TRANSHUMANIST UTOPIAS:
RETHINKING ENHANCEMENT AND DISABILITY

By

Melinda Hall

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Approved:
Professor Kelly Oliver
Professor Lisa Guenther
Professor Charles Scott
Professor Eva Kittay

This work is dedicated in memory of

philosopher, feminist, and my advisor at American University,

Lucinda Joy Peach

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INTRODUCTION

WHY ENHANCEMENT? BIOETHICS AND TRANSHUMANISM

Enhancement is the use of medical and technological strategies to augment human traits. The strategy of genetic enhancement, perhaps the most controversial, would use genetic engineering technology to achieve this end. Bioethicist John Harris claims that enhancement is good and desirable by definition; according to him, “if it wasn’t good for you it wouldn’t be enhancement” (2011, 131). Yet, “enhancement” is a loose concept that could apply to a variety of things humans can use; for example, anything from shoes and caffeine to neural implants and prosthetics could count as enhancements (e.g. Buchanan 2011, Preface and Bostrom and Savulescu 2011, 2). Indeed, for some proponents of enhancement, the moral acceptability of enhancement strategies stems directly from their supposed similarity to everyday activities of improvement, such as learning (cf. Bostrom and Savulescu 2011, 3).[1]

Ethically separating, for example, strength training and steroids seems to require uneasy notions of the “natural” or the “authentic,” wherein strength training is morally acceptable while steroids involve “cheating.” Or, the invocation of the long-contested divide between therapy and enhancement could separate reconstructive plastic surgery from cosmetic plastic surgery. Some bioethicists maintain that only therapeutic or natural “enhancements” are morally acceptable, while others such as Harris argue that all enhancements are not only morally acceptable but also possibly morally obligatory.

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[1] Some counter that novel medical interventions are a unique set of means for everyday ends – i.e., beauty (social acceptability) and the like (e.g. Parens 1998).

Meanwhile, many feminists and disability theorists find it suspect that critics of enhancement often seem forced to prove why one shouldn't do what is obviously good for one or one's children (Buchanan *et al*. 2000, Ch. 5; Ida 2011, Sandel 2004 and 2007).

Usually debates over enhancement are debates over what types of enhancements are morally acceptable. Many times they revolve around the difference between negative eugenics, which aims to cure diseases and prevent so-called birth defects, and positive eugenics, which aims, in Harris's words, to "make better people." I seek to reframe these debates in terms of the explicit and implicit goals and desired futures proposed by proponents of enhancement. Rather than enter debates over where we should draw the lines between therapeutic interventions or enhancements, negative or positive eugenics, I critically analyze the ways that *proponents'* discussions of the ethics of enhancement for humans not only involves specific goals and desired futures, but also are often less about available technology than potential technology deemed worthy of investment. For them, investment in the research and development of potential futures becomes a moral obligation. I argue that the burden in the debate should fall to proponents of enhancement, not critics, especially in light of the goals of proposed enhancements themselves, which often are couched in fantasies of possible *transhuman* futures that presuppose notions of health, ability, and the good life.

The added benefit of this re-framing of debates in bioethics over enhancement is that it allows one to critically assess the suspect claim that enhancement is good, full stop. My project, then, examines closely the goals of enhancement's enthusiasts, *transhumanists*. Because I respond to the argumentation of these enthusiasts, I take up *enhancement* in the way they do: namely, as the practice of adding to, protecting, or maximizing capabilities by way of technological intervention upon the body. I am, therefore, engaging the question of *radical enhancement*, which Nicholas Agar describes as the possibility that medicine, science, and technology would so radically improve various aspects of life that the beings who would result would not be recognizably human (Agar 2010, 1-2). I look to the extremists within the debate to gain understanding of the heart of the issue; more moderate philosophers have played it safe by making proposals with which no one would disagree, such as being sure any proposed enhancement is accessible, effective, and that harm to individuals is to be avoided at all costs. In the next section, by briefly discussing these "half-way" measures, I demonstrate that these qualifications do not get us very far. I also expose the crucial similarities between those who go further to either promote or argue against enhancement measures in contemporary debate.

Contemporary Debate

Today's bioethicists ask: is human enhancement ethically permissible? As posited, this question tends to ask "why not?" (e.g. Buchanan *et al*. 2000, Ch. 5: "Why Not the Best?"). Mainstream bioethicists and philosophers tend to seek reasons that an individual or institution should not pursue enhancement (in particular or in general), rather than asking why one should, or what reasons exist for pursuing it. As posed, sometimes the answer to the question of "why not" is, simply: there is no good reason why not (e.g. Buchanan 2011a and 2011b). After all, who doesn't want the best? One consequence of this focus is that the social construction of and the historical sources, justifying stigmas, exclusions, and implications, of pursued traits—for example, strength, beauty, I.Q. points—fail to get attention.[2] Further, the notion of enhancement itself is rarely critically investigated or thoroughly explained.

In most bioethical studies of enhancement a basic orienting framework toward possible technology is established. Many agree, first, that it makes sense to discuss possible improvements only if the related procedures are *safe* and also if outcomes are *effective* (Brock 1998, Juengst 1998); second, many concede that it is nonsense to spend money or time on improvements if they are *futile* (Brock 1998, 60; Juengst 1998, 29-30, 42). By "futile" these thinkers mean, for instance, the "arms race" of use of the human growth hormone or similar steroids (Sandel 2004, Bostrom 2003b) or the unequal nature of "positional" goods more generally (Singer 2009). A positional good is one which, in order to be enjoyed, must be enjoyed unequally; in other words, height and beauty are both thought to lack meaning when they are equally distributed. Relatedly, many bio-ethicists also wonder, will access to enhancement technologies be possible for all? If not, then clearly one is dealing with increasing inequality of a certain kind which should (but perhaps can) be ameliorated (e.g. Brock 1998, 59; Fukuyama 2004, Mehlman and Botkin 1998).[3] I do not dismiss these questions—in fact, it is important to recall that we speak of enhancements in a capitalist context of unequal resources, and enhancement appears to

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[2] One notable exception, although there are others, is *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*, a volume of essays edited by Erik Parens in collaboration with The Hastings Center (2006). For example, here the normalization of physical appearance, stigma, and social construction of concern regarding craniofacial differences and height is taken quite seriously and investigated. The helpfulness of surgeries meant to "correct" such differences is re-evaluated on the basis of the experiences of would-be or past "patients" (Aspinall 2006, Sanford 2006).

[3] For an idea of what kinds of enhancements are believed to avoid problems regarding unequal benefits, reference Buchanan 2011b, 56. Examples include immune system enhancements, enhancements of the ability to repair tissue damage, and enhancements surrounding the way humans eat and live that may release pressure on the environment (cf. Liao *et al*. 2012).

only be conceptually intelligible when some persons can realize it and some cannot (i.e., when there is no futility, and when enhancements aim toward positional goods).[4] But a philosophical investigation of enhancement will involve much more than this.

Enhancement procedures indicated in bioethical writings on the topic are a motley crew of medical interventions, both sought-after and already accomplishable. Bioethicists consider enhancement strategies to include the body-contouring effects of liposuction (a surgery requiring the use of anesthesia and the removal of fat) aimed at greater slimness, to scientific research aimed at discovering ways to counter-act the aging process in cells. But, most attention in the literature (and among the public at large) is focused upon genetic selection and related scientific and technological enhancements. The core issue for mainstream bioethics today is enhancement created through drugs or surgeries, and—often—genetic enhancement. In other words, what is at stake in these discussions is the acceptability of heritable, permanent, or semi-permanent medical interventions upon the human body in order to improve it.

The permanent, heritable, or semi-permanent features of enhancement strategies have led a few scholars at the core of the debate (who commit further than the above "half-way measures") to either speculate about exciting changes to the basic human experience or worry over forecasts of the loss of humanity. While the main-line half-way measures do not get us very far, the core of the debate represents a group of bioethicists who supposedly disagree but, as I will show, are actually in lock-step with regard to several main ideas, rather than a diverse and searching philosophical discussion. I turn to those main ideas now.

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[4] I discuss issues connected to rationing in chapter two.

In the formative years of the field of bioethics, Paul Ramsey, an original "bio-conservative,"[5] rejected the imagery of manufacture as a replacement for procreation (1970, 136-137; Kass claims Ramsey as a mentor, 2002). Ramsey believed that the "man-God" of genetic futures takes leave of humanism because it abandons (as reported by Francis Crick, a founder of the double-helix structure of DNA) the "prejudice about the sanctity of the individual" (146). This closes off possibilities and leads eventually, Ramsey worries, to species-suicide, the deliberate abandonment and dissolution of humanity (152-153).[6] Some of the most familiar *objections* to improvement and enhancement among conservative responders to new technologies follow Ramsey in spirit and therefore include the obligation to cede control over and interference in such matters to God, gods, or a causal force in a god-like role (e.g. Kass 1997; for in-depth analysis of the nuances of this point of view see Coady 2011). In other words, some believe enterprising scientists would do well to recall the Icarus myth, a favorite of conservative bioethicists—don't fly too close to the sun (Dhanda 2002, O'Mathúna 2009,

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[5] Responses to enhancement which garner the most attention tend to fall into two groups which are self-consciously placed on either end of a (alternative) political spectrum: so-called bio-conservatives (those in this group are even called "bioluddites" by some transhumanists, e.g. James Hughes 2004) and, opposing and sometimes deriding them, those who are pro-enhancement (sometimes called bio-libertarians or variations thereof, e.g. Rubin 2008, 154).

[6] Another philosopher and early bioethicist, the Australian John Passmore, took a historical approach to the question of enhancement by outlining ideas of perfectibility from Plato to twentieth-century Christian ethics (1970). According to him, no variety of perfectibility had completely disappeared at the time of his writing; each persisted through time (260). Worries about human diversity and discussion of the positions of "genetic perfectibilists" led Passmore to comment: "if we deliberately try to breed for perfection, we shall breed a population which will die out" (187; more recently, utilitarian Peter Singer rejected this concern as weak, because intervention must be sustained and directed to a very high degree in order to affect diversity, at which point the practice could be discontinued, 2009, 283-284). Yet, Passmore concludes that "in spite of these reflections, which might lead us to reject perfectibilism in any of its forms, it is very hard to shake off the feeling that man is capable of becoming something much superior to what he now is" (326). Quoting Jean-Paul Sartre, Passmore notes that "to reach towards being God" is a "useless passion" but "[human] passion is not useless, if they help [humans] to become a little more humane, a little more civilized" (327). For Passmore, then, taking control is justified if changes prove helpful and he suggests that angling for this control is perhaps just one way of being human.

cf. Passmore 1970). Ultimately, the boundaries of human nature, along with the dignity felt to be inherent to humanity, are shored up as something with to be protected from interference and temptation (Bibeau 2011, Engelhardt 1990, Habermas 2003 23-26, among other places; Sandel 2004). Tied to this are appeals to human wisdom and appropriate humility (Kass 1997, 2002, O'Mathúna 2009, 191; Sandel 2004; as satirized in Bostrom 2005a). Ramsey ventured forth into this, at his time new, milieu with the idea that enhancement of human beings through biotechnological means was, in effect, "playing God." He commented: "Men ought not to play God before they learn to be men, and after they have learned to be men they will not play God" (1970, 137).

The "playing God" objection remains important as long as bioethicists ask the question "why not," and this objection fundamentally assumes that technology allows us to be in control of such radical changes that we might as well call ourselves God. Curiously, transhumanists embrace the God-like extent of technological control—even though it might make more rhetorical sense to de-mystify technology in order to make it more widely appealing (Bostrom 2003a). Belief in the absolute power of technology over human nature via bodily intervention is shared by proponents and opponents of enhancement technologies alike. Therefore, although arguments which react to and reject, or pursue and embrace, the question of whether enhancement is permissible *appear* to cut a wide swath of argumentation strategies, "conservative" and "libertarian" responses are actually relatively uniform and often share more presuppositions than they disagree upon.

One can draw other common conceptual fixtures from what appear to be diametrically-opposed positions regarding enhancement. I argue that three further examples of shared presuppositions among otherwise opposed bioethicists are: the distinction between artificiality and authenticity, the uniqueness of human beings, and the importance of equal opportunity. With the exception of the issue of authenticity, these shared presuppositions go unnoticed by participants in the debate.

First, authenticity appears in bioethical commentary regarding fair play and competition as the goal of the search for the self, and how enhancement degrades this (e.g. Daniel 2011, 41, Elliott 2004 and 2011, Sandel 2004).[7] In the early 90s, Peter Kramer famously wrote about issues regarding authenticity and the use of the drug Prozac, showcasing the point of view of users who felt they lost their identity in taking Prozac (1993, cf. Buchanan *et al*. 2000, 98 and Parens 2009, 186). Kramer inherits worries that drove the political philosopher Robert Nozick. Nozick, writing in 1974, warned of the possibility of a "genetic supermarket" and spoke to issues of artificiality and the pursuit of authenticity. Nozick devised the well-known "experience machine" hypothetical (315n, 42-45), which he used to demonstrate that one would reject pleasurable experiences, even if very intense, if one knew they were contrived (i.e., created by machine). Moreover, Erik Parens has noted the prevalence of the issue of authenticity and its appearance in the arguments of those who do *and* those who do not support various human enhancement strategies (2009). In particular, Parens claims, both groups appear to subscribe to the concept of an "authentic self"—that is, each group believes, for its part, that either embracing or shunning enhancement technologies will promote authenticity and reconcile (or avoid) self-alienation.[8] In this discourse, I argue

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[7] See Kelly Oliver's critique of the issue of "fair play" in this conversation as connected to obsessions with sports and celebrity in 2010, 77, along with her critique of the border between the artificial and the constructed throughout the essay.

[8] Here Parens references ideas articulated by Søren Kierkegaard and, later, Charles Taylor in the context of political liberalism (Taylor 1991). Given the widely-shared commitment to authenticity, Parens believes

that the border between the "real" and the "constructed" is policed (e.g. Habermas 2003) or assumed and then transgressed (e.g. Harris 2007).

Second, both sides of the debate agree that the human being is uniquely placed among the things in the natural world. Authentic *human* living might mean, then, respecting or responding to the boundaries of what is considered unique to human "nature," which might include or depend upon parenthood (Sandel 2007, cf. Ramsey 1970) or "traditional" sexual reproduction (Kass 2002) or even some nameless X-factor (Fukuyama 2002). In fact, many in the group of conservative responders tend to reject enhancement as threatening what is valuable about humanity or the social world in which human beings find themselves. But, as transhumanists argue, the quest for authenticity and respect for human beings could also mean following the all-too-human drive toward innovation by embracing change through directed evolution, or refusing to accept things like aging and death, which cause great distress (Bostrom 2004 and 2005a, cf. Huxley 1948). Along these lines, transhumanists Nick Bostrom and Anders Sandberg argue that paying attention to human wisdom (as the bio-conservative desires) *requires* taking enhancement seriously because humans are uniquely situated to draw lessons from history and evolution (Bostrom 2004, Bostrom and Sandberg 2011, cf. Kass 1997).

Third and finally, equality of opportunity is called upon to both justify *and* object to interventionist medical and technological enhancement strategies (recall the focus on

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that some enhancement technologies will appear acceptable to the usual opponent and some may appear unacceptable to the usual proponent (2009, 192-194). For example, Parens himself is thrown from his usual critique of enhancement by the narrative testimony of transgendered persons seeking sexual reassignment surgery and drug therapy. For him, it is clear that the use of medical intervention in such cases involves the pursuit of the patient's vision of the authentic self (194). On the other hand, he suggests that proponents of enhancements would be unsettled by the idea that someone may desire to take a pill that creates feelings of sexual intimacy, and wonders whether, in this case, proponents might suggest other modes of tackling one's lack of such feelings. If they would, this would indicate a commitment to an authentic self situated in the "real" (193).

fair play). Buchanan *et al*. return again and again to the concept of equality of opportunity in *From Chance to Choice* (2000). These authors claim that the arena of justice is, in effect, a phenomenon of slow "*colonization*" of circumstances once left to chance (82-84, emphasis mine). According to Buchanan *et al*., intervention in the name of justice is only accomplishable when we have control over (have colonized) circumstances, but that realm grows all the time through new technologies and scientific understanding.

What Buchanan and the other authors of this text describe is a *technological imperative* underlying the development of new technologies. That is, as technology becomes available that can be used to intervene upon the human body, one *should* use it. When medical technology was less advanced and there were fewer available strategies, concerns of justice were restricted to that over which control could be exercised (education, for instance, is a concern for *equality of opportunity*; publically available and affordable education was and remains an issue for justice according to Buchanan *et al.*). With fresh advances, however, new interventions can be justified via the concept of equal opportunity. The authors imply that the growth of arenas of control is without limit, and that outside of those arenas only chance operates. This discussion follows from the authors' claim that Thomas Scanlon's brute luck conception of justice should not be limited to nullifying the inequality resulting from natural or social lotteries; instead, it should be applied earlier, to the genetic lottery, in order to remain consistent with its claims regarding justice and equality of opportunity (108-152).[9]

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[9] John Harris, a strong proponent of enhancement, critiques this particular application of equal opportunity strongly (2011).

Meanwhile, Peter Singer invokes the concept of equal opportunity to discuss possible *negative* effects of enhancement, specifically genetic interventions, upon persons who are not immediately concerned. He claims that genetic intervention would likely work at cross-purposes with equal opportunity unless it is regulated in some way (2011). This is because of its potential, in a global marketplace, to be used only by already-advantaged persons with ready access to wealth. Because Singer believes that enhancement via genetic intervention could be successful, this type of enhancement would solidify the advantages the wealthy enjoy over the poor by passing along advantageous traits to descendants, widening the gap between rich and poor (cf. Silver 1998). Echoing Singer on this point, Fukuyama claims that transhumanism is the world's most dangerous idea (2004). Solidified advantages enjoyed by the wealthy over the poor violate equal opportunity.

I have argued that three important features are shared by proponents and opponents of enhancement. But, as I will now argue, a fourth conceptual habit is the most important shared feature within this small but influential core of scholars: *reductions of social and political circumstances – along with hopes for change – to biological facts*.[10] Moving forward, I will refer to this as "reduction to the biological." This is an especially important feature of transhumanism, which is cashed out today as *genetic determinism*. In a biological reduction, relevant information about individual or social circumstances is read through features and facts about the body. Genetic determinism and related beliefs reads information through genes. Further, genetic determinism renders the body, taken as

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[10] Jacques Derrida makes a similar point in *Rogues: Two Essays on Reason*, where he notes that the debate on cloning—supposedly a bitter debate at a moral crossroads—is dictated on both sides by biological reductionism (2005, 146-148, cf. Mendieta 2003, 172-173).

a bundle of genes, *the* site of human (and therefore, social and political) improvement while at the same time taking for granted that technological interventions on the body, especially genetic interventions, have the power to "enhance" (as Singer does, above).[11]

Genetic determinism has two different inflections directly relevant to philosophical conversation in bioethics today regarding enhancement, including genetic testing and selection (my case study in this project, which I analyze in chapter two). The first inflection is that if a trait is identified as genetically determined, or even biologically determined, it is unchangeable (or opportunities to alleviate it are significantly limited), and responsibility for the issue falls to the individual rather than political or social institutions (Haslam 2011, 819; Lewontin 1992, 23, 36-37; Nelkin and Lindee 1995, 16, 18, 93).[12] The second inflection, important for arguments surrounding genetic enhancement technologies, is that if a trait is genetically determined it can be removed or changed if it is genetically or technologically intervened upon (Nelkin and Lindee 1995, 101). But, simply because a trait is considered *changeable* within a discourse influenced by genetic determinism does not mean that social or political elements shaping the trait are necessarily considered. In a *genetic* biological reduction, a genetic problem requires a genetic solution. For example, an intervention considered able to interrupt the work of

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[11] Influential mainstream bioethicist Norman Daniels does object to the "genetic determinism" necessary to the belief that certain enhancement strategies can change human nature (2011). But, his objection is based on the fact that "human nature" is a population concept and one that picks out certain features as important (and we could be wrong about these); therefore, he says, "we can modify human nature, but it takes a very tall tale. We must affect the (or at least a) whole population of humans, and we must do so with a trait central to that nature" (2011, 36). Modifying human nature is thus possible, for Daniels, although perhaps not in the way most worriers conceive of the possibility; he goes on to argue that whether or not one *should* do so is another question altogether.

[12] For an example of a move to individual responsibility, consider the case of allergies or genetic predispositions to certain sensitivities that would rule out a person working in certain environments. Rather than ensuring safe working conditions in a workplace, the employer has recourse to requiring a person to disclose any sensitivities and then declaring the worker not fit for the workplace (as opposed to the workplace being unfit for workers) (Nelkin and Lindee 1995, 161).

genetic determinism is to "select against" an embryo carrying an unwanted genetic trait (as suggested by e.g. Savulescu 2001a, 2001b, 2008; I return to this as my case study in chapter two).

Philosophers David Resnik and Daniel Vorhaus have argued that four common *objections* to genetic modification technologies are based in or influenced by genetic determinism. These arguments are: the freedom argument, which claims that genetic modification interferes with human freedom; the giftedness argument, which claims that children will become products rather than gifts; the authenticity argument, which claims that "talents and abilities" resulting from modification are not really one's own; and the uniqueness argument, which claims that clones are persons whose uniqueness has been violated (Resnik and Vorhaus 2006). Each of these arguments significantly overestimates the value of genetic factors.

But, arguments *supporting* genetic modification, especially because they are often motivated by the desire to achieve increased quality of life, fall into the same trap. Transhumanist James Hughes' essay "The Struggle for a Smarter World" both promotes and strongly predicts the impending feasibility of human enhancement with regard to intelligence. There, he describes a study as substantiating the claim that "genetics are the overwhelming predictor of intelligence for kids from middle-class and affluent backgrounds" (2008, 943). Hughes worries that that humans have reached the limits of their potential without genetic intervention, an argument which implicitly relies on the essentialist concept of innate potential. He claims that "twins raised in different homes have almost exactly the same intelligence," implying the strong genetic causation behind intelligence as a characteristic (2007, 944).[13] In order for investments in genetic modification strategies to make sense, some strong portrait of gene action is necessary. In other words, arguments supporting programs of genetic enhancement are immediately susceptible to the charge of genetic determinism. Making public policy recommendations that would dedicate a vast sum of funds to create genetic enhancement technologies and make them available to the public at least approaches what Mianna Lotz calls "geneticism"—the privileging of genetic causes over other factors—if not a stronger variety of genetic determinism (Lotz 2008). I return to a close description of genetic determinism at the end of chapter one and provide an example of transhumanism's commitment to genetic determinism (negative genetic selection as a moral principle) in chapter two.

In sum, I have argued that supposedly diametrically opposed positions in core bioethical debate surrounding enhancement share fundamental presuppositions, which only accentuates the need to philosophically investigate the terms upon which the debate is structured—especially genetic determinism.[14] I now turn to the strongest group of

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[13] The significant problems with regard to separating factors in twin studies are well documented in R.C. Lewontin's *Biology as Ideology* (1992, 32-33). To start, he notes that volunteers for twin studies are part of a self-selected group and that most twins have at least some contact and common environment—for example, often "the reason that twins are separated at birth may be that their mother has died in childbirth, so that one twin is raised by an aunt and another by a best friend or grandmother" (32). Lewontin also tackles problems related to IQ testing (33-37).

[14] It is important to also note the masculinism undergirding these bioethical texts; one example is the pressure individuals supposedly feel to be tall and deliberation regarding the use and distribution of the human growth hormone to the end of tallness (see esp. Daniel Brock and Eric Juengst in Parens 1998, or Buchanan *et al*. 2000, 115-119). The example is usually posed as a problem among young boys, and indeed the issue of tallness seems specifically to plague white masculinity. Historically, white males were over-enrolled in early trials of human growth hormone treatment (Rothman and Rothman 2003, 172). I argue that the insistent focus on this body issue as an example of a desired enhancement (along with the difficulty of determining the difference between enhancement and treatment in this case) obfuscates and trivializes the bodily stigma and pressure to conform felt by those whose bodies have been raced, sexed, and disabled. In fact, the constancy of this example shows that the white men who write within this literature are concerned about alleviating the impact of stigma they are *familiar* with. In this project, I also note and trace

proponents of radical enhancement, transhumanists. I seek access to the issues at the heart of the question of enhancement and an understanding of why our culturally and historically specific variety of enhancement is desired in the first place. After I introduce transhumanism, identify two key transhumanist goals, and argue that transhumanism is utopian, I explain my methods in this project and conclude my introduction.

Transhumanism

Transhumanist philosophy focuses on the potential achievements of evolving technology, the desirability of developing new technology, and the possibility of enhancing current human capabilities (Bostrom 2005b, 8). It would be accurate to classify transhumanism as a type of applied ethics, given its concern with the practical implications of technology and possibilities for its future use for improving human life. According to the "Transhumanist Declaration," penned in 1998 as a founding document of the World Transhumanist Association, transhumanists recognize that technology has the power to impact human life in a fundamental way that would "redesign" it (Bostrom 2005b, Appendix). Instead of turning away from technology or indulging in "technophobia," (the mistake of bio-luddites) transhumanists believe that new technologies, particularly those made possible by the "GRIN" fields—genetics, robotics, information, and nanotechnology—should be welcomed as potentially improving human life, although they are risky (*ibid.*, see also Garreau 2005, 115 and Rubin 2008, 137). For

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the masculinist tendencies of transhumanism. Transhumanist literature is written by white men and seems directed at the concern of white men to maintain and order the social world in such a way as to maximize their own independence and freedom. I return to this issue in the Conclusion.

transhumanists, global society should invest time and research into technology to improve cognition, anti-aging techniques, reproductive technology, and life suspension techniques such as cryogenics—all of which are cited by the Declaration—in order to understand both their risks and possibilities. Ultimately, what individuals stand to gain, according to transhumanists, is the "use of technology to extend their mental and physical (including reproductive) capacities and to improve *their control over their own lives*" (Bostrom 2005b, Appendix, emphasis mine). In sum, the Declaration claims that transhumanists "seek personal growth beyond our current biological limitations" (*ibid*.).[15] It seems that for transhumanists, only two reactions to technology—that is, passivity and activity—are possible. Activity is preferable because (or so it is claimed) technology has the potential to ameliorate or eliminate human suffering and put individuals in control, while passivity should be rejected because it may increase, or at least extend, human suffering.[16] Passivity represents ignoring possible control over one's future.

Nick Bostrom, Professor of Philosophy and Director of the Future of Humanity Institute and the Programme on the Impacts of Future Technology at Oxford University, is one of transhumanism's chief academic proponents and co-founder of the World

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[15] The aforementioned Ramsey presciently outlined the same possibilities for enhancement that represent the highest hopes transhumanists today. In *Fabricated Man*, Ramsey notes the desire for intelligent machines, hybridized with organic material, the pursuit of longer or limitless life, and the increase of intelligence (1970, 155-157, cf. Bostrom 2008, Kurzweil 2006, Savulescu 2001b, and Stock 1993). He took these suggestions from a landmark academic text of the time written by Gerald Feinberg and entitled *The Prometheus Project* (1968).

[16] Many transhumanists dismiss arguments coming from those derogatively referred to as "bioconservatives" who are believed to opt for passivity. Even bioethicist Arthur Kaplan, whose views on enhancement are relatively moderate, refers to the troubling "anti-meliorists" when he encounters critique from those worried about the aims of or limits to enhancement ("Good, Better, or Best?" in Savulescu and Bostrom 2011). But characterizing worries about radical enhancement as a refusal to alleviate suffering closes off conversation prematurely; there are, as we shall see, good reasons to worry about enhancement strategies conceived today that have little to do with bioconservatism.

Transhumanist Association.[17] For Bostrom, transhumanism stands for the "radical extension of human health-span, eradication of disease, elimination of unnecessary suffering, and augmentation of human intellectual, physical, and emotional capacities…" (Bostrom 2003b, 5). In a 2005 essay, Bostrom traces a history of transhumanism. Taking literary epics, ceremony, and religion as a guide, he notes that cultures around the world have long bemoaned death and sought immortality. He regards Renaissance humanism and the Age of the Enlightenment as primary precursors of today's transhumanist point of view, because, like transhumanism, both of these historical frames emphasized "intellectual rigor" and relied upon empiricism and human judgment to investigate the world and its possibilities, therefore eschewing dogma (Bostrom 2005b, 2). Following Francis Bacon, Bostrom argues that science should be used to "achieve mastery over nature in order to improve the living conditions of human beings" (*ibid.*, see also Rubin 2008, 137). In short, "rational humanism" is where transhumanism locates its heritage.

Among the influential ideas from these periods is the far-reaching belief that the human is an object of nature to be conquered. As Bostrom puts it: "humans themselves can be developed through the appliance of science" (2005b, 3). Thus, it is Immanuel Kant's motto "Sapere aude! Have courage to use your own intelligence!" to which Bostrom finally turns (2005b, 4; cf. Wolfe 2009, xiv). Meanwhile, Bostrom distinguishes transhumanist aims from Friedrich Nietzsche's overman, arguing that Nietzsche did not have "technological transformation" in mind (Bostrom 2005b, 4). But, he finds

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[17] Those I consider a part of the "cultural" movement of transhumanism include pop-culture icon Ray Kurzweil, famous for his articulation of the "singularity" – a future time when humans can "transcend biology" (2006). He is now director of engineering at Google. Others in this group are Natasha Vita-More and her husband Max More, who have been globally influential among laypersons interested in life extension and enhancement (Alexander 2000, Heard 1997).

inspiration in Nietzsche's 19th-century contemporary, J.S. Mill, the English liberal thinker and utilitarian (2005b, 4). Transhumanism looks forward to and promotes a future where technology reshapes the human being as it is now conceived.[18] According to Bostrom's vision, this reshaping would be directed toward improvement for human beings in terms of *capabilities*, but also, in harmony with Mill, *happiness*.

Transhumanism's hoped-for, reshaped human being is often referred to as the *posthuman*. To be posthuman, according to transhumanists, is to inhabit a state generally considered to be not only a departure from what are commonly considered human qualities but also radically better than, or transcendent of, humanity as we know it (Bostrom 2008). "Current standards" of humanity would not apply to the posthuman (Garreau 2005, 231-232, cf. Wolfe 2009, xiii). According to the "Transhumanist FAQ," a collectively authored document Bostrom participated in: "Posthumans could be completely synthetic artificial intelligences, or they could be enhanced uploads…or they could be the result of making many smaller but cumulatively profound augmentations to a biological human" (*Humanity* + 2012).

Transhumanism's sense of the *posthuman* is not the only contemporary meaning of the term. Transhumanism's posthuman is not equivalent, for instance, to the concept of posthuman used in critical animal studies to challenge philosophical investments in or the moral relevance of traditional species boundaries. For example, in *What is Posthumanism?* Cary Wolfe forcefully distinguishes transhumanism from the critical

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[18] Human-machine hybridity is already a reality in the use of prosthetics, computers, handheld devices, assistive technologies, and other complex technological systems upon which most of us rely every day (cf. Francis 2009 on complex cognition). For more obviously radical examples of hybridity, look to world-class athletes Oscar Pistorius and Aimee Mullins. While it may thus be argued, along with Donna Haraway (I return to her work below) that we are already "posthuman," here I am concerned with investigating specific *transhumanist* promotion of a special, hoped-for, future posthuman, believed by transhumanists to be so increased in capacities that it would be difficult to assign the word "human" to this being.

posthumanism he endorses. Wolfe draws this line precisely because of the humanism that Bostrom identifies as the "roots" of transhumanism, a sense of "posthumanism [that] derives directly from ideals of human perfectibility, rationality, and agency" (Wolfe 2009, xiii). Wolfe uses posthumanist critique to target these ideals, and to show that the positive "aspirations" of humanism are "undercut by the philosophical and ethical frameworks used to conceptualise them" (2009, xvi). Among these aspirations are better treatment of nonhuman animals and persons with disabilities that the confining "normative subjectivity" of humanism prevents (2009, xvi-xvii). Wolfe compares posthumanism to transhumanism in this way: "posthumanism in my sense isn't posthuman at all—in the sense of being 'after' our embodiment has been transcended—but is only posthuman*ist*, in the sense that it opposes the fantasies of disembodiment and autonomy, inherited from humanism itself…" (Wolfe 2009, xv). Bostrom's vision of the posthuman is a realization of the fantasies of disembodiment and autonomy and so supports, rather than questions, normative subjectivity.

A version of posthumanism has been attributed to philosopher Michel Foucault because of his remark that the human being, as known to us in the contemporary world, is a recent invention that may soon be left behind or die out (Foucault 1973, 386-87). Foucault's sense of posthumanism would amount to the recognition that discourse and power relations always shape human identity, which can shift and be refashioned. Unlike Bostrom, who considers the intellect trapped in the body (an inheritance from Plato, who suggested the same thing about the soul), Foucault believed that the soul was the "prison of the body" (Foucault 1979, 30). Arnold Davidson, in an introduction to the *Abnormal* lectures, explains that Foucault provides a "historical analysis" and "political history" of the body by focusing on the way that the concepts of the psyche and personality came about, contributing to "gradation from normal to abnormal" in the classification of bodies (Davidson, in Foucault 2003, xix). But, Foucault investigated and uncovered systems of subject-making and normalization precisely because he was a critic of Enlightenment humanism (Sawicki 1994, 288). Meanwhile, because transhumanism lacks Foucault's insights, which suggest that beliefs about what the human being is can impact acceptance and rejection of particular bodies, I will argue that transhumanist philosophy serves to further advance the construction and support of notions of abnormality that are in turn used to exclude certain bodies from political and social privileges.

Despite rallying around a vision of the posthuman, transhumanism conflicts with the ironic cyborg utopia first imagined by Donna Haraway in 1985. Haraway, another philosopher of posthumanism, is the author of "The Cyborg Manifesto" (1991), an iconic essay of political ironism in which she imagines border crossings that break oppressive dualisms and acknowledges that human beings are already chimeras and cyborgs. Wolfe identifies Haraway's legacy as the "cyborg" strand of posthumanism and claims that although transhumanism takes cues from her work, it does not much resemble the spirit of Haraway's attempted intervention (xiii). Transhumanism looks forward to a time when posthumans arrive, and Haraway's work argues that distinctions which uphold the figure of the human as autonomous, whole, and rational are already broken down.[19]

Just as feminists have been concerned to criticize the vision of the human as autonomous or a carrier of pure rationality, we should be concerned to criticize

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[19] Shulamith Firestone is another feminist claimed for the transhumanist point of view (e.g. Bostrom 2005c). But her call for liberating reproductive technology for women must be read as part of her feminist reading of Marx and her feminist political goals (1970).

transhumanism because it turns the boundless rationality once thought to conquer nature back upon human beings to remake them in accordance with this rational image. Transhumanists envision an extension of capabilities further into space and time and the multiplication and maximization of autonomy and intellect. In this way, rather than going beyond the notion of an autonomous rational subject, transhumanism merely expands these ideals into a posthuman world (cf. Hayles 1999, 287; cf. Wolfe 2009 xv). And what emerges from this world is not a hybrid that has no origin—as Haraway envisioned—a being outside of hierarchies that privilege men over women and culture over nature, including the human/animal, organism/machine, and physical/non-physical divides, putting stigmatizing norms into question (Haraway 1991, 151-153). Transhumanism is the realization of these hierarchical privileges, now extended.

Katherine Hayles, a proponent of her own type of posthumanism, critiqued transhumanist Hans Moravec because of his dreams of extended autonomy. She writes:

> When Moravec imagines 'you' choosing to download yourself into a computer, thereby obtaining through technological mastery the ultimate privilege of immortality, he is not abandoning the autonomous liberal subject but is expanding its prerogatives into the realm of the posthuman. (Hayles 1999, 287; cf. Wolfe 2009 xv)

While radical, promising forms of posthumanism that contribute to feminist projects like Haraway's ironic political myth exist, transhumanism's posthuman is not among these. Transhumanism uncritically adopts the tenets of classical humanism. Transhumanism's imagined "cyborg" does not celebrate difference but rather the maximization and optimization of familiar valued traits such as cognitive ability, physical strength, rational choice, and beauty. All of these ideals inform and support existing hierarchies (cf. *Humanity* + 2012). Posthuman pleasures claimed for transhumanist futures are often hyper-realized versions of current desires, as in Bostrom's "Why I Want to be a Posthuman When I Grow Up," where he suggests that posthumans will enjoy intensely pleasurable music, friendships, and special multi-player games (2008). In chapter one, I situate transhumanism within a history of enhancement strategies in the twentieth century, beginning with "physical culture" at the turn of the century and ending with the framing of modern bioethics in the 1970s and the genetic beliefs underlying today's enhancement conversation and transhumanism itself.

Now that I have introduced transhumanist thinking, I will draw out two major transhumanist goals and strategies upon which I focus in this project.

