibilities for living to flourish.

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[3]Rabinow, Paul. 2003. *Anthropos today: Reflections on modern equipment*, Princeton, NJ: Princeton University Press, 115.

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