Transhumanist Goals and Strategies

I here conduct a brief critical discussion of the specific views of Bostrom and Julian Savulescu and their respective transhumanist enhancement strategies of transcending the body and negative genetic selection. I choose these two figures because both are influential scholars in bioethics whose views have special interest for feminist disability scholars.[20]

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[20] Both Bostrom and Savulescu are influential bioethics scholars. It should be noted that besides their own numerous publications and academic institutional influence, the two are widely cited in other philosophical and scholarly works. A cited reference search utilizing both the Social Sciences Citation Index and Arts and Humanities Citation Index in Thomson Reuters' *Web of Knowledge* database yields 1,575 academic works citing Savulescu on topics ranging from ethics to social issues. Works citing Savulescu include (but are not limited to) 1,111 peer-reviewed articles, 85 book chapters, and 22 books. This is a wealth of support compared to the relatively "fringe" Bostrom, cited (according to a search conducted via the same constraints) in 148 academic works on topics ranging from ethics to social issues. Works citing Bostrom include (but are not limited to) 120 peer-reviewed articles, 17 book chapters, and 8 books. But, Bostrom features largely in the work of mainstream bioethicists, like Nicholas Agar. In his recent book *Humanity's End: Why We Should Reject Radical Enhancement*, Agar dedicates an entire chapter to the work of Bostrom (2010). Agar also references Savulescu on the topic of enhancement for elite sports (201). Agar also cites Bostrom in *Liberal Eugenics: In Defence of Human Enhancement* (2004). Transhumanism as a movement has also received considerable scholarly attention. For example, *Hastings Center Report* published a piece by Agar which takes for granted the importance of transhumanist literature in 2007 and

Bostrom promises a future of increased happiness if only we invest in enhancement technologies – not only a future of new pleasure, but also an increasingly moral and politically just future (Bostrom 2008). He bases his argument upon the desirability of an increased opportunity range and the unknown potential of increased intellectual capacity. An opportunity range is an idealized set of possibilities based on available capacities; as defined by bioethicist Norman Daniels, an opportunity range is "the array of life plans reasonable persons…are likely to construct for themselves" (Daniels 1985, 33). Because the posthuman is an erstwhile human with radically increased capacities, Bostrom argues that the opportunity range of a posthuman is larger in scope than the opportunity range of a human. These ranges can be represented by two concentric circles, with the posthuman opportunity range encompassing that of the human. Bostrom thereby contends that posthumanism should be pursued (2008). He is using the logic of extended autonomy defined by way of multiplication of choice.

Bostrom argues that the posthuman state is better, offering pleasures and fulfillments worth pursuing, although he simultaneously acknowledges that his vision of posthuman life is by definition unknowable to mere humans because it involves the attainment of new capacities and, thus, new insights (2004 and 2008, 112). He writes, as if from the future: "[Posthumans] love life every instant. Every second is so good that it would blow our minds had their amperage not been previously increased" (2010, 8).[21] This point is typical of the utopian rhetorical strategy employed by Bostrom; a fact which

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subsequently gave space to replies from both transhumanist James Hughes and Bostrom, along with a reply from Agar (Agar 2007). Also, a recent (December 2012) issue of *Zygon: Journal of Religion and Science*, a journal published by Wiley-Blackwell with an impact factor of 0.274, published 4 articles on transhumanism as part of a special issue.

[21] As Lisa Guenther pointed out after reading an earlier draft, Bostrom sounds as though he is describing the perfect orgasm.

has not gone unnoticed among other scholars, or even Bostrom himself, who seems to embrace the term "utopia" (e.g. Hauskeller 2012, Bostrom 2010). Bostrom contrasts an unknowable future of intense happiness with today's world, and describes today's world in dismal terms, taking suffering for granted. Both extremes seem unjustified. For example, regarding today, he writes: "Every way you turn it's the same: soot, casting its veil over all glamours and revelries, despoiling your epiphany, sodding up your white pressed collar and shirt" (Bostrom 2010, 2). Readers are thus exhorted to promote a transhumanist vision of the future. Bostrom asks us to recall the best moments of our lives and hold them in our hearts as an "aspiring ember"; he argues that the best moments of human life correspond with a "higher state of being," the thought of which should provide motivation enough to pursue radical enhancement (Bostrom 2010, 3; cf. 5).

Bostrom describes human bodies as fragile houses unfit for bliss and happiness: "it is not well to live in a self-combusting paper hut! ... one day you or your children should have a secure home. Research, build, redouble your effort!" (2010, 2 and 5). Bostrom is not only relying on utopian rhetorical strategy, he also feeds the fantasy of a disembodied intellect in search of a better home from which it can operate and experience life. This intellect, trapped, appears to be the real posthuman and is waiting to be released. Bostrom rejects the human body as vulnerable and issues a moral imperative (echoed, as we shall see, in the work of Savulescu) to provide new sorts of containers for one's children that are not vulnerable.

Bostrom's transhumanism is informed by the strong desire to avoid the suffering of disease and pain as well as moral urgency derived from the sense that death is unjust and society is culpable for failing to address its victims (Bostrom 2007). Yet, in order to achieve rhetorical goals, current suffering is overstated (Bostrom 2003b and 2005a). Bostrom quips: “What is Guilt in Utopia? Guilt is our knowledge that we could have created Utopia sooner” (2010, 8 and 7).[22] In Bostrom’s work and its promise of immortality or radically-decelerated aging, transhumanism represents the fantasy of wish fulfillment. Bostrom denigrates the body and, implicitly, dependence as part of his program of human enhancement, as indicated by his imagery of the self-combusting paper hut. For him, the goal of transhumanism is to leave the vulnerable body behind to protect the intellect and to augment the therefore disembodied intellect by way of technology. He views this as an integral part of the journey to a better, happier, more moral and politically just future.

I turn now to Julian Savulescu, editor-in-chief of the *Journal of Medical Ethics* and director of the Oxford Uehiro Centre for Practical Ethics. Savulescu’s work, like Bostrom’s, is motivated by moral urgency; Savulescu and Igmar Persson claim that humans must enhance themselves morally or face *extinction* because of moral ineptitude; they draw on evolutionary psychology to describe “common-sense” morality and believe that this morality must be changed to mitigate or eliminate threats such as climate change and war (Savulescu 2009 and Persson and Savulescu 2010 and 2012).

Along these lines, Savulescu argues that “eugenic” genetic selection is the best way to achieve human enhancement (with Hemsley *et al*. 2006). In other words, the population must be protected from internal threats in order to protect it from global, external threats. Savulescu calls the obligation to select for the best or better traits “procreative beneficence” (2001b, 425, cf. Savulescu 2002, 2008) and he makes clear

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[22] In contrast, Bostrom writes of the future: “What is Suffering in Utopia? Suffering is the salt trace left on the cheeks of those who were around before” (2010, 7).

that genetic markers for known disabilities are among the traits targeted as worse and to be avoided by those who are morally conscientious (Savulescu 2008). He believes that any trait which potentially curtails quality of life should be selected against. Parents are morally responsible to choose future children on the basis of particular traits in order to secure greater happiness and freedom for them – or at least provide the best chances at happiness and freedom (2001b, 415). For Savulescu, in other words, parents have a moral obligation when reproducing to select for the traits that will contribute to the best chances for the best life (*ibid.*). Given existing technology, this means employing either selective abortion on the basis of the presence of certain traits uncovered via prenatal diagnosis or utilizing a combination of in vitro fertilization and pre-implantation genetic diagnosis to select a favored embryo. Savulescu argues that the latter method is psychologically preferable for reproducers, although either is acceptable in light of procreative beneficence (2001b, 416). In the future, procreative beneficence would mean the moral imperative to use any technology available when reproducing to ensure the birth of the child with the best chances at the best life (cf. Savulescu and Kahane 2009, recall here Buchanan *et al.*'s views regarding the "colonization" of justice).

Savulescu likens the reasoning involved in selecting embryos to playing the Wheel of Fortune; no matter how weak the link between genotype and expected eventual quality of life, he argues that a parent should select the embryo, of available embryos, with the best traits – or, which is unmarked by negative test results (2001b, 414). Key among favored traits is cognitive ability, measured individually via IQ, which he argues is essential to living a good life on most major versions of moral living (420). According to Savulescu, most moral conceptions of how to live a good life are based in or could be improved with maximized cognition (419-420). Undesired traits are many, including traits for asthma and bad tempers, which Savulescu argues negatively affect quality of life significantly enough to warrant negative selection (417 and 420). In chapter two, I discuss procreative beneficence and develop a "disability critique"[23] of the view. I will argue that procreative beneficence is ableist, sexist in its disregard for women who would be required to use it, and should be of concern because it stigmatizes dis/abled and otherwise marked bodies.

Using a disability lens to view procreative beneficence helps uncover the tableau of statistical risk embedded in Savulescu's account. For example, prenatal diagnostics presents medical, hereditary, and age-related statistics along with *risk* of deviation and associated costs to potential parents; it also requires decisive action in response to those statistics (see Waldschmidt 2005, 205). Parents can, using prenatal diagnostics, choose against "misfortune" by utilizing the platform of "statistical calculation" (204-205). As Savulescu puts it, reproduction becomes a game of the Wheel of Fortune, and the fetus becomes a site of risk. Do the risks, assessed through prenatal diagnostics, justify continued pregnancy? Potential parents are thus asked to participate in the avoidance of risk, and risk is most often figured as the risk of disability.

Savulescu, in seeking a better future, suggests genetic selection as a primary enhancement strategy. But, as I will argue, his account of the moral use of reproductive technology naturalizes or participates in stigma against persons with disabilities and is sexist in its disregard for women who must use it. In a close parallel to the work of Bostrom already discussed, the prenatal diagnostics at the heart of Savulescu's

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[23] The "disability critique" is a specific point of view most famously supported by Adrienne Asch. I employ Asch's work and develop a version of this view in chapter two.

enhancement strategy emphasizes the *risks* of embodiment. I now return to Bostrom to forecast more thoroughly the role I see the concepts of disability and vulnerability playing in transhumanist argumentation.

In his parable "The Fable of the Dragon-Tyrant," Bostrom figures death as a murderous dragon waiting for its victims on the outskirts of a city (2005a). The city is forced to pay tribute to this monster, which salivates endlessly for human flesh. The tribute comes from all parts of the community, sparing no family, and grief always follows. The leaders of the city, and many within it, have become so used to the rule of this monster that they offer no resistance. Cartloads of individuals are sent to the dragon every day. Bostrom describes the desire of some brave members of the community to slay the dragon; but, these individuals are undercut by established powers. The hero of Bostrom's story is the one who finally, against the complacency of the leaders of the city, hatches a plan to slay the dragon and succeeds. Bostrom thus poses death as conquerable. When we consider Bostrom's story, we should notice the ideological struggle in particular. Who objects to the desire of the transhumanist to defeat death, aging, and the illnesses which are tied to them? Taken literally from the fable, the objector is the status quo – complacent leadership (2005a). This fits with Bostrom's indictment of bioethics as rife with "status-quo bias" and the inability of most of us to see what humanity's biggest problems really are (most importantly—death) (cf. Agar 2010, Bostrom 20087). But, I argue, a better interpretation of the "enemy" of transhumanism is the vulnerability of the body, which – if it is not rejected or ameliorated – will stymie the plan of enhancement for transhumanists. Vulnerability-as-enemy can be seen in Savulescu's contention that enhancement is necessary to stave off extinction and negative genetic selection will achieve enhancement for everyone. The dragon, representing death, inspires in transhumanists the need to defend and arm the human body. The fleshly human body becomes the transhumanist target of innovation as a result of its unacceptable vulnerability to injury and death.

While transhumanists believe all human bodies are wanting and should be enhanced, disability is a special subject of concern for transhumanism. Common human capabilities are not, for transhumanists, the endpoint of human progress but a shaky beginning. Transhumanists reject Norman Daniels' normative concept of species-typical functioning, as many disability rights activists and theorists have done. At least at first, then, it seems that transhumanists do *not* value the disabled body less than the abled body; rather, they consider all bodies to be in some sense deficient. This would be an improvement upon the view that the species-typical body is acceptable while bodies that deviate are not. But, I argue that transhumanism actually rejects the disabled body and can increase stigma against persons with disabilities for two reasons. First, it plays upon fears of disablement. As I have shown and will continue to argue, transhumanist thinkers emphasize the fragility of the body and its susceptibility to *risk*. Taking Bostrom's image of the body as a paper hut together with Savulescu's focus on pre-natal or pre-implantation genetic profiles – which make the fetus a site of statistical risk – I argue that the risk of refusing transhumanist aims is the risk of disablement. This makes a disabled body the symbol of a feared outcome and a stand-in for death. Instead of seeing disability as a complex interrelationship between the body, social structures, and social norms, disability becomes the outcome of a too-complacent posture toward death and "technophobia." Second, the transhumanist point of view endorses a hierarchy of value and well-being among lives on the basis of capabilities; that is, the *greater the number* of capabilities, the larger the opportunity range, the better the life. Disability theorists, contra transhumanists, have worked to disentangle well-being from capability and argue that while capability is valuable, the lack of a capability should not be assumed to diminish well-being (e.g. Asch 2003, 318, see discussion in chapter two).

Bostrom combines Kant's motto, which exhorts readers to have courage to use intelligence, with Bacon's imperative of mastery, and thereby encourages seeking mastery over the body. The body also appears as an impediment to autonomy, making mastery of the body even more essential (cf. Hauskeller 2012, 43). The division between intellect and body, and the possibility of intellectual release from the body through technology, recalls old hierarchies between body and mind. These hierarchies have served and can still serve as rationales for devaluing persons with disabilities, especially cognitive disability. Relatedly, Bostrom commits transhumanism to an "emphasis on individual liberties," which casts humans in an atomistic light and downplays or devalues human interdependence. Atomistic conceptions of the human are also targets for disability theory, as they tend to devalue the lives of those with disabilities (Bostrom 2005b, 4; recall Wolfe's discussion of the "the fantasies of disembodiment and autonomy"). Transhumanist visions seek to curtail or eliminate dependence and vulnerability rather than embracing these features as shared or as a starting point for ethics.

Transhumanist Utopias

Transhumanism is distinctly utopian—a point I briefly make here before turning to my methodology in this project. Transhumanist calls for the use of science and technology to make life better are appealing, and feed off common fears of death and pain. Transhumanism promises the fulfillment of wishes to avoid both. As aforementioned, Nick Bostrom advocates for the pursuit of posthumanity by way of the following argument:

> [Consider] our current ignorance and the vastness of the as-yet unexplored terrain. Let S_h be the 'space' of possible modes of being that could be instantiated by someone with current human capacities. Let S_p be the space of possible modes of being that could be instantiated by someone with posthuman capacities. In an intuitive sense, S_p is enormously much larger than S_h (2008, 122).

This argument begs the question regarding the desirability of enhancement and one is cornered; bigger is always better and better is always better. Bostrom builds a specific vision of the future by way of contrast, without justifying why his means – intervention upon the body – are the appropriate path to get to that future.[24] He invokes the idea of unknowability of that future when he writes: "You could say that I feel surpassing bliss. But these are words invented to describe human experience. What I feel is as far beyond human feeling as my thoughts are beyond human thought" (3).

Twentieth-century German sociologist Karl Mannheim's treatise on ideology, *Ideology and Utopia*, treats utopian thinking as imperative (demanding action) and notes that it refuses to consider the present on its own terms, instead viewing it through the lens of a desired future. He writes:

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[24] One should be quick to notice that a transhumanist future, and its accompanying transcendence of unhappiness and ills, is often touted as "inevitable" (e.g. Dhanda 2002, xi; Silver 2004, Stock 2002).

> Utopian thinking … [is] so strongly interested in the destruction and transformation of a given condition of society that [these thinkers] unwittingly see only those elements in the situation which tend to negate it…They are not at all concerned with what really exists; rather in their thinking they already seek to change the situation that exists (1991, 36).

Mannheim goes on: "[utopian] thought…can be used only as a direction for action" (36). Elsewhere, Mannheim defines a utopian "state of mind" as a state "incongruous with the state of reality in which it occurs" and "oriented toward objects which do not exist" (173). Finally, he points to the wish fulfillment imbued in utopian thinking: "When the imagination finds no satisfaction in existing reality, it seeks refuge in wishfully constructed places and periods" (184).

Transhumanism is utopian in that it requires action *and* its appeals for social investment often require an exaggeration or misrepresentation of the present and its suffering. Transhumanists suggest enhancement is one way to achieve long-standing goals, like reducing negative environmental impacts, because it has the potential power (if we pursue it) to create human beings who are more sociable (less selfish and more altruistic) in their dealings (Liao *et al*. 2012). Others argue that enhancement is a strong imperative since it can create humans who have greater moral aptitude, which we need to do for fear that we will become extinct (Persson and Savulescu 2010 and 2012, Savulescu 2009). Transhumanist ideals include wide access to technology, in part in order to address frequent concerns that (expensive) enhancement technology will only be available to the lucky few, making entrenched inequality even more permanent (Bostrom 2003b and Fukuyama 2004). Given that wide access to bio-technology is highly unlikely and there are no concrete plans provided for its fulfillment, I argue that this is yet another feature of transhumanist utopian thinking and desire for wish fulfillment.

Transhumanist utopias are Romantic *human* dreams. Especially in Bostrom's work, transhumanists emphasize romantic feelings of happiness, even-temperedness, relief from suffering, and "zest" – all of which are understood as a *result* of choosing one's future. In other words, choice-making unlocks bliss. Bostrom writes of physical and mental changes which will accompany a chosen transhumanist future: "You begin to treasure almost every moment of life; you go about your business with zest; and you feel a deeper warmth and affection for those you love, but you can still be upset and even angry on occasions where upset or anger is truly justified and constructive" (2008, 111). Bostrom also describes increased kindness to animals, better political efforts (more justice), and better ecological support. Finally, also recall that posthuman pleasures embedded in transhumanist futures are most often hyperrealized *human* desires, as in Bostrom's "Why I Want to be a Posthuman When I Grow Up," where he suggests that posthumans will enjoy intensely pleasurable music, friendships, and multi-player games (2008). Bostrom again invokes the unknown, a realm of complete transcendence:

> As we seek to peer farther into posthumanity, our ability to concretely imagine what it might be like trails off. If, aside from extended healthspans, the essence of posthumanity is to be able to have thoughts and experiences that we cannot readily think or experience with our current capacities, then it is not surprising that our ability to imagine what posthuman life might be like is very limited. (2008, 112)
>
> …what you had in your best moment is not close to what I have now – a beckoning scintilla at most. If the distance between base and apex for you is eight kilometers, then to reach my dwellings requires a million light-year ascent. The altitude is outside moon and planets and all the stars your eyes can see. Beyond dreams. Beyond imagination. (2010, 3)

Michael Hauskeller notes that for utopian transhumanists, the body is seen as a constraint, not merely a site, for action. For transhumanists: "[bodies] seem to prevent us from being entirely autonomous" (2012, 43). This, then, is especially true of needy bodies, bodies constructed as dis/abled. I return to the pervasive transhumanist idea of bodily enhancement as a mode of multiplying choice and creating freedom throughout this project, but especially at the end of chapter two in a discussion of genetic counseling.

Examining the utopia of transhumanists is a way to wonder about the good of enhancement and its maximizations and call into question the connection of atomized choice-making with happiness and bliss. Why is more strength, more beauty, more intelligence, or a longer life good for us? In what sense is it better? What can "better", or even "best" mean? Why is freedom (specifically freedom from un-enhanced bodies, as I argue in chapter one) viewed as choice-making, the choice to enhance, the mode of achieving intense happiness? Freedom is actively equated with both power and happiness in transhumanist literature.

John Harris scoffs at these questions, and insists that the answers are self-evident—enhancements are always about making one better, and better is always good. Savulescu assumes simply that "better" at least means more intelligent, as measured by any available cognitive tests (2001b, 414). But to the contrary, I argue that the transhumanist vision of better *relies on what society now values*, and is shaped by deep-seated prejudices concerning what bodies and lives are best. If conceptions of "better" do not question stigma, they will reify it.

I turn now to a description of my strategy in this project and, finally, a brief outline of the chapters to follow.

Methodology

Feminists, in various ways, have theorized the dependency at the heart of human life and subjectivity (see e.g. Martha Fineman, Nancy Fraser, Linda Gordon, Eva Kittay, Martha Nussbaum and Kelly Oliver in Kittay and Feder 2002). Eva Kittay argues that although interdependence is universal, the material conditions of social life disguise the dependence of some and showcase or expose that of others (Kittay 2001, 570, sees also Fineman 2002). Meanwhile, the transhumanist Bostrom is working from the assumption that subjectivity sans dependence or interdependence is normal and preferable, and deviance from that norm is to be avoided.

In consequence, I argue that critique of transhumanist philosophy is important for feminist disability scholarship insofar as transhumanist philosophy has troubling implications for persons with disabilities and women. The affirmation and extension of traditional humanism embedded in transhumanism's vision of the future supports traditional hierarchies between body and mind and among capabilities. Atomized cognitive ability, for example, is considered uniquely important to the good life — especially if it can be relieved of interference from a body vulnerable to injury and death — and the addition of capabilities is linked tightly to increased wellbeing. Philosophers of disability and feminist theorists should work in tandem to critique transhumanism for these assumptions, especially insofar as they become evidence to support investment in research and technology to be used upon bodies (cf. Garland-Thomson 2002, Rohrer 2005, and Wendell 1996). Because of its assumptions regarding the importance of capability in general and cognitive capability in particular, transhumanism seems philosophically at odds with disability rights and the aims and goals of the disabled people's movement.[25] In this project, I draw from the work of Adrienne Asch, a philosopher of disability, feminist philosopher of care Eva Kittay, and Foucauldians Shelley Tremain and Anne Waldschmidt in particular to gain a theoretical foothold in my critique of transhumanism.

Feminist bioethicist Christine Overall distinguishes between preferences and practices. In her feminist work on sex selection, for example, Overall seeks to draw attention away from individual *preferences* for male offspring, which may or may not be sexist (although she argues that such preferences are not "easy to justify" 2012, 232, n. 6) and toward the social *practice* of sex selection — which contributes to sexism in culture (Overall 1987, Ch.2; cf. Callahan 1995, 135-136). In other words, where some bioethicists focus on the morality of individual choices, Overall wants to focus on the politics of stigmatizing practices. In parallel with Overall, I want to refocus attention away from individual preferences against, for example, unwanted traits, which may or may not be ableist (prejudiced against persons with disabilities), and toward social practices involving reproductive technology that can *contribute* to ableism. But this distinction seems faulty, especially given the feedback loop between individual preferences and stigmatizing social practices. How can we focus attention on stigmatizing

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[25] I do not wish to claim, however, that the relationship between transhumanism and the disabled people's movement is a simple matter. Gregor Wolbring, a well-known disabled scholar and activist, for example, identifies as a transhumanist (Wasserman 2012). Indeed, as David Wasserman notes, transhumanist thinkers invoke members of the disability community as representative of the forefront of the potential and promise of new technologies because of their use of assistive technology and prosthetics and the community's acceptance of human bodies in a variety of forms (ibid.). Given the transhumanist goal of adding to or increasing capabilities and its invocation of the disability community as uniquely friendly to or dependent upon technology, controversy surrounding the ethics of radical human enhancement implicates disabled people in a key role. Yet, as Wasserman suggests, the proliferation of enhancement technologies might exacerbate existing prejudices by promoting value hierarchies among capabilities rather than, as Wolbring hopes, by alleviating prejudices through difference (ibid.). For more on Wolbring, see the forthcoming documentary *Fixed*: *The Science/Fiction of Human Enhancement* (www.fixedthemovie.com).

practices and cultural attitudes without morally evaluating the actions of individual agents?

For Foucault, biopolitics focuses on the "species body" and involves the "supervision" of "propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary" (Foucault 1990, 139). Recall Savulescu's concern about the extinction of the species if no recourse is made to enhancement; in this, the action of bio-power is clear. Bio-power seeks to protect the population from biological threats, or what Savulescu calls "existential threats" – the health of society must be defended (Bernasconi 2010, 207-208 and 211). Accordingly, the following examination and evaluation of transhumanist thought, informed by my feminist and critical disability lenses, focuses on a culture of stigmatization of bodily deviance and its expression in bioethics and beyond, not on individual decision-making. My investigation bears out the desire to investigate aggregate social practices and discern stigma where it appears and is fed.

The work of Foucault on biopolitics and normalization inspires and helps shape my project, as in the historical turn in chapter one, and also provides routes for philosophical examination of transhumanism and disability, as in chapter two's discussion of risk management and chapter three's discussion of minority politics. Some uses of reproductive technology, Overall writes, may involve the "presupposition…that we can ensure that only high-quality babies are born, and that 'defective' fetuses can be eliminated before birth. The foetus is treated as a product for which 'quality control' measures are appropriate" (Overall 1993, 58). Foucault's notion of biopolitics is meant to capture and discuss precisely this type of presupposition and the normalizing forces—

which distinguish between normal and abnormal traits and bodies and provide gradation and taxonomies among them—it represents. Foucault helps us identify the question I argue is at the heart of transhumanist philosophy: *the bio-political question of who should live*.

Chapter Outline

To conclude my introduction, I turn now to a brief chapter outline. In chapter one, "From Physical Culture to Genetic Culture: A Genealogy of Gene-ology," I investigate the historical and cultural context of enhancement strategies in the 20th century, which I argue are structurally linked to those of the 21st. At each moment I outline, definitions of health and wellness provide blueprints of bodily deviance, which in turn shape and construct conceptions of disability. I end with a description of genetic determinism, which I argue links the continuous reduction of social and political problems to the body throughout the 20th century with transhumanist points of view today. In chapter two, "Negative Genetic Selection: Enhancing Risk, Enhancing Disability," I take Savulescu's suggestion regarding negative genetic selection as a transhumanist case study, demonstrating its linkage to genetic determinism and stigma wielded against those identified as disabled (i.e. those whose traits lack social acceptance). From my case study I segue into a discussion of the roles risk and disability play in the setting of genetic counseling.

I take a political turn in chapters three and four. In chapter three, "Models of Disability: Medical, Social, Political," I lay out the major models of disability at play in political and bioethical contexts, arguing that disability must be viewed as significantly socially constructed and shaped by stigma. Of available models of disability, I affirm the *cultural model* and its Foucauldian heritage as the most helpful for understanding social constructions and settings of disability. In chapter four, “Reciprocity and Trope: Disability and Liberalism,” I follow through on the insights made possible by the cultural model and argue that a significant *location* of disability is liberal theory. I critique one attempt at an inclusive liberalism, penned by Christie Hartley, which I argue locks into place an endemically asymmetrical relationship between those considered abled and those considered disabled. I compare this attempt unfavorably with the more transformative political views of Kittay, whose non-ideal theorizing allows us to identify and respond to the shared dependency at the heart of the social, and Anita Silvers.

Finally, in the Conclusion, “Transhumanist Utopias in Context,” I reiterate the ground I have covered and my overall insights regarding transhumanism. There, I make special note of the political context of transhumanist utopias and the ways in which this context heightens the importance of my project.

CHAPTER I

FROM PHYSICAL CULTURE TO GENETIC CULTURE: A GENEALOGY OF GENE-OLOGY

> "Long, long ago I became convinced that nearly all the happiness and nearly all the misery of this world comes from the fact that either the right or the wrong people get married."
>
> Albert Wiggam, "Wanted: A 'Eugenics Conscience'" (1934)

In this chapter, I consider the historical setting and influencing factors of today's bioethical debate surrounding human enhancement technologies and their use by conducting a history of enhancement strategies in the 20th century. This cultural and historical genealogy uncovers a continual return to the body as a site for fixing social problems, *biological reductions*, as well as the rootedness of ableism as showcased in the rejection of deviant bodies throughout multiple modes of understanding the healthy individual. The strategies and rhetoric of enhancement upheld and reproduced social and cultural prejudices through time by distinguishing between the sick and the healthy, the acceptable and unacceptable, the good and the bad body. Strategies of enhancement are marginalizing discourses, and in this chapter I expose the shape of three key historical moments of this marginalization: physical culture at the turn of the century, the birth of the field of endocrinology in the 1910s and 1920s, and post-WWII rehabilitations of eugenic thinking in the 1950s and beyond.

Transhumanism today is a pressure point of marginalization, a discourse that shuttles between fantastic plans for the future and dismissive estimations of today and the bodies of today. Transhumanism justifies and supports ableism, oppressing and marginalizing those with targeted bodies deemed “unfit for the future” (Persson and Savulescu 2012). In a continuation of enhancement strategies present throughout the twentieth century, beginning with “physical culture” at the turn of the century (an inheritance from the Victorians), transhumanism operates by reducing questions of social change to a discussion of altering the body and rejecting deviant bodies, biological reduction which is now primarily genetic. I end the chapter, therefore, by outlining genetic determinism, which I argue is endemic to transhumanist thinking and connected in character to the biological reductions performed repeatedly in the 20th century.

The Quest for Enhancement: Anchors in History and Culture

Before I begin my discussion of three historical moments of marginalization due to enhancement strategies, I should note that I here tell an alternative eugenic history. A different approach, which I forgo, is to analyze the impetus toward enhancement technologies through reference to a history of eugenic thought to culminate with the German Nazi regime and Nazi medicine during WWII. Many invaluable scholarly works outline the history of attempts to remake the human body and improve it with direct reference to the eugenic ideology which surfaced in the German Nazi regime—but which, of course, is rooted in much earlier history (e.g. Kevles 1985, Paul 1995, Proctor 1988). Many have shown that continuous and recent attitudes toward the centrality of genetics or the rejection of persons with “marked bodies” are in line with or provided a basis for Nazi ideology (Bauman 1989, Kerr and Shakespeare 2002, Kittay 2010a, Kröner 1999, Snyder and Mitchell 2006, esp. Chapter 2, cf. Mitchell and Snyder 2000, ix).

The rejection of exposed genocidal policies and eugenic practices of the Third Reich in the mid-twentieth-century changed the topography of academia in the United States (Buchanan *et al*. 2000, 37-40). Prior to WWII, North American and European eugenicists cited one another as academic and legislative resources (Snyder and Mitchell 2006, Ch. 3; Buchanan *et al*. 2000, 38). After the war, U.S. scientists and theorists did everything they could to distance themselves from the discredited eugenic label (Buchanan *et al*. 2000, 39). This widespread, post-war period rejection led to the eventual transformation of journals and societies previously explicitly dedicated to aspects of eugenics (39).

Bioethicists today note the "shadow" of eugenics, originating with the Nazi regime, over conversations regarding enhancement technologies and ask whether this is "new" or "old" eugenics (e.g. Buchanan *et al*. 2000, Ch. 2; Crook 2008, Sparrow 2011). This leads these philosophers wonder in what sense eugenic policies *themselves*, apart from Nazi medicine, are morally wrong. Buchanan *et al.* argue that the individual policies themselves must be drawn out and discussed without reference to the loaded eugenic label in order to allow history to guide the future (2000, 9-10). One point of consensus among Buchanan *et al.* is the idea that some eugenic goals—for instance, better health for the population—become morally wrong when mixed with state coercion, but may not otherwise be wrong (cf. Buchanan *et al*. 2000, 12-13; see also Sparrow's analysis and critique of this argument, 2011). It is also argued that eugenic goals become morally wrong if they are mixed with racist ideology and false biologically-based race theories or other pseudo-sciences, but may not otherwise be wrong (Buchanan *et al*. 2000, 27, 40-41). Buchanan *et al*. also argue that genetic determinism is perhaps the decisive element of the "shadow" of eugenics, a claim I pick up on here and deepen by way of my alternative history (2000, 23-25).

Instead of pursuing a direct critique of Nazi medicine, which is done excellently elsewhere, I trace the roots of genetic determinism and follow the example of disability theorists Sharon Snyder and David Mitchell who argue that Nazi ideology is *continuous* with modernism rather than "an aberration" and also that "all bodies"—"not merely disabled bodies"—are affected by the notion that excessive hardship and deviance are embedded in embodiment itself (2006, 5). Zygmunt Bauman, likewise, sees Nazi eugenics as a continuation rather than an aberration of modernist projects (1989). An important part of these modernist projects, which I argue is still manifest today in transhumanism, is the "[promise] to rid the land of all defectives" (Snyder and Mitchell 2006, 79). As Snyder and Mitchell put it, this promise is tied up in a "uniquely modern utopian fantasy of a future world uncontaminated by defective bodies" (129). I take this fantasy as *the* transhumanist fantasy, guiding in today's enhancement discussions. I already touched on this desire in the introduction, and continue to explore this fantasy in the following chapters.

In what follows, then, I prioritize describing and exploring sometimes-neglected aspects of eugenic history. These include: 1) lasting commitments to a particular kind of discipline and transcendence of the body, 2) the equation of physical and mental health, both of individuals and populations, with morality, happiness and sociability, and 3) continuous reference to and reconstruction of what counts as a deviant body. The alternative eugenic history I draw should act as layering scenes of biological reductionism, which is deeply connected to transhumanism and genetic determinism. The structure of genetic determinism – as well as its exclusions (its ableism) – is revealed in these historical moments, although the content and meaning of the reduction to the biological has shifted and built up across time. To begin, I go to "physical culture" to reveal what, at that time, fell under the as-yet untarnished banner of "eugenics."

Physical Culture, Discipline, and Healthy Choices

In 1913, the "Life Extension Institute" was founded in the United States ("National Society to Conserve Life" 1913; William H. Taft was the chairman of the board). The scientific work of Irving Fisher and Eugene Fisk undergirded its goals and philosophy, which aimed at prolonging human life.[26] In hopes of accomplishing this aim, the Institute focused upon the elimination of disease and the sterilization of those considered unfit. Irving and Fisk co-authored the group's major tract: *How to Live: Rules for Healthful Living Based on Modern Science* (1916). The book presented a combination of recommendations regarding diet, exercise (including deep breathing) and hygiene. It recommended "thorough mastication" (Chapter 2, Section 4) and good posture (Chapter 3, "Poisons", Sec 2). More telling and less benign was its directives regarding marriage and reproduction, essay "Comparison of Degenerative Tendencies Among Nations" (286-292) and a concluding section on "Eugenics" which recommended both forced

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[26] This of course remains a primary goal of promoters of enhancement today; see Bostrom 2005a; 2008, 113-116; Harris 2004, Heard 1997, Shostak 2002, and see Baudrillard 2001 and Glannon 2008 for critiques.

sterilization (cf. 167, 323) and the works of Sir Francis Galton. Galton is considered the founder of eugenics and, in 1869, expressed for perhaps the first time the idea of parental duty with regard to heritable traits (293-324; Buchanan *et al*. 2000, 30-31; Snyder and Mitchell 2006, 25, I return to this in my case study in the next chapter).

According to the text written by Fisher and Fisk, morality and immorality are inheritable and dependent upon "family lines" (1916, 298):

> Moral Traits.—Among the moral traits known to possess inheritable elements are generosity, piousness, independence, industry, will-power, faithfulness, fairness, sociability, reliability, self-reliance, tendency to work hard, perseverance, carefulness, impulsiveness, temperance, high-spiritedness, joviality, benignity, quietness, cheerfulness, hospitality, sympathy, humorousness, love of fun, neighborliness, love of frontier life, love of travel and of adventure. The same may be said of immoral traits, such as criminality, pauperism, delinquency, irascibility, lying, truancy, superstition, clannishness, secretiveness, despondency, slyness, exclusiveness, vanity, cunning, cruelty, quickness to anger, revengefulness, etc (298).

While Fisher and Fisk's text elsewhere clearly outlines and prioritizes a set of recommendations connected to personal habits, it does not ultimately conclude that physical health and morality can be left up merely to individual behavior; instead, as this excerpt shows, such things were thought to be inheritable and therefore a "thoroughgoing eugenic program" was needed and must be used for "society as a whole" (1916, 167). Besides outright sterilization, strategies to achieve this general program involve the segregation of persons considered defective and—in addition to "wise marriage laws"—the "development of an enlightened sentiment against improper marriages" (167). Notice, just as in the case of today's enhancement advocates, transhumanists, happiness ("high-spiritedness"; recall the "zest" of which Bostrom spoke, above) and even use-value ("industry") are taken to be a biological matter which could be increased by (then proto-) genetic choice-making.

So, at the turn of the century, health and morality was linked to reproduction and segregation on the level of the population as well as the discipline of the body through hygiene and diet on the level of the individual. Prolonged life is considered an utmost goal, one that would surely improve human beings and the social world. Marriage is brought under scrutiny as part of this multi-faceted focus, and the implication is that "bad" marriages (to people with the wrong sort of biological inheritance) will result in a bad society.[27] The frontispiece Fisher and Fisk's volume reads: "Prevent Life-Waste—Upbuild National Vitality" (1916). This is the first indication in my genealogy that the health of a population is dependent upon eliminating the influence of "sick" members (Life-Waste)—and so enhancement strategies must be "chosen" for everyone. This feature of enhancement strategies is a touchstone in the pages that follow.

Today, as discussed in the Introduction, morality is still considered heritable and manipulable through science and technology; the latest writings from bioethicists who are strongly pro-enhancement include calls to improve human beings morally and socially through scientific and technological means (e.g. Buchanan 2011a and 2011b, Liao *et al*. 2012, Persson and Savulescu 2011, 2012). For example, Savulescu argues that bad

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[27] For a propaganda film of this time period regarding appropriate marriage, see *Are You Fit to Marry?* (1927), first released as *The Black Stork* in 1917 (a silent film). In it, eugenicist and medical doctor Harry Haiselden played himself as part of a personal campaign. He claimed that he and many others let "impaired" infants die, although this was unspoken, and that, as journalist Laurie Block put it, "the burdens of the disabled should not be imposed on the physically and mentally able" (Block 1996). The film opens with Haiselden viewing a child on crutches from a window, and then dialogue appears: "It's not the fault of the child, but someone is to blame." *Black Stork* follows a couple, who are told by Haiselden that any child resulting from their union would be "defective." The couple ignores Haiselden and their eventual baby is depicted as thin and sick. The mother considers what to do. She dreams that the child, grown up and disfigured (with a hunchback), is a criminal and a miserable person. He shoots the doctor who failed to kill him at infancy. Upon waking, the mother decides to end the child's life and the film ends with the infant's death. According to Haiselden: It is the will of God that this baby be born a defective, and without the meddling of surgery, it is the will of God that the child die" (Block 1996). Besides the clear eugenics theme of troubled heredity, notice the illicit connection (and reduction) of crutches, criminality, and personality to heredity. While there is no explicit racial narrative in the film, the title suggests creeping worries about race-mixing.

tempers should be curbed through genetic selection, and S. Matthew Liao *et al*. argue that increased altruism is a valuable goal of scientific and technological human enhancement (2001b and 2012, respectively). Allen Buchanan argues for enhancement of the capacity for impulse control and sympathy, among other valued social traits, and Nick Bostrom argues that it is important to enhance human capability with regard to "appropriate affect," among other things (Buchanan 2011 and Bostrom 2008, 108).

Against the backdrop of the focus on inheritability and social and personal hygiene exemplified by the aims and status of the Life Extension Institute, so-called "physical culture" flourished at the turn of the century in the United States and in Europe (Fair 2012). Physical culture explicitly linked physical health and discipline with responsibility and moral goodness, and delineated and denigrated a group of dangerous outsiders which must be dealt with: the sick and the weak. A popular magazine entitled *Physical Culture*, founded in 1899, enjoyed a print run lasting through the 1940s (Bennett 2012). The magazine, which (in line with the Life Extension Institute's recommendations) promoted diet, exercise, sunlight, and cleanliness as routes to a happy life, declared: "every influence which interferes with the attainment of superb, buoyant health should be recognized as menace" (1934, 63). In other words, one must protect one's health from continuous outside threat, especially those contained within other bodies.

Physical Culture magazine was probably inspired by a similar earlier publication in Britain produced by Eugen Sandow, a Prussian bodybuilder present at the World's Columbia Exposition in Chicago in 1893. Theodore Roosevelt (U.S. President from 1901-1909) also influenced the "physical culture movement" of which Sandow was a symbol through advocacy of the "strenuous life" and its power over his own childhood sickness (Fair 2012).

But physical culture was not merely about body-building and the wonders of strenuous exercise for overcoming disease. Albert Wiggam, a frequent contributor to *Physical Culture* magazine, declared a new standard for choosing a marriage partner, and partner reproducer, derived from the knowledge of biologists. In an article entitled "Wanted: A Eugenics Conscience," he writes:

> [The biologist] means not only that the parents shall be healthy, happy and congenial, but that they shall be carrying healthy, happy and congenial germ-cells from their ancestors and, thus, be capable of transmitting healthy, happy and congenial bodies and minds to their children (Wiggam 1934, 16).

The wrong partner can be a "menace" to the "attainment of superb, buoyant health" and so too can one's parents; one might lose all chance at happiness if the wrong match (genetic choice) is made. In contrast, a physically healthy parent was viewed as maximally important; so writes Mrs. Earl Wood, from Detroit, Michigan: "When I was born into this world, my mother had bestowed upon me one of the greatest gifts of life—perfect health" (1934, 6). Mrs. Wood must mean what Doctor X, later in the issue, calls "an *intelligence of the physique*" which would have "won laurels and plaudits" in a "simpler, more heroic society" such as ancient Greece (15). But notice that this "intelligence of the physique" is not merely a set of physical attributes, but also attributes of mind, mood and attitude: "healthy, happy and congenial bodies and minds," according to Wiggam. So we see, again, that happiness, health, and therefore social congeniality is heritable and impacted by proto-genetic choice-making—and also depends later upon choosing physical exercise, diets, and vitamins.

In the same issue, a father writing about the experience of his son's birth feels anxiety with regard to passing along his own traits and claims for himself deep parental responsibility. He writes of the events of his son's birth: "'There's a defect here!' The doctor cried sharply to the midwife. 'Defective heart action.' That was like a dagger of remorse to me for I thought I had done the unpardonable—transmitted my own bad heart to my son" (12). The mention of unpardonable action is no accident—bad health was truly considered a crime. In an oft-repeated motto printed on the front cover of the June 1947 issue of *Physical Culture*, this attitude is declared: "Sickness is a sin: Don't be a sinner" and "Weakness is a crime: Don't be a criminal." The sick and the weak, then, constituted a population of undesirables who were both sinful and criminal, threatening the health of all with their bad choices.

In fact, Bernarr Macfadden,[28] who founded the magazine, wrote the above motto, and authored dozens of books about physical culture, figured the relationship between abnormality and criminality as running both ways. He claimed that criminals "are all abnormal—there are but few exceptions" (Macfadden 1934, 4). This violent pairing is not unfamiliar to anyone versed in racist and ableist eugenic ideology (cf. Mitchell and Snyder 2006, esp. Ch. 3). He went on to write: "If we owned a cat or a dog, or any domestic animal, that was deformed and misshapen as is the average 'human,' it would not be considered worth keeping and death would end its earthly pilgrimage" (1934, 4). Macfadden, by referring to the subjection of the animal in this passage, believes he is making an argument for the subjection of the sick and the weak. Because he is advocating death for this population, he is moving to not only insulate and protect the strong from

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[28] Cf. Adams 2009 and Ernst 1991 on the life of Bernarr Macfadden and his influence on American physical culture.

criminal elements but also declaring that life is not worth living for the sick and the weak. He asks and answers the question: who should live?

In another article in *Physical Culture*, the aforementioned Wiggam again calls for a "eugenics conscience", this time a bit more directly. Here, he asks, in line with Macfadden's suggestions: "Shall We Breed or Sterilize Defectives?" (1934, 16). Who should live? Wiggam calls upon the authority of Charles Davenport[29] of the Carnegie Institution in order to argue that "migrating families" of "gypsies" ought to be sterilized so that valuable social resources could be saved—enhancement for the whole population (16-17). He is aghast that some object to the method of sterilization in response to those populations and individuals he considers undesirable and writes:

> If such persons [who would object to sterilization] would turn and consider the money expended on these worthless breeds, which ought to be used and could be used to educate and furnish jobs for their own children it would seem that this alone would answer all their objections. If they further would consider the moral corruption in addition to the havoc wrought by the spread of disease that I have myself witnessed many times in a community brought about by the sex-looseness of some good-looking feebleminded or moron girl, again it would seem this would answer their objections (17).[30]

In this excerpt, cost and benefit analyses are plainly layered upon pronouncements regarding the immorality or a-morality of deviant bodies and populations. Today, similarly, the feasibility and desirability of incurring medical costs of caring for persons with disabilities is laid open for debate; this is, however, often placed in a context of health-care rationing.[31] Savulescu considers this question with regard to cardiac care and

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[29] For a group of insightful essays on the work and legacy of American eugenicist Charles Davenport, see *Davenport's Dream: 21st Century Reflections on Heredity and Eugenics* (Witkowski and Inglis 2008).

[30] For an excellent treatment of the hyper-sexualization of the female disabled body as irresponsible and fertile, see Snyder and Mitchell 2006, 86.

[31] For a philosophical argument which argues for the necessity of medical rationing see Fleck 2009.

persons with Down syndrome, concluding that triage is necessary because resources are limited and therefore equality of access is not as attractive as it might seem (2001c). In general, the re-direction of medical resources from atypical bodies remains at issue today; persons with a-typical bodies or minds experience more difficulty accessing medical resources (for an example, see Chandler *et al*. 2006, I discuss this issue at length in chapter two).

To return to Wiggam's argument, while Wiggam brings himself to note that not all the "feeble-minded and moron people" he has in mind are "necessarily bad", he quickly establishes that, if nothing else, "they are *all irresponsible people*."[32] The linkage of personal irresponsibility—that is, *bad choice-making*—with the sick and the weak, along with the rehabilitation on the level of the population of an underlying "defective" genotype which must be destroyed, is repeated in earnest in founding, theological-bioethical texts of the 1970s (Passmore 1970, Ramsey 1970).

Irresponsible people were evidently, besides criminals, also those who use prosthetic devices—"crutches"—or are in other ways dependent. One advertisement admonished readers that "Eye-glasses Never Mar the Faces of Beauty Contest Winners" and reminded them, in skewed fonts, that "Glasses are only Eye-Crutches—anyway." A coupon is offered so that (especially women) can "throw the glasses away" (1934, 8). The secret was training exercises for the eyes, which should be taken up in order to avoid dependence on a "crutch."

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[32] For contemporary treatment of the frequent conflation between being disabled and irresponsibility (specifically with regard to labor), see Frank 2000, 71. See also Nancy Fraser and Linda Gordon's genealogical investigation of "dependency" in the United States and its nuances with regard to debates over the provision of welfare (1994).

So, while much was blamed on heritability, it was believed that exercise and vitamins were always restorative health measures and should be pursued under banner of independence. For example, the aforementioned father who worried over transmitting a "bad heart" to his newborn child, reportedly watched as the doctor "began swinging the baby up and down like a calisthenics drill," a procedure which, combined with "smack[ing] him brutally" and dips in hot and cold water eventually produced a "heart-gladdening little wail!" (1934, 13). Indeed, such calisthenics and discomfort were meant to be extended to infants and were considered extremely important at such a formative time; Macfadden published, with Marguerite Macfadden, a text entitled: *Physical culture for babies* (1904). Returning to the particular child in question, the rest of his life (according to his father) was a struggle between the food of Old Europe introduced by the child's mother and the vitamins the father knew he needed. Notice the tight linkage here between women and unhealthy heredity, and the father with rational and healthy choice-making. Any difficulties, however, were soon remedied by a return to the US from abroad and a practice of pressing his legs together and holding him upside down "by his heels" (13, 82). These rough calisthenics were enough to soothe the inherited "defective heart."

In another example of "choosing health," vitamins were suggested as an ameliorative tool to persons who were deaf in the April 1940 issue of *Physical Culture* magazine. Emanuel Josephson, M.D. argues, in "New Hope for the Deaf" that "one of the best methods of increasing the body's resistance to ear infections and of restoring hearing to a high and efficient level is by means of a vitamin-rich diet" (10). And, in a move familiar from today's "super-crip" stories of inspirational physical achievement (cf. Clare

1999, 2-9 and the treatment of Diane DeVries in Frank 2000), choosing exercise is recommended for infantile paralysis by the notable example of a beautiful young girl: "stricken with infantile paralysis at the age of eight, Nancy Merki is today the proud holder of three national swimming records, and one world's championship. Here is the inspiring story of a courageous youngster who literally swam her way from invalidism to buoyant health and world fame" (14). Discipline, then, *is* transcendence – the transcendence and overcoming of the pains of embodiment. In this peculiar moment, to have a disability meant that one wasn't taking one's vitamins—one hadn't chosen health.[33]

Throughout the turn of the century and the rise of physical culture, alongside a growing knowledge and attention paid to a proto-genetics, choosing vitamins and exercise played a prominent role in the public imagination with regard to health from the turn of the twentieth century. Sickness and weakness, as sin and as crime, could be blamed on an "irresponsible" parent who passes on inferior (read: dis-abled, raced, classed, sexed) traits, *and* someone who has not demonstrated the get-up-and-go necessary to overcome physical or mental difference or who refuses to avail themselves of the maximizing benefits of vitamins and sunlight. A variety of traits, both individual and social, were reduced to facts about the body. One could choose the correct marriage partner, thereby ensuring future happiness, and choose to enhance one's body through

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[33] *Physical Culture* magazine was not the first or last publication of its kind; in 1940, a magazine entitled *Your Physique* was launched by a young Joseph Weider, who is now referred to as the "father of bodybuilding" and is owner of a business empire based on physical fitness (Perine 2011). And the continuation of physical culture is, of course, not the only indication that we live in a culture obsessed with the biological and the look and powers of the body—consider the availability and pressure to use increasingly subtle plastic surgery and topical remedies meant to erase the look of age.

vitamins and exercise, thereby ensuring ability against the threat of disability and gaining access to a future of "buoyant health and world fame."

The features of physical culture are continued in today's enhancement debate, especially among transhumanist advocates of extreme enhancement. The valorization of certain bodies and circumstances is based in and justifies the rejection of other bodies; after all, one must protect one's health against the menace others pose, especially if that menace is an entire community who refuses to make rational choices (e.g. Wiggam's reaction to the Roma). Shared society in one's community and in one's home has become a shared gene pool, today, and we are warned that the danger is more insidious than ever—we cannot tolerate deviance, or we might go extinct (Savulescu 2009). Enhancement for one requires enhancement for everyone. I turn now to a second historical moment, another strategy of enhancement and separation of the deviant from the healthy.

The Birth of Endocrinology

This second historical moment of health and deviance is layered upon and deepens the first, the physical culture movement and its fetishism of appropriate marriages (especially to the right women), diet, and exercise. Here, we still have a reduction to the biological, but there is a renewed sense of the biological. This second moment is the birth and acceptance of the field of endocrinology and the entrance of a new conception of the human being as *hormonal*. For medical culture researchers David and Sheila Rothman, contemporary issues surrounding enhancement originate and are “embraced” (chosen) “from below,” (by individuals) (2003, xvii; a fact which they believe establishes the unhelpfulness of pursuing conversation regarding coercive eugenics in a Germany past). Rothman and Rothman trace a history of eugenics from below, beginning with the field of endocrinology.

Endocrinology gained traction as an established field in the 1910s and 20s (Rothman and Rothman 2003, 13). Because of their importance within the venture-capitalist context of medicine at the time, new ventures in endocrinology, along with the promise of waging war against aging and infertility, created a situation in which hormones and endocrinology played a role now filled by genes and genetics (13). Hormones seemed to replace the vitamins and sunlight of the *Physical Culture* days and presaged the primacy of the role of genes in today’s medical climate. The discovery and exploration of the activity of hormones meant that “nature was elevated over nurture”—another biological reduction (14). Reinforcing and reconstructing the category of the criminally weak and sinfully malnourished of physical culture, in this second moment “freaks” became “patients with glandular irregularities who required medical care” (18).

Meanwhile, there again appeared the notion of suppression and transcendence of the influence of freakish hormonal outsiders, who, if they were not eliminated or somehow enhanced, threatened the progress of all. Enhancement for individuals required the enhancement of all. In other words, there was a desire to move beyond the existence of short freaks (today’s enhancement conversation is still rife with concern regarding achieving height) and some began to envision a world without defectively hormonal bodies. Writes Herbert George Wells in 1926:

> A time will come when littleness will have passed altogether out of the world of man. When giants shall go freely about this earth—their earth—doing continually

> greater and more splendid things. But that – is to come. We are not even the first generation of that – we are the first experiment (21).

In Wells' thinking, the conceptual structure echoes the reaction of Wiggam to "gypsies" – defectives, outside the freshened and bolstered notion of the normal body, are unwelcome in a world where the norm can flourish. The defective is seen to clamp down upon and preclude the potential of the norm. This is deviance redux, an ever-present and updated notion of who fails to earn a place in the world and who should be pushed out of it. Again, we have a menace.

The drive of endocrinology to isolate masculine and feminine "principles" and use these essences to stave off the unwanted effects of aging and remedy fertility issues was supported by profit-seeking pharmaceutical companies (Rothman and Rothman 2003, Ch. 2 and 6). Companies like Eli Lilly, working closely in fateful collaboration with university researchers from institutions like the University of Toronto and Johns Hopkins (and slaughterhouses, from whence they procured animal corpses for use in their research), hawked largely untried and unproven remedies among physicians (2003, 13, 32-34, 47). This was the venture capitalism of endocrinology. Physicians reported high levels of confidence in the pharmaceutical employees who visited them with new products, and these "detail men" cynically produced guidance pamphlets with instructions on socializing with medical professionals for profit (47). New institutional collaborations had major effects upon the diagnosis, treatment, and experience of patients. Diagnoses related to hormonal "deficiencies" abounded. New and updated versions of sickness became influential; for example, "shortness of stature" became a diagnosis and "the very short child" was suddenly seen by the medical establishment as "a sick child" (Rothman and Rothman 2003, 173-174). Rothman and Rothman relate this to contemporary questions in bioethics regarding the line between cure and enhancement, worrying that new technologies define new disease states in the place of what was once considered normal (174).

Physicians prescribed what became known as testosterone and estrogen to their patients, using negative techniques to determine the usefulness or necessity of the prescriptions. If the patient—having received these remedies—experienced improvement vis-à-vis their complaints, the patient had a deficiency of testosterone or estrogen (Rothman and Rothman 2003, 31). These patient-reported improvements justified the use of the treatment plan. The same strategy of diagnosis-by-trial was later used in the case of the development of human growth hormone (HGH) (180-181). Faced with the rhetoric of potential deficiency and the promise of a better life, patients were desperate for access to the drugs. This rhetoric is in parallel to the utopia of the transhumanist – who can say no to increased happiness?

In this moment, hormone deficiency became the scapegoat for all manner of ills – including, most importantly, perceived issues in growth, puberty, fertility, and aging. In the case of growth and puberty, speed was desired; in the case of fertility, enhancement; and in the case of aging, deceleration. Hormonal influence received a cathexis of hope with regard to staving off age and maintaining health. Here we see that definitions of deviance and health are continually updated, shifting shape and "deepening" within the body over time.

I turn now toward a third moment, the post-WWII attempt at rehabilitating eugenic ideas and the construction of a specifically genetic version of normality and abnormality. This moment is a significant element of my argument because, as throughout the 20th century, it takes for granted that the body is an appropriate location for intervention in order to alleviate some social ills—it performs yet another version of a biological reduction. Additionally, as we shall see, it is a direct pre-history of today's transhumanist thinking (this moment includes the first definition of transhumanism) and indulges in the genetic visions that remain fundamentally powerful today.

Post-War Rehabilitation of Eugenic Ideals

After WWII and the denounced Nazi regime's focus on eugenics, philosophical and social-scientific moves were made to rehabilitate eugenics from its bad reputation. Julian Huxley, for example, denied that eugenics must fall to Nazi ills.[34] Leon Kass, bioethicist and prominent member of George W. Bush's presidential bioethics council, has given Aldous Huxley's dystopian novel *A Brave New World* continual attention in his writings (strangely excluding, however, *After Many a Summer Dies the Swan*, which deals with an aging man's push for immortality) (2002). Yet, perhaps not many are aware that Huxley's brother, Julian, was also a writer and a social philosopher. A number of his essays, collected under the title *Man in the Modern World*, showcased scientific knowledge gained as a biologist and a desire to affect public policy to improve modern life (1948).

In fact, it was Huxley who first coined the word "transhumanism" *prior* to the war (in 1927) and continued to be its advocate later. His definition relied on the idea that transcendence of typical human bounds was important–and such transcendence could and

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[34] Recall, from above, that separating eugenic policies from the negative shadow of the Nazi regime is still a strategy for bioethicists in the 21st century (Buchanan *et al*. 2000, 9-10, 12-13, 40-41).

should be achieved by members of the human species themselves (Huxley 1927, 195; cf. Hauskeller 2012, 39). For Huxley, then, transhumanism was about access to as-yet untouched possibilities (Hauskeller 2012, 39).

Julian Huxley strove to conceptually position the human being over and against animals in an initial essay entitled "The Uniqueness of Man." This uniqueness was exactly what, for Huxley, made eugenics possible and appropriate: "Man has the possibility of making [progress] the main feature of his own future evolution, and of guiding its course in relation to a deliberate aim" (1948, 28). Recall that this is also the argument of today's transhumanists Nick Bostrom and Anders Sandberg. Further, said Huxley,

> [Man] must not be afraid of his own uniqueness…so far as our knowledge goes, human mind and personality are unique and constitute the highest product yet achieved by the cosmos. Let us not put off our responsibilities onto the shoulders of mythical gods or philosophical absolutes… (1948, 28)

So, for Huxley, evolutionary progress can be taken up as a tool, and should be taken up as a responsibility to the species. For him, superstitions regarding the importance of ceding to outside controls (playing God) should be put aside.

In another essay, "Eugenics and Society," Huxley ventures the following regarding the obligation to eugenics:

> Once the full implications of evolutionary biology are grasped, eugenics will inevitably become part of the religion of the future, or of whatever complex of sentiments may in the future take the place of organized religion. It is not merely a sane outlet for human altruism, but is of all outlets for altruism that which is most comprehensive and of the longest range. (1948, 28)

But, for Huxley, obstacles to the efficiency of eugenics must first be overcome if the eugenic ideal as future religion is to be realized (28). This meant that eugenics must be improved as a social science in order to improve its reputation (29). Along with an increasingly *careful* study of inheritability (better genetics), eugenics must "use the results of this study for control" (32). He denounced Nazi Germany as precisely anti-eugenic because of its nationalism, which would subvert social eugenic goals by leading to "over-population and war" (55). Huxley believed that eugenicists must understand the social system and also must transform it at the risk of otherwise failing in scientific eugenic goals in the same way (33, 54, and 61). In all, this essay represents an attempt to liberate eugenics from its bad reputation and from various biases, and align it with a renewed social outlook (33). This is of key importance for the future due to Huxley's belief that there is an "inherent tendency" of the gene pool to degrade over time, an idea, as we have seen, later accepted by Ramsey (61). In other words, for individual enhancement, all must be enhanced; menaces must be destroyed from within if humans are to face menaces from without.

Generally, the importance of genetics alone, argued Huxley, should not be over *or* under-stated (41). As a factor, it was for him embedded among others. For example, although Huxley pushed for accessible birth-control facilities and "family allowances, providing for sterilization here and financial relief for children there" (54), he also argued that environmental conditions like vitamins and food have greater impact than normally believed and that researches into twins prove that genetics was only one factor among many that should be controlled (37-38). He also explicitly denied the "genetic or eugenic significance of" "so-called racial traits" (39). Yet, he seems to mean merely that their significance has not *yet* been (eugenically) scientifically established. For example, he still believed it "wholly probable that true Negroes have a slightly lower average intelligence than the whites or yellows" (41). Recall also his call for better genetics in order to avoid past mistakes in eugenic thinking.

Ultimately, despite his insistence on dethroning genetic factors, Huxley wanted to develop both social and genetic eugenic "patterns" that would improve the human being as a species. These could hold in "economic and communal life" and also "family and reproductive life" if group incentives were sought to make these patterns viable (55). Incentives could make it plausible for the individual to subordinate herself to the group (57). Enhancement for her means enhancement for everyone (57). Huxley argued that birth control, by splitting reproductive and sexual functions, could help with this removal of individualism (58-59).

The major elements of this post-WWII rehabilitation are still present, virtually unchanged, in bio-ethical conversation regarding the permissibility of human enhancement. Huxley felt the need to place the human uniquely within and among the evolution of species before arguing for the enhancement of human beings; today, we see that—for *both* proponents and opponents—the uniqueness of human nature (its inventiveness or its dignity, respectively) must still be insisted upon (e.g. Engelhardt 1990, Habermas 2003, Fukuyama 2002, Kass 2002, Sandel 2004, Harris 2007, 2005b). This helps explain ubiquitous focus on threats to human nature from technology (e.g. Baille and Casey 2005, Buchanan *et al*. 2000, 86-103; Kevles 2004, Pinker 2004, Winner 2003, 2005).

Also, for Huxley, it was important to set aside individualism through medical, scientific, or other means in order to seek the greater good of the species. Today, we see these same arguments echoed in the work of S. Matthew Liao *et al*. (2012), who argue that one solution to the plaguing issue of environmental degeneration is to look to the physical body of the human being and make changes in our physiology which might allow us to make good environmental decisions. Specifically, new reproductive technologies combined with other medical strategies could be used to attempt to make human bodies smaller. Again, the body is a site for solving social problems. But—and here the parallel with Huxley becomes clearer—another option that Liao *et al*. advocate is attempting to select for traits known to contribute to altruism. Individuals who have been selected in this way could be counted on to set individualism aside more easily.

Most generally, each of the moments I have discussed so far in this chapter – the milieu of physical culture, the birth of the field of endocrinology, and post-war rehabilitation of eugenic strategies – is structurally linked with today's genetic visions of the human being. First, each moment showcases a reduction to the biological. Second, each moment defines what is desirable at least partly by what the desirable is not—the rejected body lurks in the background, snarling a threat to individuals and the social order. Finally, a utopian promise of a better life through physical interventions is made in each moment. One can grasp happiness, be more moral, be more responsible, be taller, be more intelligent, enjoy fertility, and enjoy one's children if only one exercises, takes vitamins, accepts a hormone supplement, or makes the right choice of marriage partner and child. A better, more moral, more beautiful and blissful life awaits you – and if you fail to choose this future, you do not deserve to enjoy it. Choosing to adjust one's body is positioned as key to happiness and control over one's future.

Further, enhancement strategies and transhumanism seems to depend on the elimination of difference—written as deviance—from the human community. Unless the deviant other is eliminated or enhanced, individual enhancement is under threat. The transhumanist enhancer believes that there is a right to happiness (bliss), and that unless an entire *community* of enhanced persons (normal, abled persons) exists my enjoyment of this state will be stymied. One's individual happiness and freedom will be blocked by the Roma (Wiggam), the short (Wells), or the deviant public who know nothing of the laws of inheritance and lack birth control (Huxley, the first transhumanist). This is a perverse reversal of the feminist claim regarding the relationality of persons; I can't be excellent unless everyone is.[35]

I now turn to my concluding discussion of genetic determinism, the most recent variety of biological reduction, and its connection to enhancement and transhumanism.

Genetic Visions

The rhetorical movement from deviance to enhancement can be more deeply understood by exposing belief in genetic determinism as a variety of the biological reductions that structure enhancement debates throughout the 20th century and into the 21st. There is much recent critical research into the common vision of the human being as a thing with a genetic core and a genetic telos (Buchanan *et al*. 2000, 85; Brock 1992, Klitzman 2012, Nelkin and Lindee 1995, Siever 1997). Evelyn Fox Keller is the author of an exceptional philosophical history of what she calls the genetic century – the twentieth – and goes on to suggest that such an era should and will be superseded by other constructs (2000, cf. McNally and Glasner 2007). She argues that attention-grabbing

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[35] Many thanks to Lisa Guenther for inspiring this important line of discussion.

success in genetic research in the 20th century actually demonstrate that the gene is not the primary unit of heredity; yet oversimplifications abound, especially because they are practical for researchers in attracting money and attention (Radick 2001). For her, understanding units within a system (the gene) is clearly less valuable than tracing the dynamism of a system (the organism) itself; in future we will need better vocabulary to describe the movement of biological heredity. But, as Keller realizes, the mid-century discovery of the structure of the double-helix, paired with the interpretation of the gene as a set of specific instructions (the gene's "central dogma"), still has for now, unabated influence over the conversation regarding human enhancement, along with discussion regarding individual traits.

I take for granted that the genetic vision of the human being is firmly entrenched, especially as a result of the Human Genome Project and the international scientific community's continued work under that banner. Popular opinion considers genotype the directive fundamental core of the human being, and so, if we want to improve the human condition, genotype is a good place to begin. James Watson, Nobel Prize winner and part of the research team which first modeled DNA in 1953, is vocally in favor of utilizing genetic research in the hopes of transformation of social life, bodies, and minds. Watson advocates screening strategies and an updated version of eugenics. In 1998 he infamously remarked:

> I think it's complete nonsense…saying we're sacred and should not be changed…Evolution can be just damn cruel, and to say we've got a perfect genome and there's some sanctity? I'd like to know where that idea comes from because it's utter silliness…To try to give it any more meaning than it deserves in some quasi-mystical way is for Steven Spielberg or somebody like that. It's just plain aura, up in the sky -- I mean, it's crap (Brave 2003).

Notably, Watson's critique of a supposedly perfect genome is shared in the reflections of disability scholars also critiquing genetic determinism (e.g. Scully 2008, discussed below). But there is a different route available from this shared critique; an alternative to the conclusion that genetics should be transformed via eugenics and that the supposedly perfect and therefore sacred genome should be debased by intervention in order to end suffering. Watson's conclusion shores up the importance of the genotype in daily life by offering it as the site for interventions. Instead, one could conclude that the importance of deviance from genotype is overstated, and suggest other shared projects of "enhancement."

Most importantly for this discussion, significant genetic variations, most often simply referred to as defects, are today thought to constitute a wrongful birth or wrongful life (Buchanan *et al*. 2000, Roberts 2009, Rogers 1991, Savulescu 2008, Shiffrin 1999, cf. Ramsey 1970). At the very least, a-typical genetic structure is thought to trouble the decision to conceive or to continue with an existing pregnancy (cf. Parens and Asch 2000).).

Many bioethicists who are currently involved in the debate regarding enhancement and its ethical permissibility accept as a fundamental premise the idea that the avoidance of disabilities or diseases through genetic means is acceptable and desirable. Indeed, at the extreme, they also argue that it is immoral to fail to avoid disability or diseases (Boyle and Savulescu 2003, Buchanan *et al*. 2000, e.g. 100-101; Savulescu 2001b and 2008, Rogers 1999). In fact, as I will argue in the next chapter, transhumanists take for granted that genetic improvement via selection (thus avoiding wrongful birth and wrongful life) would provide human beings with greater freedom, or even perfect freedom, and multiply choice—thereby providing access to an enhanced life of great happiness and wellbeing. These ideas are as old as bioethics itself; forty years ago Ramsey concluded that it is consistent with both the genetic and religious visions of humanity to believe that serious genetic defects should preclude procreation (43-44). He worried about the proliferation of "hideous birth defects" and "monstrosities" and argued that a Christian ethic may actually require parents to exercise precautions against having children when they are the carriers of certain traits (1970, 8, 57-59). This, despite the fact that he felt that genetic interventions constituted playing God and should be avoided.

Proposed means for the avoidance of disability and the pursuit of enhancement are thus rendered much the same if not identical (Savulescu 2001a). That is, positive and negative eugenics are twinned in this discourse. Relatedly, bioethicists have argued that it makes sense to accept many different kinds of human enhancements, because of the deep similarity between reasons for avoiding negative states and reasons for pursuing positive ones. Peter Singer writes:

> Many people say that they accept selection against serious diseases and disabilities, but not for enhancement beyond what is normal. There is, however, no bright line between selection against disabilities and selection for positive characteristics. From selecting against Huntington's Disease it is no great step to selecting against genes that carry a significantly elevated risk of breast or colon cancer, and from there it is easy to move to giving one's child a better than average genetic health profile (2011, p. 278).

Singer uses the above, what he considers to be morally-approvable actions undertaken to avoid disability or disease states, against Michael Sandel's argument that enhancement erodes a sense of life's giftedness (2004). He claims that there must be limits on this idea, since even Sandel does not argue against

> current practices of prenatal diagnosis that are aimed at eliminating serious genetic disease and disabilities. The argument for taking life as a gift clearly has

> limits. If it is outweighed by the importance of avoiding children with serious diseases or disabilities, it may also be outweighed by the positive characteristics that genetic selection can bring (2009, p. 279).

Acceptance of the pursuit of enhancement, it seems, may conceptually and rhetorically rely on the rejection of the deviant body—this builds on my analysis of enhancement strategies in the 20th century (cf. Parens 1995, 142).

The genetic conception of the human being can be viewed as the ground of "genetic essentialism" or genetic determinism (Scully 2008, Nelkin and Lindee 1995, 38-49). Genetic conceptions have also been called "gene-mania" which "encourage[s] unrealistic hopes for genetic solutions to all sorts of problems" (Buchanan *et al*. 2000, 23, 24-25). [36] I will here describe genetic determinism and argue that some—even those who self-consciously disavow it[37]—who advocate for various kinds of enhancements operate from an unfounded belief in genetic determinism – the idea that genotype can produce a predictable set of results and is susceptible to manipulation through pure "choice" and no "chance" (Buchanan *et al*. 2000, Glover 1984, 2006, cf. the critique in Oliver 2010). I argue that the impacts of genetic determinism include increased stigma with regard to disability and impairment as well as reductive thinking that ignores social and cultural influences upon how disability is constituted or conceived.

Genetic Determinism

Genetic determinism is a view about causes which assumes the sole or primary importance of genetic factors in individual outcome (for persons—i.e., with regard to

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[36] Despite their attention to fallacies regarding genetic causation, Buchanan *et al.* still indulge in a genetically-based version of identity without justifying its fitness (2000, 85).

[37] E.g. Buchanan *et al*. 2000, 24-25.

phenotype, complex behaviors, and other traits). Often this view involves valuing gene action as autonomous cause or giving undue priority to genetic explanations over environmental or diverse multifactorial explanations (Buchanan *et al*. 2000, 23-24, Lippman 1991 and 1993, Lotz 2008, Nelkin and Lindee 1995, 2). Most scientists, especially geneticists, condemn genetic determinism as false or incorrect, and therefore scientific or philosophical beliefs and assertions that stem from it are considered highly problematic (e.g. de Melo-Martín 2005, 526, Sober 2000). Bioethicists furthermore often take care to explicitly reject genetic determinism (e.g. Buchanan *et al*. 2000, 24-25; de Melo-Martín 2005, 527; Scully 2008, e.g. 5-6). Yet, I argue, mistaken beliefs supporting genetic determinism still have an impact on bioethics, medicine, and conceptions of disability; for example, genetic determinism and related ideas support a strict binary between norm and deviance that variation in the human genome belies (Scully 2008, 24; cf. discussion of normalization in Tremain 2006). This is especially true of transhumanist discussion of enhancement technologies, which often utilize the promise of genetic enhancements.

Genetic determinism, then, as I have described it so far, would primarily influence descriptions of causation when it comes to individual outcomes. That is, mere genetic explanations are given to explain outcomes, or favor is given to genetic explanations over other possible explanations, including more complicated multi-factorial descriptions of causation. The explanatory power of genes and particular cases cited in the media often encourage what has been called the "one gene—one disease" concept, or the OGOD concept (Dar-Nimrod and Heine 2010, 12; cf. Conrad 1997 and 2002). Yet, very few outcomes are indicated by a single gene; "monogenic" conditions are in fact rare (an example is cystic fibrosis[38]), and most relationships between genes and outcomes are quite complicated and mediated heavily by unpredictable factors (Dar Nimrod and Heine 2010, 13). Many phenotypic outcomes are multi-factorial; this means that more than one gene impacts the phenotype of the individual, or that genes, environment, and individual behaviors together impact phenotype. Meanwhile, hype about isolating genes "for" behaviors and talents (e.g. "neatness") are mostly that—hype. Despite the fact that the OGOD concept accurately expresses only the exception—not the rule—when it comes to genetic causation, it is still the basic picture of gene action as portrayed in popular media and that most often endorsed among laypersons (Dar-Nimrod and Heine 2010, 4; Nelkin and Lindee 1995).

Relatedly, screening procedures for particular outcomes, even when "isolated," are highly complex and uncertain. For example, the BRCA1 and BRCA2 genes have been associated with hereditary ovarian and breast cancers. But, over 200 different mutations on these two genes have been described, and little is known about how context—both biological and environmental—impacts the relevance of these mutations (de Melo-Martín 2005, 528). Furthermore, the BRCA1 and BRCA2 genes have only been associated with a very small slice of breast and ovarian cancers – between 5 and 10 percent (Dar-Nimrod and Heine 2010, 13; de Melo-Martín 2005, 528). Touting the screening of these genes as a test "for" breast cancer is misleading. Meanwhile, available direct-to-consumer screening for the "FTO" (fat mass and obesity associated) gene has been scrutinized heavily for its "futility" and for its failure to contextualize genetic

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[38] But the fact that a disease is monogenetic does not mean that an effective therapy will immediately follow, although for many media sources it seems the isolation of a gene for a trait implies available therapy. Helen Pearson documents the as-yet unfulfilled promise of therapy for cystic fibrosis in "One Gene, Twenty Years" (2009).

information into dynamic gene-behavior relationships (e.g. Veerman 2011). According to JL Veerman, screening for the FTO gene has very little predictive power, does not add information about propensity to disease, and meanwhile can distract attention away from more efficacious health measures (Veerman 2011; see also Kolata 2012).[39]

The power to illicitly distract attention has been a special property of genetic science for decades, and descriptions of genetic action as deterministic structure attention-grabbing narratives (Nelkin and Lindee 1995). As geneticist and disability theorist Jackie Leach Scully remarks, the problem isn't that "reductive" genetic explanations are *never* appropriate, but rather that the ways in which reductive explanations are popularized and widely applied are problematic (2008, 6). Genetic determinism, at the very least, obfuscates accurate explanations of causality. Dar-Nimrod and Heine make a distinction between strong genetic explanations (OGOD explanations) and weak genetic explanations (2010, 4-5). The vast majority of genetic explanations are "weak" – that is, they describe genes as "altering risk assessments, modifying susceptibilities, [and] changing probabilities" (4). They are entered into a set of assessments regarding risk that are far from deterministic (I will return to the concept of risk assessment below in my discussion of disability and genetic screening).

Sensational media headlines are an easy scapegoat for the OGOD problem. For decades news reports have heralded "The Gay Gene," "The Evolution Gene," and genes for obsessive-compulsive disorder (Dar-Nimrod and Heine 2010, 13; Nelkin and Lindee 1995, 93). Popular books, probably familiar to you, even describe the gene in agential

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[39] The same is true for the recently discovered, non-inheritable mutation in the PPM1D gene; a recent headline declared: "New Genetic Tests Determines Breast Cancer and Ovarian Risk" (Altman 2012). The language in the body of the item is more hesitant, but the headline is the sound bite.

and even immortal terms, e.g. “The Selfish Gene” (Nelkin and Lindee 1995, 53). But, the responsibility for the ubiquity of the OGOD concept, and therefore mistaken belief in genetic determinism, does not belong to the media alone. The necessity of fundraising and attracting exciting coverage for those in the scientific community means scientists over-promise the explanatory potential of genetic research (Nelkin and Lindee 1995, 5-7). Popular media often echo the language of the scientific studies they report.

A few notes regarding epigenetics should make clear how misleading genetic determinism is. *Epigenetic factors* mediate or act upon genes to impact outcomes. A common example of an epigenetic factor is cellular differentiation; when cells differentiate to become new cell types (e.g. brain cells or skin cells) they both inhibit genes and activate them (Reik 2007). Cell differentiation is a process of selective gene expression. The “epigenome” refers to the group of chemical compounds attached to DNA which impacts the expression of genes. Methyl groups (carbon and hydrogen), another epigenetic factor, can attach to genes and silence them (Khavari *et al*. 2010; U.S. National Library of Medicine 2013). Many other unpredictable epigenetic factors exist, including environment and diet. Epigenetics is a complicated and emerging field. Recent reports, for example, show that bacteria living in the intestine have an impact on cell development, including brain development (Martone 2011).

Moving forward, it is important to keep in mind that the presence of genes does not necessarily mean that those genes will be expressed. *Incomplete penetrance* and *variable expressivity* mean that persons with the same genotype can differ in phenotype. Gene penetrance is a statistical measure of the expression of a gene among individuals (70% penetrance indicates that 7 of every 10 people with a particular genotype express the associated phenotype). Variable expressivity, meanwhile, is best explained using the example of *polydactyly,* a heritable condition which may result in extra toes or extra fingers. Polydactyly may "penetrate" (i.e., what we call polydactyly might be phenotypically apparent) but is variably expressive (Miko 2008). To return to my earlier example of hereditary breast and ovarian cancers, de Melo-Martín notes that rates of expressivity for the BRCA1 and BRCA2 genes in different contexts is unknown and varies among the 200 different mutations. This makes risk assessment difficult; mutations on either of these genes does not mean that one will get cancer (2005, 528).[40] So-called genetic susceptibility must be contextualized by behavior, environment, and other factors (Lewontin 1992, 30).

So far I have discussed the causal complications which make strong genetic determinism fallacious. I contextualized gene action among chemical, environmental, behavioral, and other factors. I have described genetic determinism as a mistaken view about causes. But, the genetic reduction involved in a picture of gene action informed by genetic determinism has influence that goes *beyond* questions of causality, and simply correcting and adjusting popular understanding of gene action will not banish the ethical and political problems associated with a strong focus on or preference for genetic explanations. In fact, this more complex understanding of gene action does not banish scientific problems, either. According to philosopher Immaculada de Melo-Martín, focusing on "interactionist" variables, "far from debunking genetic determinism, simply reinforces it, because genes are still represented as containing information about how the

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[40] Any testing or screening procedure is of course susceptible to both false positives and false negatives.

organism will develop" (2005, 526). She notes that some have suggested science needs a wholly new way to think about genes.[41]

I argue that the influence of genetic determinism also appears in insidious 1) *essentialism* and 2) *naturalization* of socially-defined and constructed categories of persons, such as those defined by sexual orientation, race, gender, and disability. In other words, genetic determinism is a biological reduction. I argue that essentialism and naturalization work together in a way that increases stigma (and therefore social alienation) and disguises the social and cultural factors that impact definitions of disease and disability. I highlight these two issues here.

I turn first to the problem of essentialism and its connection to genetic determinism, taking cues from philosophers of disability and survey research conducted in the field of social psychology. Scully links genetic reductionism with essentialism. She orients genetic determinism as one variety of biological reduction, and describes genetic determinism as the view that "DNA sequences" "encode instructions for proteins" which "determine" traits and health (2008, 5). She argues that reductive explanations of traits and behaviors that rely merely on DNA sequences establish a mistaken belief that there is a "canonical" genotype, which provides a blueprint for normal persons; this acts as an essentializing universal. Any deviation (mutations, deletions, additions) from this canonical genotype count as abnormal (2008, 6). Yet, she notes, there is no such blueprint—variation in human genotype is constant, and a strict and meaningful binary between normal and abnormal is simply not supported by genetic science. The importance accorded genetic "normalcy" is excessive; indeed, the newest chromosomal

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[41] Recall Evelyn Fox Keller's view, above; pursuing this work is outside the scope of my project.

microarray tests intended for use by potential parents indicate merely that a genome is "abnormal," that is, that it deviates from the genome of a presumed healthy person, but not what deviation means.[42]

Social psychologists Ilan Dar-Nimrod and Steven Heine demonstrate that the gene serves as an "essence place-holder"; specifically, genetic determinism maps onto the essentialist thinking (2010, 2). According to these researchers, those surveyed and studied have a tendency to presume an underlying essence unique to social categories and groups, yet this essence is "abstract" and "undefined" (e.g., the essence of a cat, a person, an African-American person, a woman, a mentally ill person) (2). Dar-Nimrod and Heine identify the elements of an essence in terms of its "causal relationship between essence and expected characteristics," its "stability," and that it is "presumed to be immutable" (2). The gene can serve as a convenient and metaphorically descriptive place-holder for already-presumed yet abstract essences and carry forward the causal, immutable, and stable properties thought natural to an essence (see also similar work in social psychology regarding essentialism and genetic bias: Haslam 2011 and Keller 2005).

I turn now to a second problem connected to genetic determinism: naturalization. I consider naturalization to be the transformation of dynamic and historically contingent medical, social, and political categories and concepts into supposedly naturally-occurring, trans-historical and trans-cultural facts about the body (see Tremain 2001, 2002, 2006 and Wendell 1996 on the social construction of disability, for example). Popular portraits

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[42] This new method of chromosomal microarray is said to have proved more reliable than karyotyping (visual screening) in detecting fetal abnormality. This method detects abnormalities in 1 out of every 60 pregnancies in which karyotyping identified the fetus as "normal." Chromosomal microarray directly compares fetal DNA to DNA from a presumptively "healthy person" to identify genetic deviations (Wapner *et al*. 2012, Fitzgerald 2012). The chromosomal microarray method thus *assumes* a human genetic blueprint—that is, a normal genotype, deviance from which will *always* be risky and open to medical diagnosis.

of genetic determinism view dynamic characteristics, behaviors, and socially-constructed traits through the presumed explanatory power of genes, thus naturalizing them and removing them from relevant contexts. If there is a “gay gene,” for example, that means that queer identity is transformed into a fact about the body. The political nuances of identity formation, the public and private pressures which have, created a system of being “out” or “closeted”, and historical and geographical contexts of the meaning of queer identity is hidden via naturalization. Similarly, the political and social nuances of personal identification as or medical diagnosis of Asperger’s syndrome and autism are lost if these conditions are considered essential or genetically-determined properties of bodies.

The recent decision of the editors of the DSM-V (the latest edition of the Diagnostic and Statistical Manual) to shift Asperger’s syndrome onto the autistic spectrum and cease to recognize it as a discrete category should showcase how important historically contextual diagnostic decisions can be with regard to disability (“Asperger’s” 2012).[43] In a memoir, John Elder Robison gave an account of how important the label of “Asperger’s” was to him as he constructed a disability identity (2008). Now, politically active “Aspies” find themselves rendered invisible by the very medical categorization schemes that previously served to (problematically) socially define them, and are newly considered autistic (a fact which will change prevalence statistics). Meanwhile, the CDC is revising its estimations of the prevalence of autism based on telephone surveys and new criteria, suggesting that 1 in 50 children are affected (Heasley 2013). Another

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[43] Additionally important to mention here is earlier categorization in the DSM of queer identity as pathological, which was eventually dropped due to the *strategic essentialism* strategies employed by gay activists, culminating in 1973 (Nelkin and Lindee 1995, 120-121).

example of the importance of historical and political context to the question of disability and its construction is the category of learning disabilities and the diagnostic and statistical blossoming of a variety of these conditions as public educational strategies and policies change.[44]

As philosopher of disability Shelley Tremain puts it in a Foucauldian-inspired discussion of prenatal testing and screening procedures, naturalization can also be described as a problem of *materialization*; that is, the transformation of discursive categories into "real" categories (2006, 39). Similarly, the strategic analogy made by disability activists between sex/gender and impairment/disability in order to support disability rights campaigns for equal protection under the law problematically treats impairment (separated from disability) as natural or uninfluenced by medical, political, legal, and social forces. Tremain therefore interrogates the category of "fetal impairment" and seeks to deflate its status as a "real" category or a "natural kind" (Tremain 2006, 39 and 49; see also Tremain 2001, 2002). I return to these issues and the social construction of disability in chapters two and three. Even if perfect genetic science were available, we would not have full "knowledge" of disability, because disability is a social and discursive category that bears upon bodies.

Bioethics and Genetic Determinism

Popular media can contribute to mistaken beliefs supporting genetic determinism, especially when reporting scientific findings and research plans regarding genetics. These

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[44] For other resources on changing constructions of social and medical categories related to disability and disability oppression, see Licia Carlson's in-depth historical study *The Faces of Intellectual Disability* (2009) and Susan Schweik's *The Ugly Laws*: *Disability in Public* about laws targeting "unsightly beggars" in the 19th and 20th centuries (2010).

findings and plans are often presented by scientists themselves in ways that problematically describe gene action. This is one issue to which bioethicists should attend and work against whenever possible. According to de Melo-Martín, bioethicists should also attend to an issue that penetrates a level deeper; that of communication about genetics within the field of bioethics itself. She argues that bioethicists, in making moral and ethical arguments, make significant mistakes in discussion which contribute to false beliefs among readers and interlocutors about gene action, which in turn support genetic determinism (2005). She identifies citing unrepresentative cases (such as OGOD cases or traits that are autosomal dominant, like Huntington's disease) when discussing what parents owe children in moral debates regarding reproductive technology as one of these mistakes (2005, 527).

Another, different mistake is to use simplified cases, as in the case of discussing the ethical ramifications of genetic testing "when information about diseases with a genetic component and the predictably of genetic tests for these diseases is presented in simplistic ways" (2005, 528). I have already discussed the case of BRCA1 and BRCA2 screening as de Melo-Martín describes it, but should note that de Melo-Martín also mentions genetic testing for Alzheimer's disease as a case that is often represented simplistically (528).

But, I argue that complex beliefs related to genetic determinism are an even more significant problem in the field of bioethics than is typically recognized. Genetic determinism poses threats within bioethics beyond threats precipitated by miscommunications between experts and laypersons, bioethicists and readers. Genetic determinism strongly influences philosophical discussion in bioethics regarding genetic screening, genetic selection of embryos, and genetic enhancement, especially when it comes to utopian transhumanist desires for enhanced genetic futures. In fact, philosophical views promulgated by bioethicists on these topics, on different sides of the issues, appear to be rooted in genetic determinism, as already discussed in the Introduction. Genetic determinism therefore shapes significant arguments in bioethics, and is more than a mere regrettable byproduct of some modes of discussion. This situation holds despite the fact that "practically every geneticist alive" (de Melo-Martín 2005, 526) and plenty of bioethicists reject genetic determinism.

Genetic determinism does not only affect bioethics as a field by delimiting advances in ethical thinking or obscuring important scientific knowledge, it also significantly contributes to the twinned force of stigma and synecdoche (I return to this in chapters two and three). Many recognize that supports for genetic determinism in the media and in communicative efforts with the public should be combated. But, the problem runs deeper than that; it is time to recognize how entrenched genetic and other biological reductions are in discussions of illness and health.

To sum up, although the gene now largely determines ideas about human health in a way which vitamins and exercise – or even hormones – once did, there is no clarity with regard to how helpful genetic indications are when predicting future disease or predicting function (Gupta 2012, Kolata 2012). These are contested issues, and, again, some argue that there is no reason to believe that the "genetic era" or the view of the human as determined by genes will last or is the best explanatory mechanism for phenotype or function (Keller 2000, McNally and Glasner 2007).

Conclusion

In the preceding pages, in order to deepen understanding regarding transhumanism and today's general bioethical conversation regarding enhancement, I turned to historical notions of health and sickness at the locations of past strategies of bodily enhancement. The alternative eugenic history I traced in this chapter allows me to point to and track locations of: the reduction of human life, morality, and meaning to the level of the biological or the physical; the rejection of the deviant body; and the lasting romantic, utopian thinking undergirding the quest for enhancement, even as that quest grew and changed. Just as in the case of transhumanism today, justifications of enhancement strategies in the 20th century operated by responding to and exploiting desires to increase happiness and freedom, and at the same time played upon fears of deviant others.

Biological reductions made it plausible to view discipline of the body, along with *choosing* health (the right marriage partner, or diet, exercise, and hormone supplements), as a route to happiness and bliss. In other words, physical and mental health, along with choice-making, were equated with morality, happiness, and sociability; the primary operating assumption is that the body is the site for any intervention aimed toward improving human life. This puts to the side any discussion regarding political and social impacts on the construction or maintenance of health and sickness, disability and ability. Yet, in fact, disability and deviance were continually referenced and reconstructed as a variety of ways to understand health came in and out of vogue. Rejected bodies are repeatedly painted as too dependent or as irresponsible and dangerous (sickness as sin;

weakness as crime) in order to justify their exclusion or even their extermination through sterilization or other means. They have failed to choose health, and therefore their deviance must be rejected as a menace to the health of the community. From the Roma identified by Wiggam to short individuals threatening the primacy of the tall in the imagination of H. G. Wells, the deviant body is seen not only as an outlier, but an "other" with the ability to preclude the possibility of the norm's flourishing. Everyone must enhance—the community itself must be normalized—for individual enhancement to occur.

Today, just as in the heyday of physical culture, the immorality and irresponsibility of sickness and weakness has yet to disappear from the public imaginary[45] and belief in the heritability of *moral* traits and *social* happiness is still apparent in bioethical debates regarding enhancement. Central to all of this, then, is a double-edged weapon for use against persons positioned as disabled or experiencing disability: either disability can and therefore should be overcome through medical or non-medical discipline, or disability must be removed from the general population by way of segregation so as to dissipate the threat to health and freedom more generally, among unmarked others in the population. Disabled lives are not worth living, and if they cannot

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[45] As Susan Sontag argues in her *Illness as Metaphor*, physical deformity and moral evil or criminality are linked together in the dominant cultural imaginary (1978/1989). Paul Longmore's essay "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures" later expanded upon this claim (1987). Longmore pointed to the consistent tropes of disability which appear in television and film. Two of the most constant are the disabled "villain" like Doctor No, Doctor Strangelove, or Miguelito P. Loveless, and the disabled "monster" like Victor Hugo's "hunchback" or the eponymous Phantom of the Phantom of the Opera (1987, 67-68). According to Longmore, who is in basic agreement with Sontag: "Deformity of body symbolizes deformity of soul. Physical handicaps are made the emblems of evil" when it comes to television and movies (66). One tenet of this process of symbolization, perhaps the most important, is "the notion that disability involves the loss of an essential part of one's humanity" (68). This supposed loss can signal the beginning of monstrosity and the perpetration of monstrous acts. Another central element of television and film is that disability precludes social integration (68-69). For Longmore, these narratives soothe audiences regarding their fears and exclusions while at the same time justifying those fears and exclusions.

be transformed, they must be rejected—or, perhaps, stifled from the beginning. Meanwhile, certain bodies are valorized as free and healthy in opposition to the disabled body, while a cost-and-benefit analysis of the value of expending resources on rejected lives becomes possible. These largely unexamined assumptions are still operative, and their perceived plausibility is used to cut off questions regarding the desirability of enhancement.

Transhumanism is rooted in the rejection of deviant embodiment; the view repeats the biological reductions necessary to support both the destructive belief that morality and appropriate sociability increase and decrease along with physical fitness and mental acuity and the attempt to solve social problems through intervention upon the body. There is an ironic paradox here; transhumanists make the body central to problem-solving while at the same time endeavoring to transcend it completely—thus rejecting any embodiment at all. While enhancement once focused on the discipline of the body and its perfection through technology, as in "physical culture" at the turn of the 20th century, enhancement in the 21st century promoted by transhumanism is focused on leaving the body behind altogether. Popular internet discourse concerning human enhancement often expresses a hatred or disgust for fleshly embodiment. Consider this comment in response to an article entitled "How to Build the Perfect Human" on popular futuristic website i09, which suggested splicing animal traits in order to gain their capabilities (Ingus-Arkell 2012). The critic wrote: "To make a better human, I'd scrap the protein and meat altogether" (Feb 15, 2012). A posthuman will transcend the neediness and vulnerability of the flesh, trading up to replaceable and strong non-organic parts. Bostrom writes: "*What is Body in Utopia?* Body is a pair of legs, a pair of arms, a trunk and a head, all made of flesh. Or not, as the case may be" (2010, 8). An intoxicated Ray Kurzweil argues that soon sex will be virtual, and if we are unfortunate enough to have sex with a fleshly partner we can take comfort in a techno-overlay which will project the image of a desired individual or celebrity upon that partner (with Grossman 2010, 96). Sex is not desirable unless we can have sex in the realm of wishes and fantasy. Kurzweil writes:

> virtual sex will be better in some ways and certainly safer. Virtual sex will provide sensations that are more intense and pleasurable than conventional sex, as well as physical experiences that currently do not exist. Virtual sex is also the ultimate in safe sex, as there is no risk of pregnancy or transmission of disease (2000, 747).

Kurzweil rejects the body as limiting pleasure and as the site of risk. I return explicitly to the rejection of embodiment at the end of the next chapter, when I consider Anne Waldschmidt's analysis of the concept of risk in genetic counseling encounters.

In chapter two, I explore another aspect of the transhuman fantasy—the child of choice, for whom freedom and happiness are unlocked. I consider Savulescu's argument that there is a moral obligation to create the best children possible—an enhancement strategy and obligation he calls "Procreative Beneficence." This idea relies upon the notion of the "right to an open future"—a bundle of rights thought to ensure future autonomy—and genetic harm or wrongful birth in order to operate (Feinberg 1980, cf. Mills 2003). The aims of procreative beneficence again call to mind Sharon Snyder and David Mitchell's promise of a world without bodies, uncontaminated by deviance and needs. This promise is the backdrop of the genetic obligation to provide future children with perfect health and an "open future." The "open future" construct should call to mind the use of a realm of "pure choice" in debates over enhancement (cf. Oliver 2010). In the next chapter, I consider the "impaired fetus," diagnosable in the womb, as the threatening and reject-able body. I argue that objections to genetic selection from disability theorists can help us understand what is objectionable about valorizing the abled body in the arena of reproductive technology, and that this valorization depends on an undergirding genetic determinism.

CHAPTER II

NEGATIVE GENETIC SELECTION: ENHANCING RISK, ENHANCING DISABILITY

> "…discourses of truth that provoke laughter and have the institutional power to kill are, after all, in a society like ours, discourses that deserve some attention."
>
> Michel Foucault, *Abnormal* (2003)

In this chapter, I bring transhumanist utopian thinking into sharp focus through the case study of *negative genetic selection*, which is suggested as an enhancement strategy by transhumanist theorists (e.g. Savulescu 2001, 2008, and Kahane 2009; Buchanan *et al*. 2000, Liao *et al*. 2012).[46] While enhancement often conjures images of superhero strength, or Kurzweil's suggestion that humans "upload" thoughts and Bostrom's suggestion that grey matter be "copied" in silicon, the transhumanist strategy of genetic selection is of great import for transhumanist visions of the future. I specifically discuss Julian Savulescu's proposed moral duty of *procreative beneficence*, a strong version of reproductive responsibility (2001b, 2008, see the Introduction above).

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[46] Genetic selection is also sometimes framed as preventative treatment. For instance, Bonnie Steinbock considers whether or not negative genetic selection is different from preventative measures such as vaccination against polio or encouraging pregnant women to take folic acid in order to avoid spina bifida (2000, 108). She concludes that while the two sets of activities have differences, they are both therapeutic and are not different with regard to commenting on the value of the lives of persons with disabilities—i.e., neither need reflect a negative evaluation of these lives (121). She also argues that the termination of any pregnancy is usually undertaken in order to avoid unwanted burdens, and that the avoidance of the undeniable burden of caring for a child with a disability is no different (119). In this chapter, I aim to show that the two sets of activities are different because of the influence of genetic determinism in the former case and the institutionalized injustices which follow from it.

Procreative beneficence morally urges those considering reproduction to apply evolving technologies as they emerge to create the "best" child possible with the greatest future options. Transhumanism, here, would preclude the existence of certain unwanted types of individuals based on genetic profiles taken before birth. This is, perhaps, the first step of the total rejection of the body—that is, carrying out a consistent and (it is believed) justifiable rejection of the "impaired fetus." The enhancement strategy of genetic selection asks and answers the question: who will live?

Genetic selection is represented as the *choice* of particular, "better" embryos or fetuses which can then lead to the enhancement of quality of life for those who are living and ensure the shared resource of an enhanced genetic pool for future generations. Genetic selection occurs regularly in the United States; for example, 19 studies conducted in 1988 show that 87 percent of fetuses identified as having Trisomy 21 (indicating Down syndrome) were aborted (Mansfield *et al.* 1999, 810). More recent estimates place this number above 90 percent (James 2009). While some believe such "risks" as Down syndrome are best avoided at any cost, I aim to show in what follows that support for genetic selection relies on genetic bias and the untenable belief that a body "marked" with a particular trait *reliably* enjoys a lessened quality of life in comparison to an unmarked body *because of* genotype. The logic of genetic selection relies on naturalized and materialized versions of disability that ignore their discursive, historical, and social settings.

For example, genetic markers for Down syndrome indicate a wide range of potential phenotypic characteristics, the meaning of which depends on reception in society, but genetic indications of Down syndrome are often represented as an all-or-nothing biological affair that reveals a “Down’s baby” whose life will be bad. Genetic selection participates in an unjust hierarchy of value that fails to interrogate the social and political forces which construct it in the first place. As Shelley Tremain puts it, “in terms of this conception of risks in pregnancy...an increasing number of variations between humans are attributed to allegedly prediscursive genetic structures” (2006, 47). In other words, a systematic disregard for stigmatizing and unjust discursive, political, and social conditions and factors feeds and is fed by an over-emphasis on genetics. This discussion continues and builds upon the discussion of biological reduction and genetic determinism in chapter one.

The most effective critique of genetic selection developed by disability theorists and advocates of the disability community is the *disability critique*. In this chapter I outline this critique of genetic selection and defend it against common objections; first, the objection that it threatens reproductive liberty, and second, the objection that genetic selection fails to produce a coherent and sustained “hurtful message” to persons with disabilities (I will in fact argue that it does more than send a hurtful message). I go on to utilize the disability critique and its insights to question transhumanist future. I ultimately strengthen the disability critique by pointing to the construction of the impaired fetus and by re-directing the target of the critique to society at large and its exclusions and value hierarchies.

My promotion of the disability critique is animated by the conviction that feminist advocates of disability rights and feminist critics of ableism should not be forced to walk a tightrope between supposedly competing interests—disability advocacy and a pro-choice stance. This conflict, between reproductive liberty and critiques of genetic selection, has appeared in disability studies for decades (e.g. Morris 1991, I return to this problem in my discussion of conservative politics in the Conclusion). What follows should demonstrate that the disability critique and its accompanying *expressivist view* of negative genetic selection can be consistent with, and even enhance, reproductive liberty (a term I bring under pressure in the following pages).

I argue, with others, that disability theorists and feminist theorists must work in tandem to pursue richer theorizing and fuller analyses of the complexity of embodiment, subjectivity, and interdependence. Judy Rohrer and Rosemarie Garland-Thomson make the case for the importance of disability theory and analysis to feminist theory; each highlights a variety of ways this work can challenge and deepen feminism (2005 and 2002, respectively). Both Susan Wendell and Garland-Thomson stress, conversely, the necessity of a feminist theory of disability (1997, quoted Rohrer 2005, and Wendell 1996). Rohrer's essay lays out, with great clarity, many areas of application which can benefit from this collaboration. She includes consideration of the simultaneity of identity, interdependence, body politics and choice (2005, 35).

With regard to my specific focus here, genetic selection against fetuses symbolically structured as disabled, there is a strong conflict between "choice" as it is commonly understood and the justice claims forwarded by disability activists who see societal endorsement of genetic selection as akin to eugenics. Rohrer writes: "The intersection of 'choice' with the valuation of a disabled life provokes a clash that rocks our rhetoric and takes us back into active theorizing about *whose humanity is supported and valued and under what circumstances*" (2005, 58, emphasis mine). In order to accomplish this active theorizing, awake to systematic oppression, I argue that feminist disability theorists need to meet transhumanists head-on regarding selection. Ableism is linked tightly to “marked bodies” of all kinds and the reasoning of sexism, racism, classism, and heteronormativity, all of which rely on a stigmatized Other whose difference is often rendered as biological (cf. Mitchell and Snyder 2000, ix). The accusation that the disability critique is anti-choice drives an unnecessary wedge between feminist theorists and disability theorists and obscures the ways in which ableism and sexism are fused together.

After exploring the disability critique, I argue that fields of risk posed by genetic selection practices and genetic counseling participate in a system of actuarial thinking (a term I borrow from Dorothy Nelkin and Susan Lindee, 1995) and decision-making that calls upon potential parents to perform autonomy defined by risk-aversion. Meanwhile, the potentially impaired fetus becomes a site of risk in this system. To conclude the chapter, I describe transhumanism’s *techno-liberal*[47] subject constructed as the disabled or deviant body’s opposite. If biology is figured as destiny, it is easy to maintain a false binary between abled and disabled, or between a realm of pure choice and a scary and dangerous realm of pure chance or risk (here, genetic chance and fetal risk). Transhumanist logic rejects the disabled body as limiting choice and describes a selected or enhanced body as enjoying access to a realm of pure choice. On this view, choosing to utilize evolving technology in the arena of genetic selection can multiply freedom and choice and therefore unlock better futures. I argue that genetic selection, as an enhancement technique, merely serves to enhance the conceptual impact and meaning of *risk* and *disability*.

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[47] I owe this neologism to Lisa Guenther.

Explanation of Terms

Before moving to the main arguments of the chapter, I here lay out more clearly the terms I will use. The phrase *genetic selection* can be used to refer to a host of activities surrounding reproductive decision-making. The roughest distinction often made among these activities is between positive and negative genetic selection, or, in simpler terms, genetic selection for particular traits or against particular traits. I largely maintain this distinction here for the sake of clarity and responding to the work of others, although I argue it problematically resonates with negative evaluations of disability traits and so naturalizes negative evaluations. In order to achieve genetic selection, screening procedures can be undertaken and are advised at many different times before or during pregnancy. Genetic selection can also be said to occur through the choice of a partner with whom one might reproduce, or the timing of a pregnancy, insofar as both of these things impact the fetus and the eventual child. But, this is not the sense in which I use it here. The disability critique usually focuses upon selecting *against* particular traits, which can be achieved through the choice of one embryo rather than another for implantation or through the termination of a pregnancy upon the discovery of a particular trait, genetic markers or genetic susceptibility.

Pre-implantation diagnosis combined with in-vitro fertilization allows potential parents to test embryos for markers and indications of both disease and non-disease traits (a commonly used distinction) prior to implantation. This testing can lead to the decision of which embryo to implant, or, perhaps, to implant no embryo at all. Prior, even, to that early stage, potential parents can undergo their own set of genetic tests to determine probabilities for carrying forward traits or risk of certain conditions to future children. For example, little people can visit a genetic counselor to discover if their dwarfism is hereditary – i.e., hereditary Achondroplasia – and take steps to have children who share this trait with them or who do not (Davis 2010, 2).[48] Finally, prenatal genetic testing can be carried out after a pregnancy is initiated. For example, amniocentesis can be conducted after a woman becomes pregnant and can lead to the termination of the pregnancy if the parent so chooses. The same is true of maternal serum screening, testing via ultrasound and chorionic villus sampling (CVS) (Parens and Asch 2000, 45-7; Davis 2010, 2). This is not an exhaustive list of the testing and screening options available to potential parents, and new tests are being developed. Recently a new test for Down syndrome was announced, called MaterniT21. This test can be used at 10 weeks into pregnancy and, unlike its predecessor, amniocentesis, does not increase the risk of miscarriage. It tests a blood sample taken from the mother's arm (Hill 2012). Additionally, new chromosomal microarray testing—said to be better than karyotyping at detecting "fetal abnormality"—is now available. Chromosomal microarray compares fetal DNA and DNA from a presumed "healthy person" to identify (mere) deviation. This way of identifying deviation from a clearly arbitrary "normal" genotype is highly suspect (see note 38 above).

For the purposes of this discussion, I treat screening procedures generally (such as those briefly introduced above) as significantly similar. Any screening procedure undertaken to assess the health of a potential child prior to its birth can lead potential

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[48] If both parents carry the gene for dwarfism there is a chance of infant fatality (Davis 2010, 2).

parents to a choice constructed by the current medical climate: that is, the choice of whether to bring a particular, diagnosed or named, fetus to term. Some potential parents may desire a child, but for a variety of reasons might object to going forward with a pregnancy. I take for granted in this discussion that cases of interest are those in which a child is desired, but screening or genetic counseling is undertaken so that potential parents can gather genetic knowledge about a specific fetus that they have the option of bringing to term. I will not consider cases in which no pregnancy is desired at all.

Recall that genetic determinism is the elevation of genetic factors to the level of autonomous causation; in other words, simple genetic determinism is the view that individual traits and behaviors and, often, social circumstances or problems can be explained solely through genetic factors (Buchanan *et al*. 2000, 23-24). This mistaken view is roundly dismissed by philosophers and scientists alike. But, as I argue, it retains influence, and that influence is full-blown in the arena of genetic selection. Mianna Lotz has referred to “geneticism” and “essentialism”, both of which are ways of over-stating the impact of genetic factors or engaging in biologically-reductive thinking (2008). She defines geneticism as the “morally arbitrary valorization of genetic factors in the understanding of human nature, selfhood and relationships” and also notes undue significance attributed to “biological and/or genetic functions” in some arguments regarding reproductive technologies (137). Abby Lippman uses the term *geneticization*, meaning “the ongoing process by which priority is given to differences between individuals based on their DNA codes” (1993, 178). I take geneticization to mean much the same phenomenon as geneticism. These ways of thinking can be destructive in conversation regarding genetic selection in two senses: one is empirical, when the predictive power of genetic testing is over-stated, and the second is evaluative, when genetic factors are considered good or bad in ways unsupported by genetics itself (cf. Lotz 2008, 137). I consider both types of impact here.

Procreative Beneficence

I turn now to an introduction and critical discussion of Savulescu's moral principle of procreative beneficence. Savulescu argues that that "eugenic" genetic selection is the *best* way to achieve human enhancement—for him, it is superior to genetic engineering (with Hemsley *et al*. 2006). His principle of *procreative beneficence* requires any available technology to be used to pursue the creation of the best child possible (2001b, 414; but as aforementioned, Savulescu believes that the use of IVF and the choice of one embryo over another has the least "psychological" consequences of all options for genetic selection). He believes parents have a moral duty to ensure children have the best chance at the best life (2001b). Despite the fact that Savulescu claims reproductive choices ultimately belong to parents, he also argues that in the case of prenatal genetic diagnosis doctors should not be prevented from trying to persuade parents with regard to procreative beneficence (425). He argues that individuals must weigh procreative liberty against procreative beneficence (2001b, 425, cf. Savulescu 2002).

Yet, Savulescu insists that if tests for non-disease genes become available, parents have a moral obligation to use them in making decisions about reproduction (recall here Buchanan *et al*.'s scheme of the colonization of justice). For him, parents should do what they have the most reason to do in response to testing results (2001b, 415). Absent any other reasons for choosing a particular embryo, one should choose the embryo with the best chances for the best life (416-417). He makes clear that genetic markers linked with disability are among the traits targeted as worse and to be avoided by those who are morally conscientious (Savulescu 2008). According to the principle of procreative beneficence, one must select against disease-causing genes or disability traits. But on must also select against any other genes that might obstruct the good life, like a "bad temper" or "asthma" (2001b, 414-15, see also Savulescu 2001a). Meanwhile, he argues, *intelligence* and *memory* are multi-purpose and can always enhance one's quality of life, no matter what one's individual goals (2001b, 420). This is because on any theory of well-being (he gives three examples: "hedonistic", "desire-fulfillment" and "objective list" theories), capacities such as "choosing means to satisfy ends," and "imagining alternative pleasures" are important (2001b, 419-421). One must be able to make social connections and absorb information about the world, both of which Savulescu believes are increased by individual intelligence.

Savulescu defines the best life as "the life of the most well-being" (2001b, 419). This hoped-for best life of heightened well-being is the justification for the use of prenatal genetic diagnosis and the moral obligation to procreative beneficence. According to Savulescu, any trait can impact the best life. For him, reproduction is like "playing the Wheel of Fortune. You should use all available information and choose the option must likely to bring about the best outcome" (414).

Savulescu admits that if procreative beneficence as he conceives it is followed, common prejudices will come into play in reproductive decision-making. But his response to the problem is unsatisfactory. He argues that if society favors men, for example, then parents have good moral reason to select embryos based on their sex (male) (2001b, 23). But he does not think that these decisions impact equality or justice issues, because before any impact is felt on the level of the population, emergent factors (i.e. intense gender disparity) would change the direction of moral obligation (423). For example, in a society which has produced too many males, but still relies on traditional sexual reproduction, a female child becomes the favored outcome of a pregnancy under the dictates of procreative beneficence.

But persons with disabilities and women, people of color,[49] and others who face societal prejudice, still have reasons to be suspicious of Savulescu's procreative beneficence. I argue here that he does not deal adequately with ableism (prejudice against persons with disabilities) and sexism. I will address the issue of ableism first. Savulescu's focus on eliminating undesirable traits biologically obscures the ways in which disability involves a lack of fit to or lack of responsiveness in a particular *social world*, which is malleable, or is *socially constructed* by way of stigma. Marking disability is historically a process of labeling; labels in turn come to refer to the whole person in a disparaging way: "the amputee" or the Down's child—a "defect" becomes a "defective" (cf. Zola 1993, 169). This process of labeling and marking is the social construction of disability identity. (I discuss the social construction of disability and stigma at greater length in chapter three.) In calling for the elimination or mitigation of disability through negative genetic selection, Savulescu's principle of procreative beneficence naturalizes the meaning of

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[49] It is clear people of color experience significantly worse societal reception and conditions than those positioned as white, so of course Savulescu is forced to also argue that one should select for whiteness (against a raced fetus).

disability and suggests that making the body malleable according to the dictates of the social is more important than the political and social goal of achieving accessibility for a variety of bodies and minds. Disability, viewed through procreative beneficence, is reduced to a genetic feature or prenatally visible trait which can be screened out or turned off by way of reproductive decision-making. Savulescu is thus performing a biological reduction, one that is specifically reminiscent of the disputed "medical model" of disability, which poses disability as purely biological and misses a critical reading of society's norms.

The visible features of the fetus are thus limited to genetic anomalies and encourage the creation of classes among fetuses, arrayed along a range of normality that corresponds roughly to the traits we tolerate among already-existing persons, already classed and, in many cases, heavily stigmatized on the basis of class (cf. Carlson 2002, 207-209). An example of such a class is Down syndrome, the "prenatal prototype" for which is selected against after detection of genetic markers in the fetus at rates over 90 percent in the United States (*ibid.* and James 2009). By way of genetic profiles and fetal diagnoses (naming), a link is forged between a fetus and existing communities that are not valued; thus, the potential child is deemed not desirable. According to Savulescu's principle of procreative beneficence, such a pregnancy should be ended or avoided as a matter of moral obligation. Unlike the gender disparity that might become a new factor in reproductive decision-making as the result of sex selection, it seems that there are no emergent reasons to curb this type of selection (or selection "against" persons of color). I return to this point, below.

Savulescu never even mentions the women who would be receiving the IVF treatments necessary to enact the principle of procreative beneficence (even in passing he refers to "reproducers" rather than "women"). Speaking to this concern, bioethicist Christine Overall argues that procreative beneficence is a burden for women, not men because procreative beneficence requires "every potential mother" to use IVF (Overall 2012, 125). But IVF involves major surgeries and is very risky, so procreative beneficence is in actuality a high-risk medical experiment for both the mother and the child. Risks to the fetus stem from the likelihood of multiples brought by the IVF procedure, and so when IVF is combined with pre-implantation diagnosis, an improved life for a potential child cannot be guaranteed. These issues are all beside the point, however, for the heavy majority of women globally; we should not forget that IVF is extremely cost-prohibitive and its efficacy depends on the age of the woman who uses it (Overall 2012, 125-127). Procreative beneficence is meant to be an ethical principle – on Savulescu's view, the only ethical way to reproduce – but it fails with regard to bettering the lives of precisely those whose participation it requires (cf. Overall 2012, 127).

Those who would critique negative genetic selection or procreative beneficence as a societal practice or moral obligation, or who would express unease regarding its various intents are often accused of attempting to restrict or restricting choice (Brock 2009, Nelson 2011, Savulescu 2001b). If it is ethically permissible to terminate a pregnancy, it is permissible to terminate any pregnancy for any reason (Brock 2009, 258; Steinbock 2000). Therefore, worries about one set of reasoning for termination should not be given credence if reproductive liberty is to be upheld. In order to rebut this prevailing objection, I turn here to a discussion of the central contentions of the disability critique, point to some ways it can be strengthened as I proceed, and discuss reproductive liberty.

The Disability Critique

Disability theorist Adrienne Asch criticizes the practice of negative genetic selection and, thus, the principle of procreative beneficence by suggesting that selecting against traits deemed characteristic of already-existing persons with disabilities is deeply stigmatizing and sends a hurtful message to those in the disability community – *viz.*, their lives aren't worth living (Asch 2003). On Asch's view, procreative beneficence is immoral.

In this section, I describe Asch's *disability critique* of genetic selection while navigating claims that launching such a critique threatens reproductive liberty or is unavoidably anti-choice. I should note that disability critique should not be taken as representative of the views of all persons who experience widely varying disabilities. It is important to avoid the common mistake of treating persons with disabilities and those in their communities as a homogeneous group with a monolithic set of interests, beliefs or circumstances. Instead, the *disability critique* is the term for a specific argument. Adrienne Asch uses this terminology and I do so here in order to pick up on the conversation she began (e.g. 1989, 2000, 2003, Asch and Wasserman 2005).

The disability critique calls into question social motivations for pre-natal genetic testing, diagnosis, and subsequent selective abortion. It can also be used to critique the overall practice of pre-implantation genetic diagnosis and the pressure to choose one embryo over another. The disability critique argues that these reproductive decisions devalue and threaten the disability community and its existing members, but it can also be extended to show that all are devalued by this practice. Essentially, the disability critique suggests that negative genetic selection is regularly undertaken based on misinformation ultimately related to ableism, is unduly swayed by the medical model of disability, and expresses a hurtful message to persons already existing with targeted disability traits—namely, that these lives are not worth living. For supporters of the critique, "prenatal genetic testing followed by selective abortion is morally problematic, and…driven by misinformation" (Parens and Asch 2000, 13). Asch further suggests that if disability is seen to detract from "what most people seek in child rearing," which she specifies as a process "to give ourselves a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud," then this is a result of misinformation (Parens and Asch 2000, 13 quoting Asch 1989, 86). So, the misinformation that Asch has in mind is connected to evaluations about the character of the child that might be created and, additionally, the way in which rearing that child would be different or unique from rearing any child (cf. Kittay 2010c).

The misinformation identified by the disability critique can take a number of different forms, but is ultimately driven by a disregard for the value of the lives of persons with disabilities or the quality of those lives. One "mistaken assumption" discussed at length by Asch is the notion that if having a capacity is good, then lacking it is inherently bad. Asch argues that one can concede a capacity is valuable without conceding that to live without it is bad, or lacking in value. Equivocation between these two beliefs makes the "quality of life" of those with disabilities seem unduly low or perhaps non-existent. Asch concludes that this misleading equivocation "is due in part to the failure to distinguish the absence from the loss of a skill, capacity, or type of experience, and in part from the overly-narrow description of what is good or valuable" (2003, 318). The overly-narrow description Asch gestures toward is repeated in the reasoning of proponents of enhancement, who zero in on cognitive capacity as perhaps the most important key to valuable life (e.g. Savulescu 2001).[50] The importance of cognitive capacity is bolstered by the idea expressed by Buchanan *et al*. that such a capacity is "all-purpose" and so does not define a particular life of value, but is rather necessary to all (2000, 49). Many arguments for intellectual enhancement define intellectual life as necessarily valuable and implicitly claim that greater cognitive capacity is always better. This means higher IQ is of vital importance (Savulescu 2001b, 414). In this vein they may also overstate the importance of genetic impact factors for cognition.

Two other elements of misinformation identified by Asch are as follows. First, discriminatory attitudes toward persons with disabilities are driven by the medical model of disability (2003, 318-19). Insofar as negative genetic selection is explicitly encouraged by medical professionals as a way of avoiding a life of hardship, Asch argues a medical model is likely being employed, which exaggerates the extent to which negative experiences often undergone by persons with disabilities are due inherently to their physical traits. The medical model of disability, on its strongest version, orients all limitation due to disability in biological facts; discomforts and lack of freedoms and limited capabilities are all, on this model, due solely to disability's character as a medical

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[50] Thomas Edison reportedly once claimed: "The chief function of the body is to carry the brain around."

or health problem (Brownlee and Cureton 2009, 75-76; Saxton 2000, 149). Rejecting this emphasis, as proponents of disability rights do, can take the form of assuming a largely social model of disability or simply rejecting the medical model. Contrary to the medical model, the social model argues that difficulties or differences in quality of life experienced by persons with disabilities are due to a lack of social accommodation rather than inherent individual or biological qualities (Abberley 1987). *Disability*, on this view, most closely refers to a set of social circumstances that are discriminatory rather than a trait or traits of an individual or the individual herself (Brownlee and Cureton 2009, 21).[51] This does not mean that the traits in question must be seen as neutral; this shift in emphasis can still consider certain traits limiting when it comes to some activities and at the same time maintain that available alternative modes of activity can ensure a high quality of life (Parens and Asch 2000, 25-26). The disability critique suggests, then, that a disability trait *need not* have the "tragic" impact it is regularly believed to have as viewed through the medical model.[52]

Second, negative genetic selection "place[s] unwarranted emphasis on the size of one's opportunity range rather than the possibility for meaningful choice and rewarding outcomes within that range" (Asch 2003, 318; recall here Bostrom's image of concentric circles). Using the language of the species-typical, Asch points out that variation from

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[51] In chapter three I argue that the most helpful model of disability is the cultural model, which refers to and investigates the context and construction of disability without assuming that these contexts and constructions are merely or only tragic or negative. This model does not assume that locations of disability are always blameworthy instances of failure on the part of the social (Snyder and Mitchell 2006). It also does not separate impairment and disability, as the social model does, claiming that the former is merely biological (i.e., resistant to social construction) while the latter is social. Chapter three is dedicated to discussing models of disability and outlining the Foucauldian inspiration of the cultural model.

[52] "Clinicians and bioethicists often discount data indicating that people with disabilities and their families do not view their lives in solely or even predominantly negative terms; instead, they may insist that such data reflect a denial of reality or an exceptional ability to cope with problems" (Parens and Asch 2000, 6, cf. Riis *et al*. 2005 and Goering 2008).

this norm does not mean that “meaningful choice and rewarding outcomes” are lost. In fact, “virtually everyone with a disability can participate in many everyday activities, experience relationships, discover the world beyond themselves, and contribute to familial, social, political, and economic life” (320).

I add here to the disability critique: emphasis on opportunity range ensconces “meaningful choice and rewarding outcomes” as inherent to or inevitable for life of an individual who enjoys a body considered more species-typical, or a specific kind of genotype. This emphasis *over-valuates* the opportunity range of the (socially) abled body, while simultaneously *denying* the opportunity range of the (socially) disabled body. Any individual may face hospital stays, obstacles, chronic illness, disease, or permanent limitation. Yet, society is not responsive to all needs and creates circumstances in which some persons are more accepted and cared for than others. Opportunity ranges can enforce a misleading binary between the disabled and the abled and, in the context of prenatal testing, encourage predictions impossible to make. Because quality of life is *dependent upon* social circumstances, prenatal testing cannot predict it.

One final issue related to misinformation is *synecdoche*, the identification of one trait with the whole, i.e. the whole fetus or the entirety of the prospects of the future child (Parens and Asch 2000, 14 and 27-28; Asch and Wasserman 2005). The original disability critique calls synecdoche into question. It sees synecdoche as a conceptual mistake which ties the value of an entire fetus or future child to the presence of a trait that has been socially-identified as problematic or unwelcome. The rejection of a fetus, then, is *by way of synecdoche* predicated on the presence of one trait. Through the lens of synecdoche, Savulescu assumes that the presence of one trait thought to impact quality of life is enough to make an embryo undesirable. Rich possibilities regarding potential persons are obscured.[53]

To add to the disability critique, I further argue that synecdoche connects with geneticism and is influenced by the mistaken reasoning of genetic determinism. Genetic determinism, again, is a version of biological reductionism, the idea that wide swaths of behavior and social phenomena can be explained solely through biological factors. Synecdoche insists that future quality of life can be measured, at least in the present time, through the presence or absence of certain genetic traits, markers or indicators. So, the biological reduction occurring in the arena of prenatal testing and negative genetic selection is a specifically genetic reduction. In this arena, it is believed that future phenomena, including perceived ills and problems on the level of the individual, can be predicted reliably by reference to genetic data, and these predictions should be actionable. This is part of a strategy of actuarial thinking. Perhaps most troubling is the notion, attendant upon the practice of genetic selection, that one might "choose" quality of life for a future child; this clearly over-emphasizes the importance of genetic factors. It showcases a bias, geneticism, toward genetic impact factors over those of environment and society.

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[53] There is slight overlap between 1) the view of proponents of the disability critique and 2) the view that parents have a significant ethical burden of reproductive responsibility including the duty to test for certain traits. For example, on both views, it would be wrong to knowingly take action during pregnancy that would harm the fetus, such as conceiving while one has rubella (Savulescu 2001, 417). This overlap exists because, I argue, there is a distinction between preventing harm for a particular child and preventing a particular child in order to avoid the existence of a disability. To put it yet another way, there is a distinction preventing harm (through the use of folic acid, for example) on behalf of a child or a potential child, and preventing a potential child because of an unwanted trait (cf. Parens and Asch 2000, 16). The difference is one of emphasis, which hearkens back to the concept of synecdoche. Preventing a potential child because of an unwanted trait can showcase an undue belief in the influence of that trait, which in turn may be inflated by undercurrents of genetic determinism. It is also a thoroughly marginalizing practice, one which presumes what types of lives are worth living and fixates on preventing specific bodies rather than adjusting social institutions.

To put these issues a slightly different way: genetic determinism positions genetic cause as ruling over individual outcome. Synecdoche, likewise, positions a "disability" trait as absolute or autonomous limitation upon individual quality of life. Synecdoche identifies one trait of the fetus as of utmost importance. It makes this partial information about genotype appear to enable the choice for or against a particular kind of a child, seen primarily through the lens of genetic traits. Using only the lens of genetic traits belies the known influences of environment, the complicated relationship between genotype and phenotype, and the fallibility of genetic predictors (Gupta 2012, Kolata 2012). Genetic selection, seen as the choice of outcomes in quality of life rather than intervention upon mere traits, would provide a potential parent with a child who is chosen as opposed to one that is the product of chance.

The other elements of misinformation I drew out from Asch's work, above, are *also* linked to biological reductionism. First, the notion that lack is always negative or that the size of one's predicted opportunity range is of primary importance relies on the idea that *biology is destiny*—certain physical facts about one's body will always be determinative for the type of life one leads. This resonates with the history of enhancement I drew in the previous chapter. Second, the medical model attributes primary importance to the physical facts of one's body, while disregarding the extent to which accessibility, stigma and bias in the social world can contribute to, or work against, one's quality of life.

The original disability critique also involves a version of a parental ethic or an ethic of parental acceptance. Erik Parens and Asch write: "In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics may occasion" (2000, 13). Parenthood, on this view, should involve acceptance of a child's traits, whatever they may be, at the risk of otherwise suggesting a commitment to an ideal that a child may have difficulty reaching. This point has been critiqued by Bonnie Steinbock as unrealistic and is similar to the thick parental ethic promulgated elsewhere by Michael Sandel (Steinbock 2000, 122; Sandel 2004).[54] Some might argue that it is inappropriate to evaluate an individual's parental potential from the outside, based on a perceived willingness or unwillingness to accept a future child. Yet, there is a significant insight buried here which can be employed to critique troublesome social circumstances and ideals, not individual parents.

I argue that first, individual women may make an assessment of their circumstances in light of the results of prenatal testing and determine that they do not have the resources, social support or otherwise have access to the tools necessary to raise a particular child. This should not be read as a failure of an individual woman, as some versions of the disability critique might suggest. Instead it should be a jumping-off point for a searching investigation of what forms of life society welcomes and a motivation to begin working politically to make the distribution of medical care, housing, and other

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[54] For Sandel, parenthood is the lynchpin for humility, a hard-won character trait in a social world bent on domination (2004, 56-57). Sandel argues that within the scope of parenthood, unlike in other areas of life, we cannot make explicit choices (56-7). Sandel also argues that genetic enhancement and selection "would disfigure the relation between parent and child, and deprive the parent of the humility and enlarged human sympathies that an openness to the unbidden can cultivate" (57). The enlarged sympathies he refers to are connected to a universal susceptibility to chance. By way of this argument, Sandel seems to suggest that genetic selection or human enhancement operate in a realm of unmitigated choice, and that chance and choice are opposed to one another rather than existing side-by-side (cf. Oliver 2010). This problematically inflates the power of genetic selection or genetic interventions.

social goods more just and equitable. While the disability critique is not usually used to inspire this conversation, I argue that it can and should be.

Second, on my view (and to further Parens and Asch's discussion of a parental ethic), *any* child will fail to reach normalized societal ideals. A *selected* genotype, taken as a guarantor of a better child (one closer to society's vision), lends support to the discredited idea that genetic factors uniquely determine phenotype, opportunity range, and quality of life. Taken as a kind of guarantee—the "selection" of a child or a life—a genotype selected for or against appears to stave off unpredictability and chance. Where a selection is made, chance does not rule, and quality of life will improve. Savulescu, in articulating procreative beneficence, does not claim that selection is a *guarantor* of success and happiness for a child. But the *impression* that this practice is a guarantee is a troubling and predictable implication of arguments for selection. Support for my view is available in the case of wrongful life suits; if it were not for the notion of a guarantee when testing *does not* uncover a trait that parents wish to avoid, these suits would not be successful in court (cf. Shiffrin 1999).[55] Parents may feel that through genetic selection they are choosing a life of unbounded possibility as opposed to known or absolute limitation. But this is an illusion—selecting against specific traits does not guarantee future happiness or an untroubled life.

I argue that the gulf between the norm ("species-typical") and deviant embodiment creates impossible standards. Disability theorist Rosemarie Garland-Thomson refers to the opposite of the abnormal as the *normate*, an empty point of

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[55] In a recent case in the state of Oregon, parents launched a multi-million dollar lawsuit against a hospital for failing to detect Down syndrome in their 4-year-old daughter. The parents claim that they were "assured" that the results of tests for the condition were negative (Heasley 2012).

reference that no one embodies. Again, here, attention to the workings of genetic determinism can deepen this discussion. “Normal” genotypes also function as empty points of reference; there is no person with a genotypic “blueprint for normal phenotype” (Scully 2008, 6, see my discussion of genetic determinism in chapter one). Negative genetic selection, as a cultural practice today, re-enforces the normate and corresponds this construct with individual happiness or quality of life. ”Canonical genotypes” are conceptual constructs built by social and cultural values, and deviance is filled out by way of what society tolerates. The basis for “normality” is imaginative—it connects biological causes to what are considered to be desirable outcomes, which in turn represent desirable characteristics. These desirable characteristics always have reference to the social world and its delineation between normal and abnormal, acceptable and stigmatized.[56] Like the “normate” (the “unblushing,” abled, heterosexual, educated male who is Christian, plays sports – the list goes on, Garland-Thomson 1996, 9) – the canonical genotype is empty. No one person is owner of the “canonical genotype” – variation is constant (cf. Scheer and Groce 1998).

Moreover, there is no reason to believe that widespread use of enhancements, even genetic selection, would create an orderly Gattacan world of unbounded successes, happiness, and pure opportunity.[57] Hope that it might, expressed by enhancement

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[56] Cf. Margaret Olivia Little’s essay regarding medical practice and the importance of refusing “cultural complicity” in stigmatizing practices (1998). Of course, also important here is Foucault’s guiding work collected in his lectures under the title of *Abnormal*; see my Introduction (2003). Bioethicist Eric Juengst notes that some enhancements can improve a recipient’s social standing but only by perpetuating the stigma involved—the problem is deeper than he realizes (1998, 41).

[57] Gattaca, DVD, directed by Andrew Niccol (1997; Culver City, CA: Columbia TriStar Home Video, 1998). In the world of this sci-fi film, there is near-universal use of genetic selection technology via IVF and selection of one embryo from among many. The hero, however, is un-enhanced, and is able to perform and excel in his space program. A second hero, enhanced, suffers under the “burden of perfection”

proponents, expresses at least *genetic bias* if not unwitting support for genetic determinism. Lurking in the background is the idea that an identified and selected genotype can produce a predictable set of results and is susceptible to manipulation through pure choice and no chance (cf. Oliver 2010). Hope that genetic intervention can at least guarantee lives of fewer obstacles, burdens, or less suffering, also expresses genetic bias. Savulescu is working from genetic bias when he advocates selection for traits connected to enhanced cognition, no matter how weak the link between genotype and phenotype, or how "accurate" the tests for intelligence (2001, 414). Genetic interventions are costly and time-consuming, both for individuals and for societies that invest in their use. If, for Savulescu, they are important enough to advocate for and invest in even when the linkage between genes and quality of life is weak, he positions these interventions among many other possible social and medical investment strategies as primarily important. Perhaps, then, these strategies are useful as a result of the bodies they reject, not the bodies they create.

I will loop back now to the original disability critique. On a final line of argumentation generally referred to as the *expressivist view*, the disability critique contends that prenatal testing and genetic selection, as attitude and practice, send a hurtful message to already-existing persons with the traits in question (Saxton 2000, 148; Asch 2000b, 236). Asch clarifies:

> As with discrimination more generally, with prenatal diagnosis, a single trait stands in for the whole, the trait obliterates the whole. With both discrimination

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(Shapshay 2009, 89); he struggles with depression and the after-effects of a suicide attempt. The contrast between these two lives and the presentation of these characters on screen is meant to belie belief in genetic determinism. Yet, many other elements of the film, such as the successful space program with its uncanny multitude of near-identical astronauts who excel physically and mentally, complicate this goal (cf. Holden 1997).

> and prenatal diagnosis, nobody finds out about the rest. *The tests send the message that there's no need to find out about the rest* (Parens and Asch 2000, 13; emphasis mine).

The hurtful message tells already-existing persons that their lives are not worth living. Ultimately, Asch suggests that "trying to screen for and prevent the birth of babies" with certain traits "disparage[s] the lives of existing and future disabled people" who share these traits (Parens and Asch 2000, 13). It also misconstrues their lives. Synecdoche upholds this message by prioritizing single traits over future wholes. Asch and David Wasserman suggest that synecdoche is a moral "failing" (notice that they do not mean the act of negative genetic selection itself, although they might mean a parental ethic or attitude behind an act) (2005, 173).

Asch and Wasserman, along with others who articulate or adhere to the disability critique, recognize that not all instances of selective abortion must be interpreted as ableist or motivated by stereotyping and stigma. Asch and Parens write: "Parents may examine themselves and conclude that they are not choosing against a child's specific traits; they may be making an honest and informed acceptance of their own character and goals" (Parens and Asch 2000, 22; cf. Asch and Wasserman 2005).

Reproductive Liberty and Genetic Determinism

I turn now to the specific rejection of the disability critique on the basis of its supposed threat to reproductive liberty. Savulescu posits that claims like the disability critique require parents unwilling to raise disabled children to create and support such children (2001, 423). He assumes that proponents of the *disability discrimination claim* (as he calls it) support a ban on genetic selection procedures and selective abortion in response to the presence of certain traits (423). In fact, as I will show, this support cannot be found among the major proponents of the disability critique.

Like Savulescu, James Nelson views the disability critique as inimical to reproductive liberty and rejects the idea that any amount of stigma suffered by existing persons could be sufficient reason to force an unwanted pregnancy (2010). Daniel Brock has argued that even if one assumes the expressivist view is correct in that negative genetic selection involves a hurtful message sent to already-existing persons, the disability critique would involve a threat to reproductive liberty (2009, 258). Steinbock situates the decision to selectively abort on the basis of a disability trait as acceptable for the same reasons any abortion is acceptable: so the woman is not forced to take on unwanted burdens (2000, 119). On my view, the above objections aiming to protect reproductive liberty are all at least partly based on a misunderstanding of the locus of the efforts of the disability critique and a dismissal of its potential insights regarding synecdoche and potential connections with genetic determinism.

Disability advocates interested in promoting a version of the disability critique need not subscribe to a view that precludes reproductive liberty in individual cases (i.e., advocating forced pregnancies) to voice concern regarding the marginalization, stigmatization, and prejudicial attitudes developed and expressed through the social practice of genetic selection on the basis of disability traits (Parens and Asch 2000, 12). In fact, Asch holds that potential parent(s) should be the primary decision-makers regarding their reproductive liberty (Parens and Asch 2000, 22; cf. Asch 2003, 317 n. 6 and 332-34). She writes: “I, and nearly all others sharing a disability rights critique of prenatal testing, maintain an ardent pro-choice stance and assert that women should be free to make any decision they wish about maintaining a pregnancy or having an abortion" (Asch 2003, 317 n. 6). As Parens and Asch articulate the critique:

> The disability community arguments are not intended to justify wholesale restrictions on prenatal testing for genetic disability. Rather, they are intended to make prospective parents pause and think about what they are doing and to challenge professionals to help parents better examine their decisions. They [should] help make our decisions *thoughtful and informed, not thoughtless and automatic* (2000, 28-29, emphasis mine).[58]

The best outcome, from the standpoint of the disability critique, is that potential parents, having resolved to have children, reflect carefully on what testing can reveal about their future child. For proponents of the disability critique, reflection should not be burdened by undue coercion from medical professionals, which can devolve into a shaming process and contribute to systemic marginalization and prejudice (recall Savulescu's contention that persuasion is acceptable when doctors seek to protect procreative beneficence). I am thinking specifically of situations like one in which a genetic counselor reportedly asked an expectant mother, "What are you going to say to people when they ask you how you could bring a child like this into the world?" (reported in Parens and Asch 2000, 7). Or, in another example, an obstetrician remarked to a woman that "the quickest, cheapest way to solve this problem is to terminate the pregnancy" (reported in Piepmeier 2013). Instead, medical professionals should encourage reflection and take care not to overstate the predictive power of genetic testing.

I argue that the potential impact of particular traits should be downplayed; as Steinbock rightly argues, this does potential parents, potential children, and the disability community no favors (2000, 119). It is, however, of utmost importance to neither

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[58] This is reminiscent of Kelly Oliver's Derridean approach to ethics, which emphasizes the importance of interrupting the "answering machines" which we rely upon to automatically respond to others (Oliver 2013).

overstate the importance of genetic factors among others when it comes to quality of life nor accept and amplify the effects of prejudice and stigma against persons with disabilities by treating these as *inherent* to certain traits without reference to the social institutions and circumstances which actually create them.

On Whom Does the Onus Rest?

I now call on my own version of the disability critique—and continued reference to the influence of genetic determinism—to argue for specific locations of application of the disability critique. On my view, the appropriate loci of the disability critique are: discourse in medical and scientific realms which exacerbates geneticism or the influence of genetic determinism or takes recourse to an unmitigated medical mode of disability; and lack of reflection upon synecdoche in social and institutional encouragement to select. Finally, the disability critique should be used to help us recognize the need to pair critique of these issues with *activism* aimed toward social and political changes in medical care, insurance, public policy, transportation, accommodation, and schools. We need to create a more just system to alleviate marginalization of and discrimination against persons with disabilities. So many social institutions effectively "hide" persons with disabilities from view—sheltered workshops, relegation to nursing homes, extreme lack of public transportation.

Here again, a model of disability which can attend to social constructions of disability and stigmas against persons with disabilities is a requirement. Unfair stereotyping of disability occurs when one naturalizes or materializes disability—that is, conflates social constructions regarding persons and groups, and stigmas connected with these, with facts about the body. I take synecdoche to be the most significant insight of the original disability critique; synecdoche works as a naturalizing pattern by focusing merely on rejected traits themselves, as materializations of disability, and so prioritizes isolated traits over social circumstances as primarily important. Synecdoche hides what is in plain sight from view.

Synecdoche is constitutive of what the original disability critique refers to as the "hurtful message" sent by the practice of negative genetic selection (that the lives of those with the trait in question are not worth living), and so is a key element of the disability critique. But, as it stands in the original critique, "the hurtful message" feature of the disability critique seems to require that one argues that individual reproductive decisions send consistent, intentional messages which fail to significantly vary (Nelson 2011).[59] Furthermore, synecdoche is not only inaccurate and hurtful, it contributes to material social conditions that render those who experience disability a heavily stigmatized and marginalized minority which cannot significantly access public life.

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[59] Nelson writes: "people's motivations and reasons, their understandings and aims, are so various as to preclude our being able to say 'this behavior can only be understood as sending a resentment-worthy message.' Abortions after genetic screenings are not sentences, nor are they even symbols—and even if they were, of course, what people mean in using sentences, or in running flags up poles, is various and contestable" (2011, 66). Nelson goes on to argue that motivations for terminating a fetus with a disability trait "will typically be less hateful" than those motivations that proponents of the disability critique might argue are behind genetic selection (67). Yet, as I have argued thus far, I think that the focus of the disability critique is better rested upon the aggregate social impact of negative genetic selection than upon women or individuals making decisions. I concede that it would be unfair and very likely incorrect to insist on arguing that particular individuals are driven by hateful motivations when they decide to terminate particular pregnancies. Instead, it seems most helpful and best to argue, especially in the context of the transhumanist utopias I am discussing, that the social practice of genetic selection and the particular urgings of the medical community have the effect of large-scale commentary on which lives are worth living and which bodies society wishes to produce. While "abortions after genetic screenings are not sentences," genetic counselors and medical professionals speak sentences, internet resources post sentences ("running flags up poles"), and in most cases these and other sentences are both *uniformly ableist* and have tangible effects on individual decision-making.

Recognizing the pervasiveness of synecdoche should encourage us to enact social changes. Some have questioned the strength of a critique based on hurt feelings (e.g. Nelson 2011). But, as we have seen, hurt feelings are *not* the extent of what is at stake for either persons with disabilities or women as they make reproductive decisions in a milieu influenced by ableism and genetic bias.

Women should not be required, at the moment they are faced with the results of prenatal testing, to recognize and weed out the impact of the unfair and false binary between abled and disabled with regard to life opportunities, as well as the influence of genetic determinism. At the beginning of this chapter I indicated that the disability critique had both benefits and drawbacks; the key drawback, on my view, is the focus in some articulations of the critique on messages sent by individual women's decision-making rather than institutions as a whole (cf. Asch and Gellner 1996, 339 and Hershey 1994, 30 as quoted in Nelson 2007, 478). My expansion of the disability critique to include the notion of genetic determinism as a common fallacy with an impact on medical discourse and the provision of care is meant to adjust this claim beyond individual reproducers and the decisions they may make. I argue the decisions made by individual parents are currently unduly *influenced by* unsupported belief in the idea that genetic profiles taken before birth have measurable and certain impact on future quality of life as well as ableism in an unresponsive society.

Reproductive liberty is considered dependent upon reliable information from medical professionals and a non-coercive setting in which to make reproductive decisions. Bias toward genetic definitions of opportunity range or the undue belief in genetic determinism can thwart these conditions. Both can complicate the transmission of good information, foster misinformation, and put undue pressure on potential parents. But, importantly, there *is no* reliable medical information about quality of life. No matter how good or predictive prenatal testing becomes, no matter how perfect the transmission of information between a medical professional and a woman, predictions like this are inaccessible. This is because the richness of one's life, the access one enjoys to others and to the world, is dependent upon social and political responsiveness, just conditions, and the acceptance of diverse embodiment.

Sterilization Abuse and Institutional Practices

I here consider further the importance of focusing on the social world, institutions, and discourse rather than individual decision-making. Angela Davis and other feminists of color concerned about the rhetoric of choice in abortion politics raise an important distinction between reproductive liberty and reproductive justice, which calls into question precisely this issue: the failure to extend questions about reproductive choices beyond the sphere of individual liberty (Davis 1981; see also Smith 2005). Davis notes:

> The failure of the abortion rights campaign to conduct a historical self-evaluation led to a dangerously superficial appraisal of Black people's suspicious attitudes toward birth control in general. Granted, when some Black people unhesitatingly equated birth control with genocide, it did appear to be an exaggerated – even paranoiac – reaction (1981, 203).

But Davis goes on to note that "white abortion rights activists" had missed available "clues about the history of the birth control movement" in the strong reactions of the black community (1981, 203-204). Historically, the birth control movement advocated racist, involuntary sterilization; this advocacy extended to Margaret Sanger, the engine of the movement in the 1900s, and Theodore Roosevelt, U.S. President at the turn of the century (204, 209, 210). For Davis—writing in the 1980s—until involuntary sterilization and racism were substantially addressed and rejected in the abortion rights movement, reproductive liberty was non-existent for many women. She argued: "if ever women would enjoy the right to plan their pregnancies, legal and easily accessible birth control measures and abortions would have to be complemented by an end to sterilization abuse" (204).

The sterilization abuse to which Davis refers was sanctioned and enjoyed broad support both within and beyond the birth control movement in recent history. Involuntary sterilization laws were in effect in many states in the 1930s; "By 1932….at least twenty-six states had passed compulsory sterilization laws and…thousands of 'unfit' persons had already been surgically prevented from reproducing" (1981, 214, cf. Snyder and Mitchell 2006, 98). Margaret Sanger affirmed this state of affairs when she announced that the sterilization was right for: "Morons, mental defectives, epileptics, illiterates, paupers, unemployables, criminals, prostitutes and dope fiends" (as quoted in Davis 1981, 214). Davis adds that Sanger believed that if sterilization were refused, these persons "should be able to choose a lifelong segregated existence in labor camps" (214).

Sterilization abuse has an analogue in the history of slavery; for black women under slave conditions, abortion was not a solution, but a way to ensure that no children of their own would be brought into slavery, physical abuse, and sexual abuse (1981, 204). At that time,

> abortions and infanticides were acts of desperation, motivated not by the biological birth process but by the oppressive conditions of slavery. Most of these women, no doubt, would have expressed their deepest resentment had someone hailed their abortions as a stepping stone toward freedom (205).

For Davis, in order to succeed and unite women, the abortion rights movement needed to critically examine the historical conditions of forced abortions and sterilizations and acknowledge the impact of these conditions on attitudes among people of color toward abortion rights. Including a condemnation of sterilization abuse would have saved the movement in the 1970s, Davis argues (1981, 215).

Davis introduces a distinction between birth control and population control; the latter was an outgrowth of eugenic thinking and defeated the "progressive potential" of the birth control movement, which should have "[advocated] for people of color...the individual right to birth control" but instead refused to address the historical complexities that made people of color the intended victims of eugenic birth control (1981, 215).

Persons with disabilities, like people of color, are historically the victims of compulsory sterilization laws in the U.S. and elsewhere around the world (Snyder and Mitchell 2006, 30, 86, 91, 127, 186). By the year 1963, it is estimated that 63,000 individuals considered disabled had been "forcibly sterilized" in state institutions (86). Additionally, those with disabilities have fallen victim (and still fall victim) to a system of marginalizing institutionalization in sheltered workshops, nursing homes, and group homes that packs a triple threat of segregation, oppression, and underpaid labor (Diament 2012a, 2012b). The sexuality of these individuals is today still controlled as part of their isolation in nursing homes and institutions. Snyder and Mitchell comment that, starting in the late 1890s through the turn of the century,

> Institutional practices explicitly sought to extract defective citizens from participation in the social mainstream. In this regard, institutions for the feebleminded … in conjunction with the passage of marriage and state sterilization laws, eugenics institutions participated in erasing disabled citizens from public view with the full sanction of state and federal governments" (2006, 91).

The institutional practices in question also involved a type of incarceration which made "public intimacy" impossible, and "posed as safe, humane places for the 'treatment' of disabilities while operating essentially as research warehouses" (2006, 91). The continued history of forced and permanent institutionalization of persons with disabilities, working along with the compulsory sterilization laws that were common in the first half of the twentieth century, parallel the experience of people of color with sterilization and slavery. Both additionally experienced, and in the case of persons with disabilities, still experience restrictions on marriage as a result of these institutions and oppressive laws (cf. Snyder and Mitchell 2006, 127; see also the story of the soon-to-be-wed Paul Forziano and Hava Samuels, who are currently suing the federal government to live together after being refused that right by their separate group homes, in Heasley 2013).

The distinction between birth control and population control is very helpful in the case of disability rights; some disability rights activists and scholars now claim, just as people of color claimed in the 1970s, that what some view as the simple exercise of reproductive rights (genetic selection) is akin to genocide (e.g. Marca Bristo as quoted in Montgomery 1999). Just like in the former case, a full account of reproductive *justice* requires awareness and rejection of injustice, historical and current, perpetrated against persons with disabilities. A further parallel between the two: one justification for the racist application of what Davis refers to as "mass 'birth control'" (1981, 204) was the supposed hyper-fertility and simultaneous poverty of people of color (209-210, 213-214). Similarly, those with assumed cognitive disability were long considered more fertile—and thus in need of containment—than others: "the feebleminded woman who marries is twice as prolific as the normal woman" (1912 document, as quoted in Snyder and Mitchell 2006, 186).

In personal correspondence, Sanger admitted that an ultimate goal of the birth control movement was to "exterminate the Negro population" (as quoted in Davis 19821, 125). To draw my comparison to a close, I would like to note here Sharon Snyder and David Mitchell's interpretation of the intent of marriage restriction, sterilization and segregation in the case of persons with disabilities. They write:

> The legacy of eugenics was sweeping, systematic, and violently pathologizing because it founded its interventions on the mistaken faith in the ability to eradicate what is believed to be undesirable degrees of physical and cognitive differences from the biological record (2006, 86).

I argue that today's societal push for genetic selection is based on the *same mistaken faith*, and that the faith involved relies on genetic determinism for its strength. Human enhancement through genetic selection is bent on the eradication of difference. On my view, any critique of or intervention upon *only* individuals who plan to reproduce will be insufficient and also highly problematic. Instead, powerful and effective critiques must be institutional. They must focus on the discourse and rhetoric that poses genetic selection as a *choice* for better future humans, framing it within reproductive liberty. This is parallel to the framing of involuntary sterilization within the abortion rights movement of the previous century. We must also focus on making our world more accessible to and accepting of diverse forms of embodiment.

A Restatement of the Disability Critique

Laura Hershey reminds us that the "idea that disability might someday be permanently eradicated—whether through prenatal screening and abortion [or otherwise]…has strong appeal for a society wary of spending resources on human needs" (as quoted in Saxton 2000, 153-4). Just as in the original disability critique, my version of the disability critique argues that misinformation and bias perpetuated by the influence of genetic determinism is one locus of concern and activism, and another is the assumption that one can control the opportunity range or quality of life of a child solely through genetic selection. I further argue that we must attend to social and political circumstances to bear out the promise of the disability critique.

For Sandra Shapshay, in an echo of Christine Overall's distinction between preferences and practices, the only way to evaluate the practice as a social phenomenon is to step away from individual decision-making and examine the "collective irrationality" that can occur as a result of the unconsidered use of new genetic screening technologies and genetic abortion (2009, 92). Examining the character of the testing and screening as a social and medical practice is an exercise of utmost importance for the disability community, but it is *also* of utmost importance for reproductive liberty insofar as it can impact the quality of the information available to potential parents (even if this can never be perfect). Increasing the quality of conversations between doctors and potential parents on these topics is of vital importance for informed consent.

Here I identify the collective irrationality Shapshay points to as a facet or expression of genetic bias or belief in genetic determinism. Genetic indications for traits are in reality part of a complex network that impact traits. A constant barrage of news reports about isolated genes for a variety of conditions and behaviors may cause the belief that a treatment, cure, or solution to a problem or perceived problem is at hand without evidence for this belief (cf. Asch 2003, 335-37; Buchanan *et al*. 2000, 23). For conversations between medical professionals and potential parents to succeed in building a space of informed consent, tendencies toward genetic determinism in the larger social world should be combated.

The disability critique can expose pervasive injustices facing those in the disability community on the basis of belief in genetic determinism or geneticism and the pressure on potential parents to test for and select for, or selectively abort in response to, disability traits. As disability activist Laura Hershey writes, “We struggle for integration, access, and support services, yet our existence remains an unresolved question. Under the circumstances, we cannot expect society to guarantee and fund our full citizenship” (as quoted in Saxton 2000, 153-4). Social support of and investment in research regarding testing and selecting procedures for disability traits seems to preclude or at least complicate investment in accessible social spaces and needed services for existing persons with disabilities (cf. Asch 2003).

Prenatal Prototypes and the Spreading Effect

I now employ two other related concepts helpful to my version of the disability critique. These complement the notion of synecdoche and its linkage with genetic determinism. First, Licia Carlson argues that the genetic profiles taken of an embryo or fetus encourage the development of “prenatal prototypes” (2002, 207-209). I introduced prenatal prototypes in the Introduction. Carlson notes that some bioethicists, including Allan Buchanan and Laura Purdy, argue that the disability critique's expressivist view—the idea that selection against certain traits sends a harmful message—fails because of the "conceptual separation between traits and persons" (207). But, she argues, these critics have not done enough when they merely assert this separation, "given the complex relationship between disabling conditions and self-identity described by persons with disabilities" (207). Further, she argues, "*this distinction between qualities and persons cannot be made at the prenatal level*" (207, emphasis mine). She clarifies: "the separation between qualities and persons is impossible when the only means of eliminating the trait is abortion" (207). According to Carlson:

> The etiologic paradox of this new screening technology is that the genotype or chromosomal anomaly is visible prenatally, yet its phenotypic manifestation remains invisible until the child is born or years later (depending on the condition). I maintain that this indeterminacy creates the possibility of what I call prenatal prototypes: cases which are applied prenatally but are taken as representative of an entire class of future persons (208).

Carlson's prenatal prototypes dovetails with the concept of synecdoche; here, what is highlighted is partial but is taken as whole.

Second, researchers in the social sciences have investigated the operation of "impact bias", that is, "a tendency to overestimate the influence that events will have on one's QOL [quality of life]." (Smith *et al*. 2008, 653). They found that in the case of kidney transplants, those who undergo the surgery overestimate the impact that the surgery will have on their quality of life (2008). In fact, they found that patients succumb to a "spreading effect", that is,

> People may over generalize the improvement that would occur in health status to other areas. Indeed, we found that some of the most optimistic predictions for

> improvements were in areas that did not change at all after transplant, such as employment and travel (657).

The researchers suggest that it would be interesting to see how this “spreading effect” impacts quality of life prediction when it comes to perceived negative events, like disability – they wonder, will individuals “believe that disability will negatively affect areas of life that will actually be relatively unaffected?” (658). I argue that this is precisely what lies behind the encouragement of negative genetic selection; there is conceptual slippage between choosing against a particular, socially-stigmatized trait and choosing for a happy and free child.

Viewing genetic selection as a choice for a child unburdened by determination is an inflation of the power of the method. Endorsing synecdoche, employing “prenatal prototypes,” or succumbing to the spreading effect supports this view. Implicitly, these conceptual schemas link a genotype unmarked by disability directly to increased quality of life while de-prioritizing other factors. Contra Savulescu, medical doctors should take care not to contribute to or encourage existing social inequalities and stigma by explicitly advocating negative genetic selection in cases of disvalued differences (cf. Little 1998 on cultural complicity).

Screening methods and fetal diagnostics are a naming process, by which a fetus is connected to an already-existing group. A medical professional may explain to a potential parent that their baby will have Down syndrome, for example, which will call forward the figures of already-existing persons as a set of references. Marsha Saxton suggests that “When we refer to the fetus as a ‘disabled fetus’…the fetus is named as a member of our [disability] community” (2000, 159). If this calling forward were literal, involving meeting and getting to know actual members of the disability community, perhaps progress could be made. The calling forward, however, is merely symbolic; medical professionals name by way of diagnosis, which involves medicalizing the predicted condition of the potential person.[60] Saxton, referring to the work of Hershey, notes that "medical language reinforces negativity." Hershey claims: "Terms like 'fetal deformity' and 'defective fetus' are deeply stigmatizing, carrying connotations of inadequacy and shame." Medical practice, she contends, also tends to unfairly view the disabled as *permanent patients* who are "subject to the definitions and control of the medical profession" (as quoted and discussed in Saxton 2000, 149, cf. Scheer and Groce 1998, 34). Again, critique of the medical model is helpful. Persons with disabilities are patients sometimes, as are persons who are abled. Viewing the disabled as permanent patients ignores universal vulnerability and contributes to a fundamental binary between the abled and disabled. Most importantly, it is marginalizing and inaccurate.

Saxton further argues that testing "demands that the mother or couple face the moral task of identifying a potentially and *justifiably* rejectable 'other,' the 'defective fetus'" (2000, 158, emphasis mine). It is difficult to interpret Saxton's argument with regard to the identification of an "other" without reference to genetic determinism or bias. Genetic determinism leaves out and covers over ableist culture by naturalizing it as biological and genetic—biological reductionism. Instead of recognizing the conceptual roots of abnormality in a restrictive view of species-typical functioning or an unjust commitment to genetic ideals, the medical model refers to genetic mutation and birth injuries. The construction of the other seems natural, a specific consequence of variation

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[60] Parents whose newborn or infant children have a fatal condition request strongly that on-site medical professionals call their children by their given names (personal correspondence in April 2012 with Donna Patno, a nurse at the Cleveland Clinic Fetal Care Center in Ohio). I argue that this may be a reaction to naming via diagnosis.

from the normal genotype. But, once the normate and its varieties, including the genetic, are uncovered, work can begin to recognize its social construction.

Social and political goods for already-existing persons are at stake here, and are tied in an inverse relationship to the construction of a justifiably rejectable other. Overall, the practice of prenatal diagnosis and testing for disability traits can systematically perpetuate misinformation about disability (Parens and Asch 2000, 20-22; Saxton 2000, 149). The combined effects of the practice, as described above, can curb the distribution of social and political goods to perceived members of disability communities.[61] This is especially true in the current social and political context, in which persons with disabilities already experience marginalization and prejudice.

Without the guarantee that society will fund the citizenship of the disability community, there is a constant worry that already extremely scarce political and social goods (like appropriate housing, medical insurance, transportation and other goods and necessities) will disappear (cf. Hershey, above). It is with this worry at the forefront of my mind that I argue against the pernicious social and medical attitudes related to genetic determinism and synecdoche, which serve to uphold ableism and a false binary between the abled and disabled body. In this sense, members of the disability community demand respect that can only be expressed through a strategy of acceptance: *embracing* or *celebrating* disability as only one part of persons whose "lives—impairments and all—are respectable, acceptable ways to live" (Asch 2000b, 243; cf. Silvers 2009). The disability critique need not seek to ban certain reproductive decisions. Instead, it critiques the misinformation and bias of an ableist culture.

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[61] As James Charlton notes, individuals do not get to choose whether or not they are disabled—the choice is made for them in the social world (Riley 2005, 8-9).

Closing Thoughts on the Disability Critique

The transhumanist utopias with which we began have specific goals (futures) in mind, and Savulescu makes these explicit in his argument promoting the principle of procreative beneficence. For him, reproduction is like playing the Wheel of Fortune (2001, 414) – and genetic profiles of embryos and fetuses can provide us with the information necessary to discover what future child has the best chance at the best life. The disability critique, ultimately, is a path toward questioning the leap that transhumanists and Savulescu make when they consider genetic selection a route to a better life. Savulescu supports genetic determinism when they claim that selecting embryos is a key move (and a morally obligatory move) in providing one's children with the best chance at the best life (e.g. Savulescu 2001a). Savulescu's moral principle of "procreative beneficence" requires pre-implantation genetic diagnosis combined with IVF or, alternatively, the (for him) less psychologically attractive for parents but still compliant procedure of prenatal testing and selective abortion (Savulescu 2001a, 2001b, 2008). These are costly procedures that afford no guarantees. Again, Savulescu does not claim that embryo or fetus selection is a *guarantor* of happiness and health for an eventual child, rather, he claims that the procedure is like playing the Wheel of Fortune, in which unwanted traits like "bad tempers" and "asthma" are avoided by making the most of available information (Savulescu 2001a, 414, 417, 420). So, his focus with regard to the aims of procreative beneficence is certainly a case of privileging genetic factors over others.[62]

The encouragement of selection *à la* Savulescu has stigmatizing effects because it mimics the way stigma itself operates; that is, Savulescu disregards other factors impacting quality of life by focusing attention on particular, unwanted traits identifiable by genotype prior to birth. Stigma operates by fixating on the presence of a single trait, a trait then used to justify or provide a basis for social rejection. This is sociology's "spreading effect" – an inversion of value which makes parts more important than wholes, mimicking synecdoche. The part or trait commands attention and makes it possible to ignore the claims of the whole (Goffman 1963, 5). Put briefly: stigma is operative when communities draw conclusions about the imperfection of wholes on the basis of the single traits (*ibid.*, I return to stigma in chapter three). In the next and final section, I discuss how genetic counseling provides the framework for the transhumanist leap to genetic determinism and discuss the issue of choice in more detail.

Enhancing Risk, Enhancing Disability

In this section, I introduce genetic counseling and analyze how it presents genetic information and makes this information operational. Genetic counseling is a key part of the medical and cultural context of genetic selection. In the United States, genetic counselors can be genetic experts, physicians or other medical professionals (Davis 2010,

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[62] Given the more accurate "interactionist picture" of gene action (still influenced, de Melo-Martín notes, by genetic determinism—recall my discussion of genetic determinism in chapter one), even from a scientific point of view it is worse than myopic to focus on providing children with the best genes. Such a view focuses on genetic factors in a non-contextualized mode.

5). Or, they can be specifically trained through graduate study in accessing, presenting and interpreting genetic testing, earning a Master's degree and certification by the American Board of Genetic Counseling ("KidsHealth" 2012). Genetic counselors assist individuals curious about their own genotype and family history or who seek information during the reproductive decision-making process.

Genetic counseling may also occur much less formally, as through the data provided by private companies like 23andMe which offer at-home testing kits. According to 23andMe's website, "23andMe can help you manage risk and make informed decisions" (23andMe 2013). This service, in addition to its $99 at-home tests, offers an online "collection of education materials to guide you on your personal journey of genetic discovery. Explore our learning resources and discover the world of genetics" ("Genetics 101"). Sonia Gawel, a satisfied customer whose endorsement recently appeared on 23andMe's homepage, writes that the company is "seriously amazing! Learning so much about my genetics/disease risk/traits, etc. Now I can design my lifestyle for prevention!" (review posted to website June 26, 2012). In other words, the genetic data Gawel received from the company may allow her to interpret the risk posed by certain activities on an individual level (a healthy diet and exercise may help alleviate the genetic predisposition to cardiovascular disease) and bring information about her traits to the table when it comes time to reproduce. As I mentioned at the beginning of the chapter, genetic counselors can help those with known conditions (like hereditary dwarfism) understand how these traits may appear among future children.

Genetic counseling in formal settings is ruled by multiple strong norms of professional conduct. I will discuss two of the most important norms here. First, genetic counselors reportedly value and seek to maintain the autonomy of their clients above all else, a fact which Dena Davis claims is easily explained by a handful of factors, including awareness of the threat of coercion (informed by cultural knowledge of eugenic history) and the fact that many consider reproductive decision-making to be an extremely private affair (1997, 7 and 2010, 13-17). Second, genetic counselors are committed to nondirective counseling, as stated in the Code of Ethics of the National Society of Genetic Counselors (quoted Davis 1997, 8). Nondirective counseling is articulated by the profession as the presentation of facts and the exploration and realization of parental values without interference or input stemming from counselor values or outside influence (quoted Davis 1997, 8).

There are two ways to read the concept of choice (and, therefore, autonomy) in the arena of genetic counseling. First, through the work of Anne Waldschmidt, I will consider the production of an autonomous subject who can choose to avoid risk ("Now I can design my lifestyle for prevention!"). Second, I will consider Dena Davis' argument that the choice parents enjoy with regard to reproduction is at times trumped by a child's own right to a future autonomy, an "open future." Exploring the play of choice in these two ways will allow us to uncover the mythos of the disabled body as a site of risk, and the unmarked or abled body as a site of choice. This leads me to the conclusion that in the logic of biology as destiny, the disabled and abled bodies are figured as opposites. I will also describe the way in which the fetus is presented as a site of risk—an "impaired fetus" to women or partner reproducers. I conclude that the milieu of prenatal testing and genetic counseling is a realm that "enhances" the concepts of risk and disability.

Anne Waldschmidt's essay "Who is Normal? Who is Deviant?" brings the practice and influence of genetic counseling into view through a Foucauldian framework of governmentality (Waldschmidt 2005). Foucault's work, again, is meant to capture the operation of normalizing influences in the creation of the subject and the boundaries and character of subjectivity. In the case of genetic counseling, "risk management" becomes the management of the subject and the development of the roles of parent, impaired fetus, and "value-free" counseling in a network of actuarial thinking.

Waldschmidt insists on a distinction between "normativity" and "normality", arguing that normativity "refers to the power of social and legal norms that are imposed upon people" while normality "involves comparing people with each other in light of a standard" (2005, 193). While the former no longer has great purchase in neoliberal societies which focus upon autonomy, the latter appears and operates in "data-oriented societies" (194). Statistical data comparing subjects has a tight relationship with norms; "evaluations and expectations" (notice: not "value judgments") tag along after statistics themselves are crunched and publicized (194).

As we have seen, the contemporary field of genetic counseling relies fundamentally upon the principle of client (parent) autonomy, which is upheld through nondirective counseling (Davis 1997, 8). According to Waldschmidt, the practice maintains governing force over clients through *normality*. Genetic counseling presents medical, hereditary, and age-related statistics along with *risk* of deviation and associated costs to the potential parents and requires decisive action in response to those statistics. "Evaluations and expectations" are communicated and comparisons within the population are produced, but no value judgments are expressed by the counselor. The counselor expects the potential or actual reproducer to express their autonomy by taking action, and the expected action which best expresses autonomy in this context necessarily involves removing oneself from a field of perceived risk or protecting oneself against risk in some way (Waldschmidt 2005, 205). Not acting upon received genetic information can be seen as a refusal to exercise autonomy. Risk transforms the counseled individuals into specific subjects: autonomous subjects who can choose against "misfortune" by utilizing the platform of "statistical calculation" (204-205, cf. Morrison 2008).

In a hypothetical situation built from counseling experience, genetic counselor Dena Davis presents a case of risk communication and decision-making carried out between counselors and an older, relatively uninformed couple, Missie and Hank. Medical experts had determined from ultrasounds that the fetus Missie was carrying likely had spina bifida, a condition encompassing a range of impacts (2010, 9). While the experts were unsure whether the fetus would have spina bifida and were also unsure about how severe such the impact of this condition would be, Missie sought certainty. Remember, here, Carlson's prenatal prototypes, which are taken as guiding even when fundamentally indeterminant.

Davis reports that "the counselors, among themselves, had agreed that it was probably in Missie's best interest to abort. They had a 'gut sense' that the fetus was damaged, despite the slight chance that it was healthy" (2010, 10). After asking without success for more information, Missie told them: "Okay, I'll do whatever you tell me. Tell me what to do" (10). In response, "the counselors gently but firmly declined" to give Missie direction, and so eventually she made an appointment for an abortion, which the counselors considered provisional until Missie confirmed it from home (10). Despite

Missie's repeatedly expressed desperation for advice, the counselors refused to provide it, instead communicating only statistics and the prenatal prototype. Missie used this information to make her "autonomous" decision, which the counselors believed they had safeguarded by way of the communication of statistics only in compliance with their norm of non-directive counseling.

To analyze the context of Missie's decision, note that Missie was to absorb the possibility of risk and respond to it in an expression of (highly individualized) autonomy. She sought to connect personally with others in the context of her decision-making but was refused for fear of interrupting her autonomy. Waldschmidt evaluates the role of risk in communication between genetic counselors and potential mothers. She argues that the concept and deployment of risk establishes a gloss of neutrality and objectivity in genetic counseling, thus obviating the need for counselors to give "explicit advice" to mothers but still communicating a specific message about appropriate action (204). She argues that contrary to common perceptions of objectivity, statistical data developed regarding risks are constructed in highly contingent ways and can be expressed in a variety of forms which have predictable affective impacts on the individual to whom they are communicated (199-203). Her argument is supported by the narratives of women who are given or who have sought genetic counseling (Parens and Asch, 2000, 7; see also Saxton 2000).

Further, according to Waldschmidt, "risk" attaches itself to bodies (fetuses and mothers) through the practice of prenatal diagnostics which have been the subject of this chapter so far (197). She calls this the "individualization of risk" and argues that it operates as a "normalizing technique" in the case of decision-making (198). Autonomous and individualized decision-making, the goal of genetic counseling, is a complex process of situating oneself alongside or within a range of statistical normality and participating in the avoidance or management of risk. She writes: “In the past, experts could give direct advice; in the days of neoliberal government, however, they may only help clients to identify their own positions in the broad terrain of normality and deviation” (198). Sonia Gawel’s endorsement of 23andMe testifies to this focus on risk when Gawel equates risk with genetic data itself, enthusing that she is: “Learning so much about my genetics/disease risk/traits, etc.” Gawel takes up the role of risk management when she writes: “Now I can design my lifestyle for prevention!”

So, the body is a site of risk, and risk is most often interpreted as dangerous threat by those who encounter it or are told they may be susceptible to it. Any predisposition or tested trait deviating from a norm within a population becomes a risk and marks the body through prenatal diagnostics. Disabled embodiment—and even the bodies of mothers themselves, who should undergo genetic counseling even without any prior indications—becomes inherently risky, a dangerous threat. Recall that the newest diagnostic testing procedures merely compare fetal DNA to DNA from a presumptively normal person who stands in for a canonical genotype. Any deviance is risk—tracking individual linkages between genotype and trait becomes unnecessary.

Increasingly, at-home genetic testing kits (direct-to-consumer, or DTC kits) are being made available. The availability and marketing of these kits highlights the focus on autonomy and privacy that is made so paramount within the field of genetic counseling. It also represents an effort to provide individuals with as much data as possible so they can participate in autonomous decision-making, especially with regard to reproduction. But, to the contrary, Waldschmidt shows that the communication of statistical risk governs and normalizes the subject, which means that this increasing individualization and privacy promotes autonomy only on the surface. Continuing emphasis on individual choice and the proliferation of individualized data regarding genetics obscures the pointed goals of testing and screening. Genetic data is meant to provide individuals with tools toward ends already specified in medical and popular culture. These ends are the avoidance or elimination of certain conditions, seen through the imperfect (partial) lens of genotype.

Prototypes are here made operational. Writes Waldschmidt:

> statistics and prognoses are presented to real people, people who face real decisions and constraints - women who must quickly decide whether they wish to carry an unborn child to term, or abort it. And, of course, the normality-risk concept and the entire (insurance) setting within which the risk is presented do not allow any doubt about what kind of decision is expected from the individual woman: the decision not to have a child with a congenital impairment (2005, 205).

Waldschmidt exposes the value system at the root of the "facts" of heredity and genetic statistical risk. Employing the norms of genetic counseling requires a strong distinction between facts and values, but this distinction is unfounded. Remember the gut instincts held by the genetic counselors in Missie's case. Genetic data as presented in counseling sessions is anything but value-free and nondirective. Risk, used to communicate complex statistics, is a concept with affective resonance. It presents the probable or potential end state as a dangerous threat to be avoided, even when this characterization is unjustified.

Beyond acceptance that deviance is to be avoided, there is little significant reflection about what conditions should be targeted and what tests are important to develop and invest in.[63] The most frequently screened condition, Down syndrome, is targeted again and again as an undesirable condition, yet is not fatal or painful. Nemours, a pediatric medical system with hospitals in several states, maintains a website focused on children's health which provides information regarding genetic counseling for curious parents. This resource has the following advice to offer potential parents: "Experts recommend that all pregnant women, regardless of age or circumstance, be offered genetic counseling and testing to screen for Down syndrome" ("KidsHealth" 2012). Justification for this recommendation is not provided. And misleading statistics and outdated information regarding the cost of raising a child with Down syndrome have been used in recent years. For example, potential parents have been advised that their child may be either relatively typical cognitively or severely cognitively limited. This poses the chances of severe cognitive limitation as if it were 50 percent. But, in reality, the chances of severe cognitive limitation for a person with genetic indication for Down syndrome are below 5 percent (Elkins and Brown 1995, 18 cited Carlson 2002, 209). In fact, according to Carlson, "seventy-five to ninety percent of persons with Down syndrome are capable of living independently of their families and are employable as adults" (2002, 209).

Procreative beneficence *à la* Julian Savulescu could be brought forward as one strategy useful for reflection about what conditions to target and the avoidance of repeated prejudices. But, as I have already argued, this principle is laced with genetic bias

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[63] In a separate register, testing can be undertaken on behalf of the fetus. For example, in the case of fetal diagnosis of PKU, dietary changes alone can almost erase the impact that this metabolic disorder can have on bodily function. These dietary changes cannot be made unless doctors and parents are aware of the diagnosis. A second example is Rh negative disease, which refers to the conditions in the womb when the mother has a negative blood type and the fetus has a positive blood type. The mother's body has an auto-immune reaction to the fetus's blood and begins to destroy the fetus's red blood cells (Gale 2012). Lacking this information gleaned through amniocentesis, the condition is fatal immediately after birth.

and also fails to remedy the issue of repeated and reinforced existing prejudice. Procreative beneficence will consistently recommend to a potential reproducer that the best choice is to have a child who will be favored in existing society. Savulescu fully admits this result, but denies that such choices would likely produce significant inequality (defined, it seems, by population count) and if the choices did do so, procreative beneficence would require that new choices be made (2001b, 423).

Savulescu uses sex selection as an example, stating that a culture favoring males and selecting for males would eventually need to select for females, otherwise the privileged position of masculinity would actually be undesirable (because there would be no females to copulate with) (2001b, 423). But this is an unhelpful response to critics, because if Savulescu had used a different example (like race or disability) he would not be able to come to the same conclusions. In the case of persons with disabilities, because they experience societal stigma, their existence is not desirable on Savulescu's view and should be avoided as a matter of moral obligation. There are no emergent reasons to reverse course in the most cases decided by stigma.

Savulescu further argues that improving social life through tackling social inequalities and prejudices should not be attempted by way of reproductive decision-making, but this statement probably contradicts his view given that he attempts to improve individual lives through reproductive decision-making (2001b, 423). Surely it begs credulity for Savulescu to argue that he means this "improvement" to have no effect beyond the individual level. And, if his interest in individual improvement is not informed by social conditions, then it is cause for even greater concern—he fails to recognize the importance of social conditions for happiness.

Another conceptual option that might assist in the determination of what tests and screening procedures should be developed is the aforementioned “right to an open future” first promulgated by Joel Feinberg in 1980. The “right to an open future” is a bundle of rights that includes rights held “in trust” – those that a child cannot yet exercise, but which should be protected for future use (1980, 125). Examples include the exercise of religion, thought to be the arena of adults, or reproductive rights. This bundle of rights meant to ensure future autonomy and, therefore, an adult life with the most options or opportunities to articulate and pursue various versions of the good life. Translated into a genetic sense, violations of the right to an open future could include refusing to test for certain disease or non-disease traits, or choosing to create a child with what might be considered a limitation or risk. Savulescu’s procreative beneficence is meant to preclude precisely these assumed violations, among others.

Dena Davis picks up on this concept; she believes that genetic counselors and doctors should continue to respect parental autonomy in counseling settings, but also asserts that respect and protection of autonomy must not stop there (1997 e.g. 7-8, and 2010). Davis argues that a child’s *future autonomy* must also be respected and protected, and that sometimes concerns for the child must trump the strong norms of value-free information and nondirective counseling. Davis asserts that genetic counselors are rightly troubled when potential parents may deliberately seek what most consider the risks of reproduction: deafness, for example, or hereditary Achondroplasia (1997, 8). Specifically, she considers the dilemma posed to genetic counselors in the case of Deaf[64]

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[64] Deaf with a capital “D” denotes members of Deaf culture who see their status as deaf as neutral and consider themselves part of a political minority.

parents who wish to select for a deaf child and would potentially reject a "healthy" child.[65]

Davis worries that "elevating respect for patient autonomy above all other values" may make it "difficult to give proper weight to other factors, such as human suffering" and would perhaps be misleading in this case (1997, 7). She wants to reintroduce "space in which to give proper attention to the moral claims of the future child" (7). Davis re-frames the issue at hand, whether or not it is wrong to deliberately create a deaf child, as pitting "parental autonomy" against the "child's future autonomy" (8). In this case, she believes that the child's future autonomy is the most important factor and the value-free counseling that genetic counselors usually employ should be abandoned. The genetic counselor should refuse to help the Deaf parents.

Yet, in line with what I have argued so far, this assumes that "the right to an open future" is the purview of the abled body, a body which becomes the imagined site of undetermined choice. It is as if the open future is chosen and the closed future is discarded when one chooses negative genetic selection. This logic works only if one indulges heavily in genetic determinism and believes that prenatal prototypes, or single traits, give fully flowered information regarding a future child. This logic of the "spreading effect" also operates on the basis of a hierarchy between abled and disabled bodies – the marked body will always have a "more closed" future on this view, a presumption that is untenable. Some may venture that a child with Down syndrome will have fewer opportunities than a neurotypical child; but, even this assertion meets with

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[65] This is a difficult case, and while I here critique Davis' assumptions in her *response* to the case, I should note that I think the desire common among parents in Deaf culture to have deaf children can be expressive of the troubling aspects of synecdoche.

difficulty. Any particular child with Down syndrome could have more opportunities and pleasures than any particular "neurotypical" child, because opportunities and pleasures are structured by social reception, which can be hostile or welcoming. The "right to an open future," translated in the genetic sense while turning one's back on social factors, leads one to behave as though disability is equal to limitation and unmarked or abled bodies are the privileged site of choice.[66]

The woman or potential parent is constructed by the field of genetic counseling and the availability of prenatal diagnostics as a "risk manager"—an autonomous agent who responds to and manages risk. But I argue along with Waldschmidt that in these processes and practices risk attaches to bodies themselves. For instance, the woman's body becomes risky when she undergoes testing for genetic traits she may pass on to offspring. Furthermore, the fetus is the primary site of risk in these schemes. A new discursive category—the "impaired fetus" (the defective fetus) is brought into focus and augmented by these practices and innovations in these practices. While strong social models of disability tend to separate impairment and disability (in an echo of the construction of sex and gender) in order to argue that disability is socially constructed while impairment is not, it is important to notice that here impairment is socially-constructed via the establishment of the fetus as a site of risk and deviance (Tremain 2006).[67]

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[66] For an excellent feminist critique of the right to an open future, see Claudia Mills' "The Child's Right to an Open Future?" (2003).

[67] For more on the topic of risks, pregnancy and biopolitics from feminist perspectives see the work of Catherine Mills (2011) and Lorna Weir (1996, 2006).

Prenatal testing and selection strategies are not an enhancement strategy for individuals, as transhumanists imagine. Instead, these practices merely “enhance” notions of risk and notions of disability—that is, they amp them up, attach them with increased meaning, and link their management to the expression of reproductive autonomy in medical contexts. Extensive modes of normalization attend these practices. Autonomy is expressed by asking the question: what makes a livable life? And answering: a life without risk.

Rationing

Actuarial thinking in genetic counseling settings is heightened by systems of medical resource rationing. Stigma against persons with disabilities in the context of genetic determinism is especially important to discuss because of increased certainty, especially in the United States, that rationing health care is necessary, and because of various proposed means by which this rationing would be carried out (e.g. Fleck 2009). The technical meaning of “quality of life,” along with its measure, QALYs (Quality-Adjusted Life Years), was developed in the context of rationing and questions regarding the efficiency of health care. These quantitative concepts have nothing to do with subjective satisfaction; they are deployed to measure health care efficacy. A system of objective measures estimating quality of life calls into question, especially, the provision of expensive health care measures to ill, disabled, and elderly persons (Amundson 2006). Savulescu has explicitly called into question the appeal of equality of access when he considers cardiac care for persons with Down syndrome (2001c). Meanwhile, a recent “secret shopper” style study shows that persons using wheelchairs are already denied access to subspecialty medical care (gynecology and psychiatry, among others), although no strong rationing procedures currently exist (Lagu *et al*. 2013). This is true despite the legal provisions of the Americans with Disabilities Act meant to protect equal access. The study found:

> Of 256 practices, 56 (22%) reported that they could not accommodate the patient, 9 (4%) reported that the building was inaccessible, 47 (18%) reported inability to transfer a patient from a wheelchair to an examination table, and 22 (9%) reported use of height-adjustable tables or a lift for transfer. Gynecology was the subspecialty with the highest rate of inaccessible practices (44%). (Lagu *et al*. 2013, 441)

Today’s rationing conversations occur in an environment which already excludes and therefore stigmatizes persons with disabilities.

With regard to genetic enhancement and selection, bald cost-benefit analyses are often made. For instance, bioethicist Daniel Brock, in a talk regarding the prevention of “severe disabilities,” argued that “it’s a mistake to think that the social and economic costs are not a legitimate concern in this context” (quoted in Tremain 2006, n. 3).

Genetic screening for Fragile-X, a genetic indication that can cause cognitive impairment but *does not always* cause it, was undertaken in the 90s under explicitly economic terms. Proponents in Colorado noted that “the savings for the state” resulting from testing and selective abortion would be tremendous” compared to the cost of caring for those with cognitive impairment connected to the presence of Fragile-X (Nelson and Lindee 1995, 162-163). Alison Piepmeier, who interviewed women choosing to continue carrying a fetus which tested positively for indications connected to Down syndrome, writes: “One mother I interviewed was told by her obstetrician, “the quickest, *cheapest* way to solve this problem is to terminate the pregnancy” (Piepmeier 2013, emphasis mine). In 1989, an insurance company refused to cover the child resulting from a fetus which tested positively for cystic fibrosis (a monogenetic disease), citing the fact that the child would have a pre-existing condition (Thompson 1989).

The certainty of particular conditions and related characteristics for potential children varies according to what condition one considers and the specific tests and screening procedures applied. But, the influence of genetic determinism undergirds the cost-benefit analysis and rationing philosophy that drives and motivates testing and screening in public policy arenas. Genetic information must be taken very seriously as compared to environmental, behavioral, and other factors in order for the conclusions of such cost-benefit analyses to make sense. One must be reasonably certain that costs will decrease as a result of testing and selection and must downplay the costs of health care for "unmarked" fetuses (those that pass testing and selection procedures). This type of actuarial thinking is highly suspect and, as I have argued in these pages, is structured by the idea that disability is a genetic concept that can be rooted out. Its everyday usage and acceptability structures disability as a *risk* (of pregnancy, of genetic deviance) and so persons with disabilities become the inhabitants of risky and preventable bodies, the blame for which lies outside of social and political institutions.

Conclusion

A sustained critique of the promotion of genetic selection as a strategy of enhancement is necessary for feminist disability scholarship. It can expand issues of reproductive choice to those of reproductive justice and attend to the normalization attendant upon prenatal testing practices. In the preceding pages, I continued my consideration of the role of genetic determinism in discourse regarding medical interventions. I used the notion of genetic determinism in a restatement of the Adrienne Asch's disability critique. I also strengthened the critique through a renewed focus on institutions and social conditions. In the course of my discussion, I also defended the original disability critique against the objection that it aims to curtail reproductive liberty.

In conclusion, I name a central feature of utopian transhumanist futures: a chosen subject, selected because it is *not* marked by disability and so is thought to be impervious to chance. According to Mannheim, utopian thinking is focused on objects that do not exist. In the general case, utopian thinking obscures the present state of affairs by wishing fervently for a non-existing state of affairs. Transhumanist utopian thinking, I argue, focuses on a subject that is not real, a fantastic subject; that is, what I will now call the *techno-liberal subject*. The most pernicious feature of transhumanist utopian thinking is that the non-existent subject obscures and devalues the lives of all embodied persons. It wishes fervently for a subject whose absolute autonomy is ensured via choice-making mediated through technology. Through the lens of this wish, embodiment becomes inherently risky and undesirable. The limitations of embodiment are dramatized and villainized in transhumanist thinking.

One method used by Dena Davis, a genetic counselor, to justify choosing children in prenatal diagnostic or selection contexts is the concept of a "right to an open future," which I introduced above. I argue that this conceptual structure is key to understanding the specific utopianism of transhumanism. No person can have an unencumbered and *individual* right to an open future, because such a thing would imply that chance plays no role and an absolute proliferation of choice is available to that individual. Inhabiting an open future is the underlying goal of enhancement, and the vision is created without reference to holding a future *in common*, open because we can be in control of it together. The transhumanist version of utopia is peopled by subjects autonomous in that they are *undetermined by others*—but mediated by technology, that is, techno-liberal subjects. Transhumanists seek a kind of absolute freedom, chosen and controlled individually.

In this vein, parents are urged to make choices in order to ensure the choice-making capability of their future children—i.e., unencumbered space for individual autonomy. In other words, they are asked to determine what child they will have so that the child will be undetermined. Popular focus in bioethics on “designer children” obfuscates the point, since focusing on the “designed” character of progeny cannot capture the overarching quest for non-determination. There is a move here from urging reproducers to seek comparatively enhanced choice-making capabilities in future children (better, more, greater, most opportunity) to urging reproducers to seek an absolute choice-making character for their future child ensuring that child will experience no interference from chance. For the transhumanist, in order to achieve this end, the risks of embodiment must be subverted through reproductive choice-making. Choice-making is both the goal and the means of enhancement. To control the future and force it “open,” the transhumanist must absolutely determine it and attempt to preclude determination from any other source (anything or anyone else). The future is open to me when it is chosen by me.

Disability traits are risks – possible limitations on future freedoms. The transhumanist subject, by contrast, must be one that engenders no risks. A body carrying a disability trait, then, is this subject's opposite; it is viewed purely as risk through genetic counseling and figured as avoidable determination. Traits that can be screened in utero are seen as limiting; the future for the "impaired fetus" is imagined as a history already written—the transhumanists close this future. Un-enhanced bodies, then, seem to be locked in a field of risk. In sum, transhumanists seek to improve life through biotechnology. But the notion transhumanists have of improvement is rooted in utopia, specifically a utopian subject: the techno-liberal individual. This is, of course, an overly narrow and exacting version of what a good and fulfilling life looks like. The choice for the techno-liberal subject is a choice against certain kinds of bodies in the hope of improving life—positive and negative eugenics are here paired together. The transhumanists make a biological reduction while at the same time attempting to transcend the physical.

My discussion throughout this chapter, especially my presentation of the disability critique, leads to a more in-depth discussion of disability and a variety of models of disability, which I pursue in chapter three. I will consider a variety of models used to describe disability. I include the social model, employed in this chapter as part of the original disability critique, and the medical model, which I have argued is closely related to the fallacy of genetic determinism and which naturalizes the stigma of disability. I will argue that the "cultural model" of disability, with its Foucauldian roots, is the most helpful available model of disability. I also describe social constructions of disability and end with a focus on the issue of stigma.

CHAPTER III

MODELS OF DISABILITY: MEDICAL, SOCIAL, POLITICAL

> "I am constantly asked, after I have argued that disability is simply part of the human condition and intrinsically no better or worse than other aspects of that condition, if we shouldn't work to prevent disability. The expected coup de grâce is usually, shouldn't we do everything we can to prevent the birth of babies with disabilities? I answer quite seriously that this is an abstract question to me. What preconceptions do we start with, I ask in return? What particular social conditions will these particular kids grow up in? Then I pose a question in return. If we can prove statistically, I ask, that most baby girls born in certain districts of New York, Los Angeles, or Chicago or in any number of places throughout the Third World will have difficult lives, do we then start trying to prevent baby girls from being born? Of course not. We work to change the social reality those children live in. The fact that most children with disabilities face difficult lives has much more to do with the social environments they live in than their intrinsic physical or mental qualities. So the question of prevention always remains a question abstracted out of real life."
>
> James Charlton, *Nothing About Us Without Us* (1998)

> "We also know that what is a severe impairment and a mild impairment, what is a disability and what is not, is frequently determined by the way in which the persons with impairments are viewed."
>
> Eva Kittay, "The Ethics of Philosophizing" (2009)

> "The risk of basing identity in biology is that supposed biological difference has often been used to justify inferiority, whether in the case of black people, women, lesbians and gays, or disabled people."
>
> Tom Shakespeare and Mark Erickson, "Different Strokes" (2001)

In this chapter, I consider many competing models of disability. In the previous chapter, I troubled transhumanist promotion of genetic selection as a moral obligation and discussed prenatal testing and screening procedures. I take the transhumanist fantasy to be centered upon a chosen subject that is opposed to the risky disabled subject, so it is important now to linger on who counts as a disabled subject and what I mean by disability. I use the *cultural model* of disability and the concept of *stigma* in order to navigate these issues and argue that disability is deeply socially constructed, especially insofar as those marked as disabled are subject to systematic exclusions. The disability community can be traced by tracking stigma. While the disability community can be viewed politically as a minority community, like other groups that have sought civil rights and equal treatment, it is important to avoid the ways that a pervasive "minority model" might contribute to the marginalization of persons with disabilities and positions them as a *competing* group that participates in policing the border between disability and ability.[68] In what follows, I discuss this and other issues in order to explore the consequences of different ways of thinking "disability" and its social construction.

Thinking Disability

To further motivate the problem of defining disability, I will analyze Dena Davis' work on genetic counseling, particularly her latest book, *Genetic Dilemmas* (2010). In it, she slips between different ways of conceiving disability in a way that will help us get clear on what some of the main difficulties are in conceiving disability.

As discussed in the previous chapter, Davis makes explicit what kind of harm she believes can be connected to disability when disability is *chosen* by parents; specifically, a futural harm of narrowed possibilities, a closing-off of the so-called right to an open future (e.g. 2010, 59-60; 1997, 14). But she also seems to peg harm as an *endemic part* of

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[68] I elucidate this point with reference to Foucault in the course of my discussion in this chapter. Thank you to Lisa Guenther for stopping me in my tracks and pointing to the importance of this line of argument.

her definition of disability, especially when she talks about her primary case study: deafness. For instance, as a response to the Deaf community's self-identification as a cultural minority, Davis writes: "On the other side of the argument is the evidence that deafness is a very serious disability. Deaf people have incomes thirty to forty percent below the national average. The state of education for the deaf is unacceptable by anyone's standards; the typical deaf student graduates from high school unable to read a newspaper" (1997, 12-13). But how are these statistics *evidence* of disability? Given a context in which most deaf students are not provided with an interpreter in the classroom,[69] it seems that the statistics Davis lays out here are merely evidence of prejudice and stigma and do not signal something inherent that one might call "disability." We could parallel these statistics with statistics regarding, for example, the low-income status or imprisonment rates of racial and ethnic minorities—these numbers are evidence of prejudice, not direct results of features such as the color of one's skin, one's lineage, or one's birthplace. Similarly, it is not the fact of deafness that leads to the educational difficulties Davis mentions; instead, it is a lack of accommodation. Also, note that Davis is opposing "cultural minority" with "disability"—she assumes that the two concepts cannot overlap, without interrogating them.

Another example of the way Davis slips between the notion of disability and harm is apparent in the following passage: "Ethically, we would certainly include destroying someone's hearing as being a '*harm*'; legally, one would undoubtedly receive compensation if one were rendered deaf due to someone else's negligence. Many deaf

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[69] For complete analysis of the Supreme Court Case in which a deaf public elementary student was denied an interpreter, see Anita Silvers' discussion of *Board of Education of the Hendrick Hudson Central School District* v *Rowley* (2009, 180-181). I consider this case and Silvers' analysis of it in some detail in chapter four.

people, however, have recently been arguing that deafness is not a *disability* at all, but a linguistic and cultural identity" (2010, 65, emphasis mine). So, if deafness is not a disability for the Deaf community, Davis seems to be saying, they would not consider it harmful – therefore, disability and harm are employed here as one and the same thing.

Finally, Davis considers the famous Gallaudet University movement in 1988, when University students and faculty demanded a Deaf president for Gallaudet, protesting the appointment of a hearing president made by the board of trustees (The "Deaf President Now" campaign). Of it, she writes: "Looking at photographs taken during those tumultuous weeks, it is clear that the Gallaudet students regarded themselves as one more oppressed minority, not as a disabled group" (2010, 65). Here, Davis opposes the concepts of "oppressed minority" and "disabled group" as if it were impossible for one collective to be both at the same time. This is another slippage: if Davis believes these two ways of describing a group are mutually exclusive, she fails to make her reasons explicit.

Because Davis focuses on Deaf culture, it's important to note that Davis is correct when she asserts that "many deaf people, however, have recently been arguing that deafness is a not a *disability* at all, but a linguistic and cultural identity" (2010, 65). In other words, at least some deaf persons, who identify as part of the Deaf community, reject the label of disability. The questions we are left with include: what is disability? Is it embodied "harm"? Does it make protest impossible? If disability culture exists, does that make it necessary to shed the label of "disability," as some in the Deaf community and Davis seem to believe? Why does identifying as "disabled" seem to eclipse and delimit other identities which a person might take up?

As we have seen, one of the reasons defining disability and working with disability as a political identity is a difficult task is that current and historical prejudice must be taken into account (cf. Parens and Asch 2000, 5). For many in the disability rights community, “discrimination results when people in one group fail to imagine that people in some ‘other’ group lead lives as rich and complex as their own” (8). Activist William J. Peace has argued that the confines of the current euthanasia debate, which tends to assume that death is preferable to living a life with disability, expresses this failure of the imagination (2012). Surely, however, as he also argues elsewhere, dismal institutional failures and a lack of social responsiveness are also to blame and can be sources for these imaginative failures (2013a, 2013b). At the very least, it is clear that the notion of disability is fraught with value judgments and subject to deep and multiple exclusions; I drew an alternative eugenic history of a group of these judgments in the first chapter. To call someone disabled involves just as much an evaluative judgment as a description. Imported into the concept are complex and shifting stereotypes that are difficult to reverse. And, politically, the negativity connected to illness and limitations connected to disability makes politically ironic “reversal” moves open to other groups, like people of color, much harder to accomplish. Disability theorist Irving Zola writes of disabled activists: “Could they yell, ‘Long live cancer’ ‘Up with multiple sclerosis’ ‘I’m glad I had polio!’ ‘Don’t you wish you were blind?’” (1993, 168).

Further, isolation issues among persons with disabilities make it difficult for individuals to organize together. A person may be integrated with family or friends who may not and likely do not share their disability, and so, writes Zola, “they are socialized into the world of the ‘normal’ with all its values, prejudices and vocabulary” (1993, 167).

This particular kind of isolation is somewhat unique to the case of disability, although others—including those who identify or are identified with excluded sexual identity—will share in the problem of isolation.

Another reason discussion of disability generally is so difficult is that, if disability as a phenomenon at least somehow begins in traits borne by the body, there are no uncontested frameworks for which traits *count* as disabilities—what about mental illness and alcoholism? Furthermore, many tend to think of disability traits as existing along a spectrum from more to less serious or debilitating, an inherited tendency of looking at disability through a medical lens (I discuss the "medical model" in detail below). So, layered on top of the difficulty of saying whether someone with diabetes, for example, has a disability, we also encounter the difficulty of describing which, among a variety of traits, are considered "serious" disabilities. And, of course, professionals with power to impact the shape of discourse, like the genetic counselors I discussed in the previous chapter, cannot agree, and the very act of creating these types of hierarchies and taxonomies shapes the contours of disability, creating gradations of stigma and a variety of responses. According to Parens and Asch, "genetics professionals have very different ideas of what is and what is not" a trait that is significantly disabling (2000, 9, cf. 261). Specific examples of contested traits for geneticists include: "cleft lip/palate, neurofibromatosis, hereditary deafness, insulin-dependent diabetes, Huntington disease, cystic fibrosis, sickle cell anemia, Down syndrome, and manic depression." These traits "were deemed serious by some professionals and not serious by others" (9). Serious presumably means that such traits should be medically intervened upon—i.e., that they are in need of correction. And, of course, in addition to inherited traits that have taken center stage in my project so far, illness or accident is also commonly considered disabling; examples include blindness, deafness, paraplegia or limb loss, along with traumatic brain injury and myriad other conditions.

Uneven allegiance to disability identity among persons who might fall under these categories contributes to the complications of the *political* question of disability identity. Some will object that there is no disability community—that such a thing is too inchoate to be discussed in practical terms because of the heterogeneity of the potential members of the community.

As for more thoroughgoing schemes, the World Health Organization (WHO) distinguishes among *impairment*, *disability* and *handicap* in a way helpfully summarized by Bonnie Steinbock:

> Paralysis of the legs (perhaps resulting from polio or spina bifida) is the impairment; the inability to walk is the disability; but it is 'the social consequences of that disability—the refusal of employers to hire a disabled person…that renders him or her handicapped.' A disability becomes a handicap due to the choices of individuals and organizations. Handicaps are the result of social choices; they are not part of the 'fabric of the moral universe.' Because they are chosen, they can be changed (Steinbock 2000, 113-114, quoting from Scheer and Groce 1998, 24).

It seems clear from this tripartite scheme that at least some people would agree that disability is both physical and social. In other words, perhaps we could tentatively say that collective political action can relieve a "handicap" or "disability" through social measures, and medicine can relieve an "impairment," both of which have bearing upon a person's potential or actual disability. Yet, from here, the issue only gets more complicated. Consider the way that an impairment/handicap or impairment/disability distinction operates as an analog of the sex/gender distinction—are impairment and sex therefore "natural" categories that are not constructed symbolically or socially?

Furthermore, schemes like this serve to deny or hide positive aspects of disability identity. How do the biological and the social interact, and in what sense does medicine play a role in the lives of persons with disabilities? Should medicine play this role? How does this identity actually operate? To begin to answer these questions in a serious way, we must turn to diverse work in disability theory.

In the previous chapter, I briefly introduced the notion that there are different models of disability, and discussed two in particular: the *social* and the *medical* models. Here I re-introduce these models in their place among other ways of conceiving disability, and discuss the drawbacks and complicated reception each has received among theorists. These models set out to accomplish very different things, and so I orient models of disability not only conceptually but also in terms of the goals and motivations for their construction. Taking a birds' eye view of models of disability in the pages that follow will help illuminate the way in which persons posed as "abled" and posed as "disabled" meet each other at the border between these two roles.[70]

Models of Disability

There are a number of models of disability, which are either posed as solutions to problems facing persons with disabilities or which have been constructed to approximate what is found to be problematic about existing conditions. That is, I argue, models of disability are typically meant to either *symbolize* or *solve* problems of exclusion and

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[70] I am not exhaustive here in my consideration of models of disability; there are a few models I will not consider here, such as the "consumer" model, which would position persons with disabilities as an untapped market (cf. Riley 2005). Also, there are many variations on the models I consider here that are beyond the scope of this project.

stigma that come along with physical and mental difference. More rarely, methods are used to symbolize what it is like, experientially, to have a disability; for this, something like a phenomenological or materialist account is needed (for this type of work, see Iwakuma 2002 and Scully 2008; I return to these more fluid schemes, below, by way of the "cultural model"). In disability studies, experiential accounts are also expressed through non-fictional, first-personal vignettes (e.g. Finger 2007), life writing (e.g. Mintz 2007), fiction (see *Ragged Edge Online*), and poetry (see Kuppers 2006 and *Ragged Edge*).

The Moral Model and the Charity Model

The "moral model" and the "charity model" are primary examples of models elucidated principally to persuade those who consider them to reject them as inappropriately limiting. Both also serve the higher purpose of telling a nuanced disability history and building an understanding of the social influences that form disability experiences in the US and globally. The *moral model* has been described as the oldest model of disability, primarily because it appears in ancient theological texts such as the Bible, Koran and the Midrash. On this model, disability of any sort can be understood as the result of sin—perhaps generational sin which is passed down from one's ancestors, or perhaps personal sin which has resulted in affliction from above (cf. Goffman 1963, 1-2). Disability historian Henri-Jacques Stiker writes: "This is illustrated in the Pharisees' question to Jesus concerning a blind man: "Who sinned? Was it he or his family?" (1999, 27). This model figures disability as impurity, attached to a body rendered therefore unfit to be in the presence of a higher power, and has been the basis for "ritual exclusion" in diverse religious contexts (Stiker 1999, 25).

The notion of moral desert when it comes to disability has not disappeared with time. This is evidenced in the rhetorical question "What have I done to deserve this?" It also appears in popular entertainment, which regularly uses markers of physical and mental differences as a way to indicate moral inferiority or the beginning of an immoral career to audiences (e.g. The Joker and Two-Face in *The Dark Knight*; and in thrillers, like Al Pacino's iconic role as Tony Montana in *Scarface* and Ernst Blofeld in *You Only Live Twice*; see also note 30 above regarding the work of Paul Longmore and Susan Sontag; see also Zola 1993, 169). Disability theorists Sharon Snyder and David Mitchell develop a theoretical understanding of use of the disabled body as prosthesis for the movement of plots and as dramatic device in their work *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000).

The *charity model* is much newer if we use an ancient timeline, but also has deep historical roots that continue to reverberate today. This model captures a particular mode of response to persons who are considered disabled: the response of charity, which construes persons as objects of pity. Charity as a response determines the characteristics that persons experiencing disability are expected to have. These expectations, in turn, limit the opportunities of those with disabilities. A very recent example of the charity model is the oft-cited Jerry Lewis telethon (funded by the Muscular Dystrophy Association), an organization that actor Lewis has defended against objections from the Disability Rights Movement (DRM) claiming that the telethons and associated advertisements are degrading ("Jerry Lewis" 1991). Lewis has been accused of infantilizing disability and obtaining income for his charity merely through generating pity among viewers, thereby frustrating the goals of disability rights activism (Stevenson, Harp, and Gernsbacher 2011). Lewis' defense of the telethons and his own infantilizing attitude has been bitter; he once shot back: "If you don't want to be pitied because you're a cripple, stay in your house" (Ervin 2009, quoted in Stevenson, Harp, and Gernsbacher 2011).

Snyder and Mitchell exhaustively detail the nuances of the charity model in the 19th century and forward. For example, they investigate classical literature, such as Herman Melville's *The Confidence-Man: His Masquerade* (first published in 1857). They write:

> Charity organizations assured that "excessive" need could be met with stern disapproval, moral disapprobation, and patronizing religious instruction. At the same time charity also provided a public benefit in recognizing individual contribution as a sign of beneficence, generosity, and commitment to capitalist values of self-reliance. Charity's provision of such an outlet for moralistic example demonstrates what disability historian Paul Longmore defines as the practice of conspicuous contribution: a cultural ritual in which the "economically able" garishly donate in public venues to help disabled people and bolster their own renown. Within these economic rituals, "disability" itself becomes a matter of performative interdependency as disabled bodies are made to appear unduly dependent and donors further solidify their own social value as able benefactors" (2006, 41, quoting Longmore 1997, 146).

So, charity simultaneously sets up a role for the abled person and a role for the dis/abled person, and the model itself circumscribes a particular level of dependence for the disabled while also reinforcing some of the capitalistic values that oppose disability and ability in the first place. And, the charity model provides a moral education for persons who are abled *by way of* the disabled person and their body, the object of charity.[71]

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[71] I return to moral education by way of disability in the next chapter's response to philosopher Christie Hartley.

Thus far we can see that both of these models, the moral and charity models, were constructed in order to say something about and protest historical treatment of persons with disabilities; in other words, to describe these models is to simultaneously protest their continued influence in the lives of those with disabilities. No part of either model is meant to isolate what disability “means’ or propose definitions of disability for the future.

The Medical Model

Meanwhile, the *medical model* of disability is still supreme in mainstream culture but just as highly charged for disability theorists as the moral and charity models. In the previous chapter, I noted that the medical model of disability, on its strongest version, orients any limitations in biological particulars. Negative experiences encountered by a person with disability, including discomforts and lack of freedoms and capabilities, are all, on this model, due solely to disability’s character as a medical issue of the body—a problem of health, to be dealt with medically (Daniels, Rose, and Zide 2009, 75-76; Saxton 2000, 149). This model is built to describe what disability itself is. What the World Health Organization described as “impairment” (e.g. paraplegia, polio, loss of vision) becomes the entirety of the concept of disability. To put it more succinctly still, the medical model (broadly construed; it has many variations) orients disability as limitation located in or stemming from the body (see Smith 2009). So, on the one hand, the medical model is constructed in earnest in order to analyze and consider the effects of disability.

Yet, on the other hand, what some consider an earnest model, that is, a model meant to describe what disability actually is, has stimulated wide critique and is the fountainhead of stigmatizing and marginalizing taxonomies, labels, and stereotypes. For the DRM, the medical model is "an inaccurate interpretation of disability forming the basis of oppressive and exploitative relationships between non-disabled and disabled people" (Smith 2009, 15). In the previous chapter, especially through the work of Adrienne Asch, I discussed good reasons for thinking the medical model is misleading and therefore inaccurate. But further, as aforementioned, the medical model views individuals through the lens of their role as a "patient"—as if everyone who has experienced limitation or been stigmatized for a trait is by that count a permanent patient (Saxton 2000, 149). This is a problematic framing that causes unnecessary social isolation and negative treatment.

Thus, the medical model and its categorization of disability as pathology and illness contribute to the isolation of persons with disabilities. As long as persons with disabilities are labeled "ill" and their identity as disabled is tied up in interactions with the medical establishment, they become part of a hidden minority which is accounted for statistically (cf. political theorist Talcott Parsons, quoted in Zola 1993, 168). The representation of disability through statistics leads to the circumscription of disability as a risk of embodiment, as discussed in the previous chapter.

Mainstream reliance on medical understandings of disability also leads to pervasive institutional abuses, because the medical model makes the clinical institution the appropriate home for persons with disabilities. In 2012, federal officials sent Florida Attorney General Pam Bondi a letter on behalf of more than 200 children (including infants) who have been living in nursing homes for (on average) three years; the regulators allege that the state is violating the Americans with Disabilities Act and the children's civil liberties by housing them there. Florida State University law professor Paolo Annino, along with other attorneys in Florida, has filed a suit in corroboration with the letter sent to Bondi. They note that more than 3,300 children will be rehoused in nursing homes because of state funding cuts eliminating the nursing services that would allow the children to remain at home. Nursing homes, meant to care for the aging, are ill-equipped to deal with the young and present significant blocks to maturation, relationship-building and sexual development—the result of basic institutional restraints on schedules and rooming (Kennedy 2012). According to the press,

> the suit and federal regulators say children languish in facilities, sharing common areas with elderly patients and having few interactions with others, rarely leaving the nursing homes or going outside. After visiting children in six nursing homes, investigators noted that children are not exposed to social, education and recreational activities that are critical to child development. Educational opportunities are limited to as little as 45 minutes per day (Kennedy 2012).

I argue that housing young children and infants in nursing homes is only intelligible through a medical model that considers disability a medical condition for which health services are the primary, or even only, concern.[72] Because social sites for the responsive reception of persons with disabilities are sorely lacking, these individuals are marginalized and hidden by inappropriate placement in nursing homes. In impact, the move to institutionalize in nursing homes (as well as group homes, depending on the circumstances, and other types of institutions I have referred to in these pages) serves the same purpose as "ugly laws" or "unsightly beggar ordinances" in California, Chicago, Columbus, Ohio, and Omaha, Nebraska Chicago's turn of the century "ugly laws" – which made it illegal to be in public spaces with many disabilities (Schweik 2010). Social

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[72] For more on the long history of institutional abuses that persons with disabilities have been subjected to, see Jeff Moyer's audio CD *Lest we forget*, an important piece of disability history, including interviews (2006), and Snyder and Mitchell 2006.

marginalization is socially constructed, and it is easy to "minoritize" groups that one cannot see.

Further problems exist. The medical model cannot accept social factors playing a role in disablement, and so necessarily ignores the stigmatized construction I consider in this project. It conflates the prejudicial treatment experienced by persons with disabilities or simply their social experiences generally with traits of the body—it naturalizes them. Philosophers Kristjana Kristiansin, Simo Vehmas, and Tom Shakespeare explain problems with the model in this way:

> This position views disability as the inevitable product of the individual's biological defects, illnesses or characteristics. Disability becomes a personal tragedy that results from the individual's pathological condition. … Disability has become, among other phenomena such as alcoholism, homosexuality and criminality, a paradigm case of medicalization (a term which refers to a process where people and societies are explained increasingly in medical terms). The expression *medical model of disability* has become a common nickname for a one-sided view that attributes the cause of individual's deficits either to bad luck (accidents), to inadequate health practices (smoking, bad diet), or to genes (2009, 2).

The medical model, therefore, is a model which describes the causes of disability as individual, and divorced from social life, and is also a model which treats disability (even if disability has social aspects known to be negative) as naturalized and inevitable. There is no one to blame but the body, unless of course, one also chooses to blame an individual's bad lifestyle and unhealthy decision-making. On this model, one can call disability "tragic" and yet evade responsibility for the tragedy of poor treatment (cf. Smith 2009, 16).

Disability theorist Steven Smith further argues that the medical model is *essentialist*. Disability under this model is necessarily a "fixed" and "permanent" condition, which "inevitably causes 'dependency' between disabled and non-disabled people;" resulting dependency is likewise depicted as permanent (Smith 2009, 15, cf. Barnes 1991, 2). The medical model insists that disability cannot be separated from dependency, but under this model, dependency is a product of biology, not interpersonal relationships. Therefore, differences between non-disabled and disabled persons are essentialized (Smith 2009, 16-17). Meanwhile, normality is also naturalized under this model (17). Recall here my discussion of genetic determinism in chapter one and chapter two, which I argue also serves to naturalize and materialize disability.

The Social Model

The *social model*, first articulated by British disability scholar and activist Michael Oliver[73] in the early 1980s, is meant as a direct response to and rejection of the medical model. In that sense, it perhaps swings the pendulum back too far in the other direction, thus leaving itself open to inevitable revision. This model has served as a rallying cry and a very effective political tool for the DRM and disability activists globally. Unlike the charity and moral models, it is not articulated in order to be rejected, or to illuminate the past; instead, on a practical level, it could be called future-oriented. That is because it describes disability primarily as originating in social failures with regard to *accommodation* for difference, and to describe it this way is to strongly suggest radical social change at the same time.

As I stated in the second chapter, the social model argues that difficulties or differences in quality of life experienced by persons with disabilities are due to a lack of social accommodation rather than inherent qualities of the individual experiencing

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[73] In the United Kingdom, the Union of Physical Impaired Against Segregation (UPIAS) was a seminal part of the development of the social model (Kelly 2010, Scott-Hill 2004, Snyder and Mitchell 2006, 6).

disability (Abberley 1987). Steven Smith calls a very common version of the social model the "politics of disablement" interpretation, in which "attention is directed…toward changing the social and political environment" (2009, 18). He writes:

> This interpretation offers a structural, as distinct from an individual account of disability, in effect bracketing the personal experience of disability, other than what an impaired person might experience in relation to the social and political environment (2009, 18).

Here, a distinction is made between impairment and disability: "Impairment is associated with a particular medical condition, which may (or may not) lead to a disability" and "disability [is] associated with various social and political restrictions often (but not always) imposed upon people with impairments" (Smith 2009, 18). This distinction is in radical contrast to the medical model's conflation of impairment and disability, but fits with the WHO scheme (above). Importantly, many versions of the social model do *not* claim, as is sometimes supposed, that disabling traits are themselves neutral (e.g. Daniels, Rose and Zide 2009, 75). Rather, the more common claim is that the majority of regrettable aspects of disability *can be* neutralized as long as society understands and accommodates disability (e.g. Parens and Asch 2000, 24). This point has caused confusion.

The social model improves upon the medical model in a number of obvious ways. It places new responsibilities on society to make room for physical and mental differences, and rejects the idea that one's body or "impairment" must necessarily lead to social and political restrictions. But, it also involves drawbacks which arise primarily from the framing of its rejection of the medical model. That is, in the social model's definition of disability's limitations as merely social, it throws a veil over the body and embodied first-person experiences in social contexts, a point anticipated in the excerpt from Smith, above. It can invalidate pain, and serves to untether discussions about disability completely from the body, because on this model impairment relates to the body while disability relates to the social world. That is, impairment is naturalized. Strictly working from the social model, we can lose key elements of stories like that of poet, theorist and disability activist Eli Clare in his "Exile and Pride," wherein Clare relates his painful and difficult experiences of mountain-climbing as a person with cerebral palsy and the way his unsteady step takes him through rocky terrain (1999). This story, for Clare, unlocks the door to the realization that he has internalized the "supercrip" trope of a person with limitations who overcomes the odds. (I return to this trope and to Clare's response to it in my commentary on Christie Hartley's political theory in chapter four.)

The pervasiveness of the social model among disability activists has made it difficult to revise or abandon. For instance, Mairian Scott-Hill[74] encounters the social model as a "new orthodoxy" (2004, cf. Kelly 2010). Scott-Hill "proposes a postmodern, communicative paradigm which 'takes the view that social relations between people are necessarily complex'" (Kelly 2010, quoting from Scott-Hill 2004, 163). But, she experiences strong backlash; she claims that her view "tends to be interpreted by 'orthodox' social modellists as threatening the unity of disabled people's political campaigns and accused of promoting a relativistic world in which the 'fact' or 'reality' of disability can no longer be assured" (Scott-Hill 2004, 169). In other words, for some who promote the social model, if disability is seen as fluid, contingent on social relationships, or to have shaky borders, political disability identity is threatened. This is a very

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[74] Usually published under the name "Mairian Corker".

undesirable standoff, especially since the social model is ostensibly meant to capture the highly interpersonal nature of the "politics of disablement."

But the social model has opened up very important discussions and historically made activist disability politics possible, helping highlight accommodation and justice issues. The social model breaks free of the medical model's essentializing insistence that disability is, in its entirety, a quality natural to the body. But, the distinction that the social model makes between impairment and disability leaves impairment itself a naturalized category—i.e., immune to social construction—and deprioritizes discussion of the body, pain, and limitation that feminist philosophers of disability, like Liz Crow, Liz French, and Jenny Morris, seek. According to disability theorists Tom Shakespeare and Mark Erickson, these thinkers: "do not deny that society causes many problems, [but] they also feel that their bodies may cause difficulties, and they want any theory of disability to take account of the physical dimension to their lives. They suggest that in developing a social and structural analysis the disability movement has omitted a key facet of their experience" (Shakespeare and Erickson 2001, 195). The social model throws a veil over the body in its attempt to make an analogy with the distinction between sex and gender (cf. Tremain 2006).

The social model presents one final problem. That is, the social model considers the concept of disability to be merely negative. On this model, "disability" conceptually marks a *failing* on the part of the social world and signals a *lack* of accommodation; when disability is discussed in this sense it falls into the trap of asserting that disability is inherently and also merely negative. For the DRM, which is focused on the potential of persons with disabilities to be independent,[75] this is not a good result. The social model, as an activist view, should be able to support the idea of disability as a banner and a positive identity that brings people together—disability should be more than simply a problem to be solved. But if disability *is* social failure, and accommodation problems are overcome, does the concept of disability disappear, along with disability identities themselves? It appears that for the social model the answer is yes: the social model valorizes "ordinary citizenship" insofar as it takes accomplishing this type of citizenship for all as the aim of ameliorating lack of access in the social world (Smith 2009, 19, cf. Kelly 2010). In that sense, the social model will not represent a cultural critique of the complex relationship between norm and deviance, or negation or lack and social acceptance. Tanya Titchkosky writes:

> So common is it to map disability through a series of negations that it might be easy to miss the strangeness of such a process. This strangeness is revealed when we try to map others in a similar fashion, for example, a man is a person lacking a vagina. It would seem ridiculous today to conceive of gender in terms of negation. However, it is still common to regard the disabled body as a life constituted out of the negation of able-bodiedness and, thus, as nothing in and of itself. (2002, 103)

Although perhaps the negativity of disability does not rise to the level of tragedy under the social model the way it does under the medical model, simply moving the concept of disability from the body to the social realm is not enough. Mairian Scott-Hill (Corker)

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[75] Christine Kelly argues that disability activism has been unduly influenced by disabled white males, who focus on goals like independent living. According to Kelly, organizations like the US-based ADAPT retain the echoes of this hidden identity of disability activism; she writes: "reinforcing independence as the ultimate social value is also a political act that maintains the status quo" (2010). ADAPT, she argues, assumes the superiority of the nuclear family and is heteronormative in the construction of the family. For systematic uncovering of the concepts of dependence and independence, as well as the fuzzy borders between the two, see Fineman 2003, Fraser and Gordon 2003, and Francis 2009. For an alternative idea of what disability activism aims for, consider disability theorist and activist Paul Longmore's words: "[activists] declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community" (quoted in Rohrer 2005, 36).

received backlash for her "postmodern" view of disability, which calls into question disability as concrete fact; yet, the social model should be called into question for its characterization of disability as only a negative marker of social failure, while simultaneously failing to investigate the cultural constructs of deviance and disability.

The Minority Model

The *minority model* of disability overlaps tightly with the social model, but presents its own set of unique issues for advocacy. Taking the social model's interpretation of disability as a basis, it primarily focuses on the attainment of civil rights (Dell Orto and Marinelli, 1995). But, unlike the social model, it seeks to neutralize the perceived negativity of disability traits. This is accomplished, for instance, by claiming that wheelchair use is variation rather than limitation, and calling into question the normalcy of walking as a mode of mobility. The Deaf community takes up a variety of this model by way of its claim that Deafness is the root of a culture, not a disability. But it is unclear why the label of disability or disability as an identity and minority claims of culture must oppose one another—it seems that in order to make a "minority" claim, some believe that a "disability" identity must be shed or shifted elsewhere. I will use the example of the controversy surrounding "direct funding" in order to begin describing more concrete problems connected to the minority model.

Direct funding refers to a situation in which persons with disabilities receive government funds to "hire and sometimes train" service (care) providers and thus "manage their own personal assistance" by disbursing payments for their own care (Kelly 2010). This is a major goal of "personal assistance activism" and fits with a minority model scheme of disability. Personal assistance activism, however, puts to the side concerns about minimum wage, labor standards, and working conditions for those providing the care work. Because funds available to persons with disabilities are limited and often far too low, part of "personal assistance activism" will be the attempt to keep payments for care work as low as possible in order to manage one's budget. In other words, minority politics advocacy around "direct funding" pits persons with disabilities against care workers in a struggle over scarce resources. It places those with disabilities in a position of power over those workers who provide their care because little to no oversight is built in to the system (Kelly 2010). Paying higher amounts for care work means that those who need the care have less money in their already severely limited bank accounts.

Playing one's part in minority politics will exacerbate and multiple problems like the one represented by the direct funding controversy. Christine Kelly argues that models for advocacy must shift and expand: "Advocacy around direct funding must expand in ways that understand personal assistance as 'disabled work', that is, work that is inherently devalued in our society, just as disabled bodies are" (2010). Kelly argues:

> One of the ways to transform the cultural meanings of disability is to improve the social status of attendants and the value attributed to their work. There is incredible potential for disabled people to work alongside attendants for the improvement of direct funding programs, but this would require a broadening of identities and mandates endorsed by advocacy groups." (2010)[76]

This echoes Rosemarie Garland-Thomson's call to consider "disability" a "pervasive cultural category" (2001, 18). When "disability" is taken up in the context of identity

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[76] This connects with Eva Kittay's call for "doulia": "Just as we have required care to survive and thrive, so we need to provide conditions that allow others—including those who do the work of caring—to receive the care they need to survive and thrive" (1999, 68, cf. 107). Care work is devalued by its proximity to the cared-for, and both are locked together until a critique of this devaluation can pull them apart.

politics that pits one "minority" (marginalized) group against another, opportunities to ferret out places that certain lives and labors are devalued are lost.

Foucault's work provides further theoretical resources to critique minority "disability politics." Adopting roles within the scheme of the minority model involves disabled advocates directly in the management of their own disability "identity" and policing the border between disability and ability.[77] Seeing "disability" as another minority community pits this group against others in a struggle for rights and access, and further minoritizes and marginalizes persons with disabilities, emphasizing deviance from a norm. In an essay written from a Foucauldian point of view, Helen Liggett notes that "the minority group approach is double-edged because it means enlarging the discursive practices which participate in the constitution of disability….in order to participate in their own management disabled people have had to participate as disabled" (Liggett 1988, 271). Shakespeare, meanwhile, argues that "disability politics, by its very nature, often rests on a fairly unreflective acceptance of the disabled/non-disabled distinction. Disabled people are those who identify as such. Disabled leadership is seen as vital" (2006, 78).

The Cultural Model

I turn now to a Foucauldian-inspired model that will be able to avoid some of the problems embedded in the models I have reviewed so far. The *cultural model,* exemplified by the work of Sharon Snyder and David Mitchell, seeks "locations" (constructions, including historical constructions) of disability and deviance. It responds

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[77] As Shakespeare notes, this recalls Denise Riley's discussion of "the dangerous intimacy between subjectification and subjection" (Riley 1988, 17, quoted in Shakespeare 2006, 78.)

critically to the false choice of *either* the social world *or* the body as an explanatory mechanism (cf. Shakespeare and Erickson's desire to find a third way, 2001). On the one hand, it claims that we can investigate the context and construction of disability without assuming that these contexts and constructions are merely or only tragic or negative, marking "discriminatory encounters" (2006, 10). On the other hand, the cultural model attempts to understand locations of disability as complex interplays between *both* embodiment *and* the social world, and so does not want to exclude individual (negative) experiences of stereotyping and problematic models like the medical model from an understanding of the way that individuals have built their identities (Snyder and Mitchell 2006, 6-7). This means that the cultural model does not *assume* that disability is negative, but it can incorporate the workings of stigma and prejudice where they occur into an understanding of what disability, and disability identity, involves in a variety of contexts. Snyder and Mitchell write:

> "Disability" … in keeping with current formulations informed by cultural and identity studies—is largely, but not *strictly* synonymous with sites of cultural oppression. It does not *solely* represent the social coordinates, as Liz Crow puts it, of restraints "that we must escape" (2006, 6, emphasis mine).

Snyder and Mitchell go on to clarify that they do not wish to "hide the degree to which social obstacles and biological capacities may impinge upon our lives" (2006, 206).[78] Their work, instead, recognizes that "environment and bodily variation (especially those traits experienced as socially stigmatized differences) inevitably impinge upon each other" (207).

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[78] In other words, they speak to the following concern articulated by Susan Wendell: "I do not think that my body is a cultural representation, although I recognize that my experience of it is both highly interpreted and very influenced by cultural (including medical) interpretations" (1996, 62).

To reiterate, for Snyder and Mitchell, defining disability will necessarily involve "a combination of profoundly social and biological forces"—a recipe that neither the medical model nor the social model is able to accommodate (2006, 7). Activist and disabled scholar Zola writes: "biology may not determine our destiny; but, as with women, our political, mental and biological differences are certainly part of that destiny" (1993, 170). Lifting the veil that the social model has thrown over the body is immensely important. In this vein, Shakespeare and Erickson write:

> biological and social and cultural processes weave together in complex ways to produce the phenomena which we experience. Just as the best versions of the biological story stress the dynamic processes in nature, the inextricable involvement in the environment with the expression of genes and the crucial role of development, so an adequate social science must acknowledge the bodily and ecological parameters within which humans operate. (2001, 203)

Most importantly, the cultural model is informed by philosophy which can highlight discursive constructions of disability—such as that of Michel Foucault—and therefore can interrogate impairment *itself* as socially constructed, as I attempted to do in the previous chapter's discussion of genetic counseling, prenatal prototypes, and risk (Tremain 2006).

At the outset of this chapter, I mentioned Irving Zola's worry that the reversal strategy of political identity—finding pride in precisely the traits that are stigmatized—was largely unavailable to persons with disabilities. But, the insights of feminist theory, which I argue are in accordance with the cultural model, demonstrate that this kind of reversal is not impossible. Feminist theorist Judy Rohrer, in articulating the entwined interests of feminism and disability theory, points to the strategy of *political ironism*, precisely the type of reversal to which Zola refers.

For Rohrer, irony as a political strategy stems from the work of feminist political theorists, including Donna Haraway and Kathy Ferguson (2005, 43). This strategy allows one to "live with ambiguity" and, in the words of Ferguson, provides "a way to keep oneself within a situation that resists resolution in order to act politically without pretending that resolution has come" (43). Of disability, Rohrer writes:

> The disabled subject position generates irony through the inescapable friction between living in a disqualified body and *living* at all. Disability is easily understood as a contingent, ambiguous, and multiple category…it reminds us of our incompleteness, of the fluidity of our subjectivity, and of the disciplinary practices that shape our bodies and our thinking (44).

Irony can "call attention to imposed (mis)representations and new self-definitions while at the same time acknowledging the contingency and fluidity of their identity claims" (44). Rohrer uses "OH" as an example, an acronym which originally refers to "orthopedically handicapped" (a passive verb; cf. Zola's grammar, above). But the use of "OH" by persons with disabilities can become a "double gesture": "Expressing them both at once highlights the fluidity, contingency, and multiplicity of identity claims" (2005, 44). Ironism is a route to reclaim and stigmatized identities without negating original meanings; rather, it allows the original meaning to be expressed at the same time as a new meaning.

Throughout this project, and especially in my discussion of "fetal impairment" and risk, I have implicitly and explicitly referred to the "social construction" of disability. Keeping one's eyes open to social construction is an important part of the cultural model even though the cultural model does not affirm a strong social model of disability. In the next section, I describe the social construction of disability in more depth through a return to my focus on genetic determinism.

Social Constructions of Disability

I have argued that genetic determinism serves as a support for the stigmatizing essentialism and naturalism regularly faced by persons with disabilities. To elucidate my point, I here expand on the argument that disability is socially constructed. I did not introduce complications into the portrait of gene action (in chapter one) in order to argue that a more accurate scientific picture of gene action, or better scientific understanding in general, will provide more reliable or complete information about disability and thereby render it a problem science is finally ready to solve. As already indicated, I consider the meaning of disability, and even impairment (as mentioned above, these are often distinguished in an analogy with gender and sex) to be socially conditioned and constructed. This means that strict biological or genetic descriptions of disability will miss the opportunity to critique and analyze the social, political, and other factors that brought them into discourse.

Susan Wendell points out that there are multiple ways to view the social construction of disability, and the discussion need not be limited to "disability" as a social category while leaving to the side "impairment" as a set of biological categories; in fact, she does not think it is easy to disentangle the two (Wendell 1996, see esp. Ch. 2). She writes:

> I see disability as socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies. (1996, 58)

For example, political decisions regarding war, the prevention (specifically: the lack of) of violent crime, and differential access to health care can create illness, injury, and therefore have disabling impact (1996, 58-59). Simple architectural decisions regarding stairs and elevators can also construct disability:

> poor architectural planning creates physical obstacles for people who use wheelchairs, but also for people who can walk but cannot walk far or cannot climb stairs, for people who cannot open doors, or for people who can do all these things but only at the cost of pain or an expenditure of energy they can ill afford. (1996, 60-61)

Wendell explains that as a professional academic, she stands on shifting sands with regard to her status as a disabled worker at her university; at the time of her essay, she took one-quarter time disability leave and worked three-quarters time. Increased teaching loads due to changing institutional standards may, she noted, require her to take more disability leave in the future, up to half-time; but nothing about her physical status will have changed (1996, 60). Wendell refers to this constructive phenomenon as “the pace of life,”—that is, changes in standards and expectations which leave persons more or less disabled (59).

Obesity is another example of the social construction of disability and its meanings. Food deserts, poverty, and social inequalities of all types impact rates of “obesity,” which most people consider a disability trait. But definitions of “obesity” and its social meanings are also determined discursively. Certain foods are considered “bad” or “good” (fats and dairy are good examples) according to evolving standards and changing ideas about what constitutes a healthy diet. Access issues contribute to the idea that persons with disabilities make bad food choices. The need for shopping assistants and prepared foods makes it difficult to obtain and enjoy one’s preferred foods, and for those who are able to prepare their own meals, it remains difficult to fulfill the expectations of an increasingly "gourmet" food-centered society and keep up with what some have called "the gentrification of taste" (Gerber 2007). As Elaine Gerber notes, "foods that are easy to prepare or acquire are also often the same ones that deserve criticism for their nutritional shortcomings. Fast foods and pre-prepared foods…are the foods that are commonly consumed by disabled people" (Gerber 2007). Meanwhile, food that is considered healthy, green and organic is precisely the type of food often made inaccessible by contingent social and political factors (poverty, poor urban planning, and "poor architectural planning").

Recall the FTO "fat" gene, introduced in chapter one, and references in the media to other "fat genes" (Miles 2013). Genetic determinism, among other mistaken beliefs, makes it easy to treat being "fat" as an essential property or a natural kind. Speaking of sickness and health strictly in terms of biology, and especially strictly in terms of genetics, hides social and political factors structuring ideals of sickness and health; the influence of genetic determinism and other reductions to biology jettisons the philosophically critical chance to analyze and assess these factors and their differential impacts. Conceptions of disability and impairment

For the purposes of this project, the binary between normal and abnormal created by portraits of canonical genotypes and genetic deviance is a key example of the construction of disability and impairment. In other words, genetic determinism also constructs disability, especially insofar as it is considered natural, essential, immutable, or adjustable via genetic intervention. Testing procedures which approach testing for genetic deviance itself, deviance of a particular fetus from the genotype of a presumed healthy person, encourage the wrongheaded connection of a type of statistical abnormality to risky embodiment, disability, or illness (see Kelly 2012 and Wapner *et al*. 2012). And quality of life predictions based on genetic information taken in utero (genetic profiles revealing "prenatal prototypes" à la Carlson) discount or ignore myriad social, political, and environmental impacts on quality of life and so foreclose potential alternative measures of this concept. All of these processes contribute to the construction of the "impaired fetus" (Tremain 2006).

As I argue in the second chapter, synecdoche parallels the logic of genetic determinism, and both of these also have significant conceptual resonance with stigma. In the next section, I further express my affirmation of the cultural model by tracing more directly the concept of "stigma," which Snyder and Mitchell reference and which I have already briefly discussed several times. I seek "locations" of disability. Bodily variation comes to the foreground when it involves stigma, and so investigating this concept is necessary to arrive at a clearer picture of what disability (in both its social and biological senses) is about in various contexts. I argue that it is possible to view the disability community through a lens of physical and mental differences that attract stigma, but *also* consider these differences as the building blocks of disability identities that are not merely negative.

Stigma and Identity

In 1993, landmark disability activist Irving Kenneth Zola produced a brief but important essay on the importance of naming and labels, and there adduces a few of the effects that naming can produce upon a person with disabilities. Zola claims that "we must go beyond a list of 'do's' and 'don'ts' to an analysis of the functions of [labels]" (1993, 168), and so focuses on function rather than the search for "better" terminology. He argues that labels are both "connotational and associational" (168). First, when one is seen as "sick" or "crazy," a multitude of other traits are brought forward that are frequently associated with illness and madness: "weakness, helplessness, dependency, regressiveness, abnormality of appearance and depreciation of every mode of physical and mental functioning" (168). Second, the label becomes the foundation for explanations of far-flung behavior and signals a set of permanent characteristics:

> Call a person sick or crazy and all their behavior becomes dismissible. … Because someone has been labeled ill, all their activity and beliefs—past, present, and future—become related to and explainable in terms of their illness. … In the case of a person with a chronic illness and/or a permanent disability, their traits, once perceived to be temporary accompaniments of an illness, become indelible characteristics (Zola, 1993, 168).

Zola also argues that labels have the "potential for spread, pervasiveness, [and] generalization" meaning that the labels come to refer to the person in general and are interpreted in black or white terms. Think here of referencing "the amputee down the hall" or interpreting blindness to mean "totally without vision," something untrue for most blind persons (Zola 1993, 169). This links to the "spreading effect" I consider in the previous chapter. Spread and generalization are central to stigma. Longmore calls this a "spoiling process"; when a trait "obscure[s] all other characteristics behind that one and swallow up the social identity of the individual within that restrictive category" (Longmore 1985, 419, quoted in Zola 1993, 169). So, we see here that a trait is emphasized over the whole in situations of labeling; this precisely mirrors my analysis of the problematic situation in bioethical conversations regarding new reproductive technologies, which I discussed at length in the previous chapter.

Zola argues in conclusion that often the grammar of labels produces effects beyond the power of the labels themselves (1993, 170-171); I here briefly go through the grammar of labels in the manner he does, piece by piece, to show the tensions involved. Zola argues that the use of nouns and adjectives ("Blind," "One-Legged") necessarily positions one's trait as primarily important. Nouns "can only perpetuate the equation of the individual equaling the disability. No matter what noun we use, it substitutes one categorical definition for another" (170). Adjectives, meanwhile, "tend to treat the whole person" and are "far from connoting a specific quality of the individual" (170). Prepositions are better (as in "persons with disabilities" and "people of color") primarily *because* they are awkward and create pause; also, the relationships indicated between the terms they combine necessarily separate the terms: prepositions "imply both 'a relationship to' and a 'separation from'" the attribute which is referenced (170). Finally, verbs have both passive and active tenses and so can be limiting; Zola here uses the difference between "using a wheelchair" and "being confined to a wheelchair" to express the distinction (170). The fine distinction between to "have" and "to be" becomes important in these cases, because verbs either "can categorize" or "relate attributes" (170).

Throughout this catalogue of grammar we can see that the issue of primary importance is releasing the person with a disability from definition *merely* by way of the disability; this is not a rejection of the trait but a rejection of definition via the trait. The preference is strongly for using language to express attributes, not to categorize, as Zola suggests. This fits with my analysis regarding *synecdoche*, which I would now like to explicitly connect with the notion of stigma.

In short, the concept of stigma captures the core of the issues I have discussed so far, including spreading effects, emphasis of traits over wholes, and generalization on the basis of socially-undesirable traits. Investigating stigma suggests an answer to what kind of community the disability community is. I argue that one can consider it a community made up of persons who have experienced the effects of fear, isolation and prejudice on the basis of actual or perceived bodily or mental difference.[79] This is not the end of the possibilities for disability identity, but it *is* the beginning in today's political context. The medical model has already taught us why the concept of disability is considered exhausted by way of the notion of limitation. But, investigating stigma helps us fill out the picture of the disabled subject by suggesting answers to questions that have been haunting this project from the beginning—specifically, how is disability linked with death and fear?

The mainstay text in disability studies for accounts of stigma is Erving Goffman's sociological study, *Stigma: Notes on the Management of a Spoiled Identity* (1963). According to Snyder and Mitchell, Goffman's "theory of stigma…has been influential to cultural model discourses because [it formulates] theories of passing, psychic formation, and materiality as social processes" (2006, 7).[80] Goffman's work takes the notion of

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[79] The text of the Americans with Disabilities Act has the issue of perception built in to its definition of disability, claiming disability status for persons who are perceived to have a disability trait. "The term 'disability' means with respect to an individual (a) a physical or mental impairment that substantially limits one or more of the major life activities of such an individual; (b) a record of such an impairment; (c) being *regarded* as having such an impairment" (ADA quoted in Riley 2005, 7; emphasis mine).

[80] Snyder and Mitchell give similar priority to Judith Butler's work on "sex/gender binaries" (2006, 7). In this chapter, I speak briefly to the problems tied to the attempted analogy by the DRM and other activist

stigma from the field of social psychology, and notes that there it is considered "the situation of the individual who is disqualified from full social acceptance" (1963, Preface, cf. 8). Yet, Goffman's work is prescient because of the way in which he receives and adjusts the idea of stigma; he writes that for him, "stigma …will be used to refer to an attribute that is deeply discrediting" (1963, 3). So, while acceptance is still at issue, Goffman links the social and the biological in his treatment of stigma. Goffman explicitly addresses spread and generalization by exploring the discrediting effects of certain traits.

Goffman specifies that stigma is produced when there is *lack of fit* between an ideal (in his words: "virtual") and an actual identity; without a norm, stigma loses its footing (1963, 2-7). In other words, stigma arises "where there is some expectation on all sides that those in a given category should not only support a particular norm but also realize it" (6). The operation of a norm and perceived lack of fit with that norm can produce shame for the individual experiencing stigma (7). More importantly, however, for this discussion, is the social response attracted by the stigma. Goffman writes,

> An individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us (5).

The presence of a single trait provides a basis for social rejection that is, at least in part, explicable by way of the "spreading" or "generalization" effect that is stimulated by that trait. Goffman argues that others not only "impute" further "imperfections" on the basis of one trait but also tend to assign "some desirable but undesired attributes, often of a supernatural cast, such as 'sixth sense,' or 'understanding'" to those with the

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groups between sex/gender and impairment/disability, but further discussion is outside the scope of this project.

"imperfection" (1963, 5). This latter phenomenon should be familiar to anyone who has seen the trope of exceptional wisdom and insight played out on television or the movie screen, an attribute regularly assigned to the ill and dying as well as to the physically or mentally different.[81]

Goffman's articulation of a "trait that can obtrude itself upon attention" is resonant with synecdoche (the identification of a part with a whole). He suggests that in the case of stigma, "imperfections" are assumed on the basis of one trait encountered in another person (1963, 5). Genetic determinism, meanwhile, is also a case of a single trait obtruding upon attention. Furthermore, it is connected to essentializing and naturalizing moves that make particular traits simultaneously highly important and a signal of a "natural kind"—for example, the natural kind of a "disabled" or "defective" person.

Goffman helpfully pushes one toward a rejection of a false binary between abled and disabled precisely by way of his analysis of stigma. He notes that although one may not already be discredited, one can always be interpreted as *discreditable*:

> The most fortunate of normals is likely to have his half-hidden failing, and for every little failing there is a social occasion when it will loom large, creating a shameful gap between virtual and actual social identity. Therefore the occasionally precarious and the constantly precarious form a single continuum, their situation in life analyzable by the same framework (1963, 127).

We can read the echoes of Goffman in the work of Rosemarie Garland-Thomson and her discussion of the normate.

Lerita Coleman Brown's "Stigma: An Enigma Demystified" represents a helpful conceptual bridge into theorizing about disability (2010). Drawing on Goffman's work, Coleman Brown argues that "stigma is a response to the dilemma of difference" (179).

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[81] I return to this, below, in my discussion of Christie Hartley's work.

She writes: “What is most poignant about Goffman’s description of stigma is that it suggests that *all human differences* are potentially stigmatizable” (179, emphasis mine). So, for Coleman Brown (as well as for Goffman), “stigmas reflect the value judgments of a dominant group” (180). With a turn, again, to social psychology, Coleman Brown categorizes stigma as a mode of “cognitive processing” which helps us categorize and respond to difference (183). But, she is especially intent to argue that the *fear* so often involved in stigma as a complex affective response specifically expressive of learned behaviors: “interest and curiosity about stigma or human differences may be natural for children, but they must *learn* fear and avoidance as well as which categories or attributes to dislike, fear, or stigmatize…certain negative emotions become attached to social categories” (183). *Stigma thinking* for Coleman Brown is thus deeply connected to schemas and stereotyping.

For Coleman Brown, stigma is a “special and insidious kind of social categorization” which is a “process of generalizing from a single experience” (2010, 184). Like Goffman, she argues that stigma is “the attribute that colors the perception of the entire person” and “other aspects of the person are ignored” (184). So, as we have seen, the notion of stigma perfectly captures the general thrust of the *disability critique* of negative genetic selection, specifically with regard to synecdoche. Overall, for Coleman Brown, stigma “maintains” the status quo of social relations and brings stigmatized and unstigmatized persons “together in a perpetual inferior/superior relationship” (184, 185, 189). This binary is maintained despite Goffman’s insight that stigmatization exists on a continuum to which no one is immune (cf. Coleman Brown 2010, 187). While the workings of stigma can help uncover the openness all have to stigmatization give the fact of human difference, it also maintains itself through the encouragement of social exclusions and its support of the status quo.

It is clear that to be stigmatized is undesirable (cf. Goffman 1963 and Coleman Brown 2010, 187). But Coleman Brown helps us glean slightly more from the concept of stigma when she suggests that stigma causes fear because it is, at root, "uncontrollable" – "human differences serves as the basis for stigmas" and so one can be stigmatized at any time (2010, 187). In that sense, Coleman Brown argues, the structure of stigma imitates the structure of death:

> The unpredictability of stigma is similar to the unpredictability of death…the development of a stigmatized condition in a loved one or in oneself represents a major breach of trust—a destruction of the belief that life is predictable. In a sense, stigma represents a kind of death—a social death…nonstigmatized people, through avoidance and social rejection, often treat stigmatized people as if they were invisible, nonexistent, or dead (188).

As our overall discussion of disability reminds us, the linkage between stigma and death does not stop there, especially when stigmatized traits are precisely traits that remind us of human vulnerability or mortality. As Coleman Brown argues, "many stigmas, in particular childhood cancer, remove the visual disguises of mortality. Such stigmas can act as a symbolic reminder of everyone's inevitable death" (188). At this point it should be clear that to those who would seek immortality, like transhumanists, stigmatized persons represent a particularly painful reminder.

It is important to note, before moving on, that exclusions and stigma which accompany bodily difference are very strict (cf. Goffman 1963, 127-128). Ectrodactyly and syndactyly, which result in missing fingers and toes and the "partial fusion of the bones of the fingers and toes," may seem relatively insignificant over the course of a life (Parens and Asch 2000, 8). But when Bree Walker Lampley, a news personality who had both these traits, called ectrodactyly "minor" and stated her intention to continue a pregnancy although she knew the resulting child would have that particular trait, the media was scandalized and she was widely criticized as "irresponsible" (9). Another testament to the stringency of stigma is the fact that, as Goffman argues, a stigma which has been "repaired" or "corrected" is still a limiting stigma:

> Where such repair is possible, what often results is not the acquisition of fully normal status, but a transformation of self from someone with a particular blemish into someone with a record of having corrected a particular blemish (1963, 9).

The faintest whiff of deviance from the norm is enough for the pernicious effects of stigma to operate; this speaks to the strength of operative norms.

Genetic definitions of normality and abnormality, health and deviance, are an important front line of stigmatizing responses to what Coleman Brown calls the "dilemma of difference" (2010, 179). Stigma can attach to any perceived difference, but difference (as opposed to identity) is everywhere. Overly-deterministic conceptions of genetic action support idealized "canonical genotypes" and serve to mark deviance from this canon as abnormality. But, as Scully points out, variation in the human genome is constant. As I have argued throughout this project, choosing a presumed "normal" genome as a standard useful for measuring deviance is a mistake. This mistake contributes to stigmatization against persons with behaviors and characteristics which are presumed to be determined by genetic factors.

Conclusion

While issues of disability identity and disability models are of course not resolved by way of my analyses and discussion here, I would note that it is fully consistent with Rohrer's political ironism to accept the ambiguity surrounding disability. It is also a testament to the important linkages between feminism and disability theory. To accept stigma as part of disability identity is not to resign oneself to the idea that disability is a merely negative identity.

In the next chapter, I investigate images of disability in theories of liberalism as another way to pursue "locations" of disability. I do so also because I seek to outline the ways that discourse in bioethics, including transhumanism, which paints the disabled body as risk or limitation, is echoed or finds its corollary in political discussions of disability. I argue that in the contractualist Christie Hartley's version of liberalism, reciprocity and exchange among citizens is interpreted and presented as an inescapably asymmetrical experience for the cognitively limited, but is not presented as such for abled others. This is yet another iteration of the false binary between the abled and disabled body, dependence and independence. I suggest that there are more transformative views of political life available, and highlight those forwarded by Eva Kittay and Anita Silvers.

CHAPTER IV

RECIPROCITY AND TROPE: DISABILITY AND LIBERALISM

“*His* Courage Made *Them* Champions.”

Radio film tagline (2003, dir. Michael Tollin, emphasis mine)

In this chapter, I first lay out criticisms of Rawls raised from the perspective of disability studies. Second, I take up Christie Hartley’s attempt to work within a Rawlsian framework to better accommodate people with disabilities. I argue that although her theory is an advance on Rawls’, it still has limitations for creating just political conditions for persons with disabilities. Finally, using Eva Kittay and Anita Silver’s analyses, I show that there are more transformative ways of discussing and theorizing within the liberal tradition. This chapter represents an attempt to engage the question of disability outside of bioethics, where the binary between ability and disability at play in bioethics still has the power to impact even the best attempts at inclusion. I here follow through on my work throughout this project to attend to “locations” of disability.

In both traditional liberal and bioethics literature, I argue that an ideal subject has real-world negative implications for persons with disabilities and contribute to their stereotyping and oppression. This ideal subject is a choice-maker with an open future, evades stigma and risks associated with embodiment, and is fully rational and independent. In short, this ideal subject is constructed against the stigma associated with disability and the disabled body.

John Rawls and the Heritage of Liberalism

The political philosophy of John Rawls is often the subject of significant critique on the basis of its exclusions of persons with disabilities. This debate occurs both inside and outside of the social contract tradition (e.g. Davis 2002, 107-108; Hartley 2009a, 2011; Kittay 1999; Nussbaum 2007; Reinders 2000; Silvers and Francis 2005; Stark 2007; Young 2006; Wolff 2009). Serious issues for disability rights include Rawls' construction of personhood, which is exclusionary, especially of those who experience cognitive limitation (1996, 18-19); Rawls' stipulation that those behind the veil of ignorance are abled (2001, 18, 21);[82] problems stemming from Rawls' difference principle (Silvers 2009, 179); and the explicit avoidance of disability as a problem for justice in his account (Silvers 2009, 79; cf. Rawls 1996, 20). Eva Feder Kittay, Martha Nussbaum, Anita Silvers and Leslie Francis have critiqued Rawls regarding issues such as these and on the basis of their significance articulated discreet liberal theories of justice which seek to open up and re-define liberal citizenship and personhood (Kittay 1999 [justice as care]; Nussbaum 2007 [capabilities approach to justice]; e.g. 140-5; Silvers and Francis 2005 [justice through trust]). These efforts are also met with critique (Engster 2005; Fine 2005; Hartley 2011; Silvers 2009; Wong 2007).

This critical literature from a disability perspective coalesces on Rawlsian characterizations of liberalism, as well as John Rawls' specific theory of justice as fairness, in order to discuss the ways in which the disability community is excluded or included in liberal political frameworks. Some, like Martha Nussbaum and contractualist

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[82] I owe this point to Stacy Clifford, who articulates it in "The Disabled Contract: Explaining the Exclusion and Function of Disability," a paper given at Vanderbilt University in November 2011.

Christie Hartley, accept Rawls' characterization of liberalism's basic tenets while at the same time developing new themes around capability and cooperation, respectively. Others, like Eva Kittay and Anita Silvers, seek to substantially transform liberalism as well as critique Rawls.

Importantly, as Rawls admits, there is no "settled meaning of liberalism." Instead, "it has many forms and many features" that can represent its ethos and yet differ in content (2007, 11). That said, by reading Rawls, we can isolate key thesis, including liberalism's general conception of the state and its prescribed role in the lives of individuals and the theoretical character of citizens in a liberal state. This work has already been done excellently elsewhere, so I will not cover it in detail here.

Let me instead outline what I consider the highlights of the "liberal" subject in Rawlsian-style accounts: first, this individual must not bear cognitive difference, for fear of being displaced from social life. Second, this individual is "atomistic" and can evaluate and perhaps participate in the building of a legitimate regime. Third, access to freedom, equality and membership in society all appear to hinge on whether or not an individual can conceive of the good in a variety of ways. Without the two moral powers or two types of reason Rawls outlines, social recognition of personhood is in peril. Any blockages to this type of function can only be temporary; the liberal subject will not have permanent deviation from the Rawlsian conception of personhood. The liberal subject is reasoned, moral, and atomistic, and is *not* a person with cognitive disability. The liberal subject is either disabled and excluded, or not disabled and included; there are no gray areas with regard to fitness in the Rawlsian account of the political subject.

A Contractualist Account of Liberalism

In a discussion of obligations of justice to persons with cognitive limitations, Christie Hartley attempts to solve the difficulty of extending social contract theories to include such persons by replacing what she interprets as basic political relationships of *mutual advantage* with *relationships* proper (2009a, 142-3). In doing so, however, she not only extends values already embedded in contractualism into a trope, but also relegates members of the disability community to the role of virtuous helper to the abled – a move that invokes the very problems (related to mutual advantage) she attempts to avoid. I argue that Hartley ultimately makes the mistake of valuing persons with disabilities on the basis of the edification provided to the abled by way of their inclusion; this is reminiscent of the *charity model* of disability, which I described in chapter three. In addition, I argue, Hartley's unfortunate description of the benefits connected to including persons with cognitive difference within the scope of social relationships mirrors the problematic figure of the "magic Negro" in Hollywood film (Glenn and Cunningham, 2009).[83] In this vein it is helpful to consider the way in which black oppression and disability oppression operate by similar logic. Most generally, I link the notion of reciprocity or mutual advantage in the context of social contracts, which assumes a binary between ability and disability, to the stereotyping of persons with disabilities.

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[83] Unlike Hartley, I will avoid using the term "mentally disabled," except where it is absolutely necessarily to refer clearly to her argument. I reject this label because it refers to a heterogeneous group with terminology that not only reifies a blurry and unstable category but also encourages a monolithic view of disabilities (Carlson 2010, 113-20). The phrase also emphasizes traits over persons.

Like other critics of Rawls and social contract theories, Hartley notes that common sentiment considers persons with cognitive limitation subjects of justice, but leading theories of justice fail to provide the structure necessary for this inclusion (2009a, 138). Given the difficulties stemming from Rawls' notion of personhood, Hartley chooses to return to the "core ideas" of contractualism, which she considers the background for Rawls' view, in order to establish grounds for more universal inclusion (Hartley, 2009a, 141; 2009b). Contractualism, for Hartley, includes theories of "domestic justice" that understand society "as a system of cooperation over time" (2009a, 141). A system of this sort "is just when the terms of cooperation are fair and establish a society based on relations of mutual respect among members viewed as free and equal" (142). While she accepts much of what Rawls considers important for fair cooperation, including publicly recognizable rules for interaction and terms that are reasonable for all parties to accept, she departs from his account when she takes care to characterize the "contractualist idea of fair cooperation" as distinct "from the idea of cooperation for mutual advantage" (142).[84]

Hartley rightly worries that cooperation for mutual advantage can support significantly unequal terms of cooperation in liberal contexts, given the requirement that cooperation makes parties "better off" than they were outside of the cooperative context. This requirement can make bargaining among already unequal parties ineradicably asymmetrical, as she outlines (2009a, 142-3). Meanwhile, Hartley contends, *contractualists* would "require that terms of cooperation among members of society be reasonable or justifiable to all members *viewed as equals* and not *merely* terms that are

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[84] Cf. Hartley, 2011, 122.

rationally advantageous to all members in the sense of allowing individuals *to better their situation* by working with others" (143, emphasis mine).

Hartley goes on to make two significant revisions within the scheme of "cooperation for mutual advantage" in order to make the terms of fair cooperation acceptable to the contractualist requirement that members are "viewed as equals." First, she desires a conceptual change, endorsing the idea of *reciprocity* rather than mutual advantage, which would suggest that fair cooperation "does not require that those who count as cooperating members of society be such that their cooperative contributions to society outweigh the costs of their participation" (2009a, 143). This, reasons Hartley, abolishes the problem of unequal bargaining power among parties. Second, Hartley wishes to replace the too-prevalent "production model" of cooperation, which figures cooperative social relationships as primarily productive of goods that are external objects, with the "relationship model" of cooperation, which would figure cooperative social relationships as creating and transforming relationships themselves to a particular end (143-4). That end is the contractualist ideal of "mutual respect" among free and equal persons (139).

Yet, Hartley cautions, "it is important to keep in mind that cooperation of any kind involves individuals working together with others for a common end" (2009a, 143). So, taking society to mean a sphere in which cooperation occurs over time, with *relationships* as the focus of production rather than *production of goods*, Hartley's key move is the insertion of "reciprocity" as a norm in social relationships, along with the aforementioned commitment to "relationships of mutual respect" (139). Her revisions, she hopes, mean that "those with mental disabilities should indeed count as members of society since they have the capacity to engage in cooperative projects that are of fundamental importance to contractualist society" (139).

More specifically, and to reiterate, Hartley has reason to believe that contractualists can uniquely include the persons with cognitive disability under the umbrella of justice "by properly appreciating the numerous ways in which persons with mental disabilities make substantial contributions to the creation, establishment, and maintenance of a society based on relations of mutual respect" (2009a, 139). It is important to note that Hartley also considers it necessary that the interests of those who lack Rawls' two moral powers should be represented by a trustee genuinely committed to the interests of those they represent (146-147). This is a point I will not consider here, in favor of focusing upon Hartley's vision of reciprocity in relationships.

To accomplish her aim of including in a theory of justice those who lack the two moral powers outlined by Rawls, Hartley details these "substantial contributions" and explains how they are connected to the aim of creating, establishing, and maintaining a "society based on relations of mutual respect" with reciprocity as ruling norm. Remember that Hartley is attempting a partial *reworking* of cooperative social life (2009a, 139). An immediate aim, then, is to replace the central notion of cooperative *production* with the broader cooperative *relationships* (143-4). This move, Hartley believes, substantially revises the list of goods relevant to justice in a way unavailable to non-contractualist approaches.

Because Hartley values reciprocity over mutual advantage in social cooperation, she includes persons with cognitive difference as "free and equal" members of society who deserve "mutual respect" on the basis of their contributions, whatever they may be, and even if the costs of including such individuals outweighs the benefit (2009a, 142). Yet, her definition of cognitive disability highlights lack in the very area of *contributions*, however widely the concept is construed. She writes: “I understand a mental disability to be any kind of mental impairment that interferes with someone’s ability to form, pursue, or carry out valued projects in society” (139). Elsewhere, she notes that “what is important…is that an individual is able to cooperatively contribute to one of the main institutions [of society]. Nearly all human beings, excepting infants with anencephaly or the permanently comatose, can do that” (2011, 128). Despite this near-universal description of what cooperation is and can be, Hartley’s definition of “mental disability” *retains the substance of the binary and hierarchy* so often operating between the disabled and the abled. For her, the disabled can do what the abled can do (although not everything), but with interference. Understanding cognitive limitation this way belies the “mutual respect” to which Hartley is committed. How can all persons be viewed as “free and equal” when reciprocity must be interpreted as an endemically asymmetrical experience for the mentally disabled, *without being interpreted as such for others*? Reciprocity suggests that cooperative relationships need not be tit-for-tat; instead, one person can contribute in one way, while someone else may contribute in another. Yet, if the disabled can do what the abled can do, but with interference, it seems their contributions must always fall short of what an abled person could do in their stead.

Again, the central project of Hartley’s contractualist effort to include the mentally disabled rests on her view of *reciprocity* (within cooperative relationships, not merely relationships of production). Hartley is seeking ways to describe how a person with cognitive difference engages in relationships of reciprocity, relationships in which these individuals are typically viewed as the only beneficiaries (because they are considered fundamentally needy or inescapably vulnerable) (2009a, 139; 2009b, 29). Keeping this general setting in mind, a closer look at the relationships of reciprocity Hartley outlines shows that there is a further dead end for inclusion on her account. This goes beyond the asymmetry touched on above.

In her account, Hartley tends to describe the benefits of cooperating with members of the disability community as *primarily existing for the enjoyment of the abled*. To put the point slightly differently: while it is taken as a given that persons with disabilities are fundamentally needy, Hartley's way of justifying responses to that neediness involves tropes that play on what (given an abled/disabled binary) an abled person might have to gain from a disabled person. As it turns out, what the abled have to gain is of personal advantage to them; this means that Hartley has fallen back on the idea of mutual advantage at the same time as she is trying to escape it. This problem appears in all of her subsequent examples (subsequent to the initial, economic example) of cooperative contributions that those with cognitive limitation might make on the level of relationships (2009a, 150-5).

I turn now to her examples in order to make my critique more concrete. To discuss the cooperative contributions she has in mind, Hartley relates several primary narratives about persons with disabilities. She details the relationship between Eva Feder Kittay and her daughter, Sesha, who, despite her constraints in the area of language, "communicates some of her preferences" and enjoys music, experiences which can be shared (2009a, 151). Hartley also reports that Sesha provides Kittay with emotional support that Kittay estimates as invaluable (151). Hartley further mentions the relationship between Sophia Wong and her son, Leo, who helps "the Wongs realize the importance of patience and compassion," when the family plays card games together (151). Hartley writes: "By resisting the temptation to take advantage of him and go for a win, the members of Leo's family develop skills that are distinctive of *fair* cooperation" (151). This fair cooperation, as I have shown, is a key component of Hartley's contractualist account.[85]

Hartley's main narrative features Radio, the title character of *Radio* (2003). Radio is described as an extraordinarily virtuous boy, who embodies many characteristics praised in widely-accepted schemes of morality, as well as virtues helpful in a contractualist context. His primary relationship is with a local football coach and his team. According to Hartley, Radio encourages the coach and those on the team to focus on "what is of value in life," to be selfless and kind, and helps them "better understand their own humanity" (2009a, 154). Hartley emphasizes Radio's gain through these relationships when she writes: "Radio was not always this way. When he first met Coach Jones and others at school, he would not speak and was extremely shy. With tenderness and attention from others, Radio's personality was revealed" (154, fn. 42). Of Radio's personality itself, Hartley provides the following details:

> Radio is not concerned with material success or social reputation. He is not prideful. He is genuinely kind to everyone he meets and is happy to be included in whatever is going on, valuing and making the most of what is before him. Those in Radio's community who develop relationships with him gain a new perspective on what is of value in life (154).

Because Radio "isn't arrogant or proud," Radio provides one key service to those around him; namely, he "*humbles* those before him" who are reminded that those attitudes are

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[85] While I critique Hartley's *depiction* of Sesha and Leo in relation to the Kittay and Wong families, my criticism is in no way targeted toward the families themselves and should not be interpreted as such.

not valuable (154, my emphasis). Like the “fair cooperation” encouraged in the Wong family by way of playing board games with Leo, for Hartley humility is a virtue of utmost importance in the society she envisions. She writes, “the ability to humble those who are arrogant or proud is an especially important contribution to a contractualist society because of the danger arrogance poses to relationships of mutual respect” (155).

Overall, Sesha, Leo and Radio all provide lessons in key contractualist virtues for those around them.[86] Hartley focuses on the one-dimensional idea that Sesha provides emotional support for her mother (the benefit of which is taken with Kittay as she enters other interactions). Leo, again, provides the lesson of fair cooperation to his family, a virtue of contractualist justice. Radio provides the lesson of humility, yet another virtue of contractualist justice. Taking these primary examples together, we can conclude that cooperating with those who are disabled, on Hartley’s view, is meant to edify the abled in our (specifically contractualist) political and social interactions. It is important to note that Hartley cannot be suggesting that Sesha, Leo and Radio are the only possible sources of these experiences and benefits; rather, it would be appropriate on her view to see such persons as only one possible source of edification in contractualist virtues. Further, on Hartley’s view, it seems persons with disabilities can be *counted upon* to embody traditional social values that they can impart to those around them. This means that caring for the disabled, as seen from the view of the abled, can be considered of “mutual advantage” in the very way that Hartley would like to avoid.

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[86] Hartley does briefly acknowledge that not all disabled persons are “kind like Radio” (2009a, 155). Yet, she fails to expand upon or incorporate this idea theoretically or through narrative. She does not, for example, present an individual whose characteristics might typically be considered “a-social” but with whom one should cooperate regardless. I deal with Hartley’s intermediate case (Donna Williams) below.

Moreover, the disabled persons Hartley describes usually have stable families, as evidenced by the centrality of her narratives regarding Sesha and Leo (2009a, 150-5). Yet, familial stability is usually enabled by wealth and shaken by poverty. Because the financial costs of maintaining care for persons with cognitive limitation are high and social support is scarce, financial difficulty and disability often go hand-in-hand, with disastrous results for family life (Kittay 2001, 572). While Hartley's inclusive contractualism as presented relies on capable, loving families with access to resources and a tight, formative connection between family and society, she does not provide an acknowledgment that specific measures are necessary to support such families or this connection (2009a, 150 and 152). Additionally, in Hartley's description of the Wong and Kittay families, abled members are free to leave (free to enter the social world), while the disabled member is relegated to a role within the home—providing a type of education in values that is useful to the abled as they enter the social world (152, cf. the moral education of the charity model, above). Family members take their lessons away with them, and Leo and Sesha are left behind (cf. Fineman 2002).

Despite Hartley's intent to make the creation and transformation of relationships a central goal of social cooperation in a contractualist context (2009a, 143-4), her examples outline a particular set of pre-defined contractualist virtues as the end goal of social cooperation.[87] That is, a cooperative relationship is not valuable as such but only insofar as it fits into these virtues or values. This distinction, though fine, is important. Hartley has not demonstrated that creating and transforming mutually-respectful relationships are ends in themselves; such relationships are not fostered for their own sake, but valuable

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[87] The pre-defined contractualist virtues to which I am referring are, again, as per Hartley's examples, emotional support, fair cooperation and humility, among others.

contractualist virtues are fostered *by way of* relationships. This effectively places the emphasis on these virtues rather than relationships themselves. The relationships are subject to a *telos* that is fully articulated regardless of, and perhaps despite, fresh or otherwise suppressed social relationships and modes or methods of relating. In contrast, the work of disability theorists and activists like Robert McRuer take for granted that liberating movements would transform the social world, not simply allow persons with disabilities into the one that already exists (2006).

Hartley is responding to a supposed need to justify, in some reciprocal (if not mutually-advantaged) way, social support and justice for persons with cognitive limitation. Hartley's lack of specificity with regard to benefits belonging to these persons within the greater social world (beyond foundational care or home life) is problematic and maintains focus upon the abled and their reasons for providing this foundational care. Reciprocity in the social contract context seems to rely (perhaps intractably) upon the idea that disabled persons embody opportunities for the edification of the abled, while maintaining a strict distance and delineation between the groups. This requires the endorsement of destructive tropes, including the idea that all persons with disabilities are (or should be) loving, kind, fair, and so on. This is a view rife with extremely limiting and unfair expectations.

The Magic Negro, Black Oppression, and Disability Oppression

There is a close parallel between the position of persons with disabilities in the reciprocity Hartley discusses (which may be, merely, mutual advantage after all) and the view of the "magic Negro" as it is presented, historically and presently, in media and film, which highlights the difficulties with her view. Cerise L. Glenn and Landra J. Cunningham present the theme of the “magic Negro” in their essay “The Power of Black Magic: The Magical Negro and White Salvation in Film” (2009). There, Glenn and Cunningham explain the connection between images seen in films and traditional prejudices against black individuals. Arguing that the relationship between blacks and whites is “unsettled” and still evolving, they conclude that images in movies are extremely important (136). Likewise, I argue that the relationship between the abled and the disabled is unsettled, as are the categories, which are fundamentally unstable, and therefore relating images to the oppressed disability community should be an enterprise undertaken with the greatest caution and the homogeneous ascription of personality traits to such persons should be avoided at all costs. Hartley has already introduced the medium of film into her account by taking the figure of Radio as a central narrative. Given this introduction, Hartley either believes that the relationship between the abled and disabled is settled such that the image of Radio can be used unproblematically in a theoretical space, or she sees the relationship as unsettled yet has not considered the impact that film images may have upon both theory and the interaction between the abled and the disabled.

To draw out the relationship between Hartley’s descriptions of Radio, Leo and Sesha and the figure of the Magic Negro, I turn to a description of the figure and its connection to relationships between black and white characters in film. Glenn and Cunningham note that many products of Hollywood, including recent and historical films, appear to be celebrating relationships between black and white characters, but, the plot, themes and characterizations have racist undertones and relate back to "racist stereotypes, such as mammy, jezebel and Uncle Tom, as well as the mainstream traditional association of Blacks with folk wisdom and spiritual insight" (2009, 136). In this manner, blacks have appeared as one-dimensional caricatures: "Instead of having life histories or love interests, Black characters possess magical powers" (137). Glenn and Cunningham note that these images seem chosen particularly to "comfort and appeal to white viewers," and the problems related to such images are only exacerbated by the lack of interaction with black persons among "Hollywood screenwriters" (137).

Flat and misleading representations of black persons may seem like a problem of the past, when "Sidney Poitier and other Black actors were placed in White worlds to help White people improve themselves"; "These magical Negroes were often wise, morally upright Blacks who serve as the moral conscience of White characters" (Glenn and Cunningham 2009, 137). But, such flat versions of black characters (created, it seems, merely to draw white characters along a moral path) have not disappeared over time. According to Glenn and Cunningham, the magic Negro crops up in many recent blockbuster films, including (to name only a few) *The Green Mile* (1999), the *Matrix* trilogy (1999 and 2003), *The Legend of Bagger Vance* (2000), *Nurse Betty* (2000) and *Bruce Almighty* (2003).

The magic Negro image trades on "the superior moral nature associated with the oppressed" (Glenn and Cunningham 2009, 138); for example, "the magical Negro is [seen as] markedly selfless" (151).[88] A black character in this guise will assist her white counterparts, "help him or her discover and utilize his or her spirituality," or represent

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[88] Recall Goffman's description, above, of the "sixth sense" and "understanding" often associated with stigmatized traits.

"folk wisdom" in order "to resolve the character's dilemma" (Entman and Rojecki, 2001, quoted in Glenn and Cunningham, 2009, 138). The magic Negro often lacks significant aims or goals of her own, figuring merely as a helpmeet or guide for other characters. Citing the work of bell hooks (1995), Glenn and Cunningham worry that "because these roles depict a utopian relationship between Blacks and Whites, Whites may believe that these ideal harmonious relationships depict current social status; therefore, racial problems only exist in the minds of Black people" (2009, 137).

Likewise, I worry that Hartley's depiction of persons with disabilities describes a "reciprocity" between the disabled and the abled that emphasizes moral benefit and improvement for the abled at the expense of empowered roles for the disabled. Hartley's image of the "mentally disabled" individual, like the magic Negro, seems to position these subjects within political life *primarily* for the moral improvement of the abled. The improvement available is specifically with regard to contractualist virtues, and does not refer to new or transformative relationships themselves—again, a fine distinction, but a vastly important one. Like the magic Negro, Hartley's image of the disabled individual lacks significant aims or goals of her own; like the magic Negro, Hartley's image trades on "the superior moral nature associated with the oppressed." This idealization creates unfair expectations and limits persons with disabilities in ways that persons seen as abled need not experience. Again, this is reminiscent of the problems perpetuated by the magic Negro image. Among abled persons, a stingy or humorless person is not viewed as less deserving of rights than a generous person. Our view of the contributions of persons with disabilities (specifically those salient for affording such individuals rights) should not be clouded by expectations regarding how ennobling one considers the experience of their company. For an example of an ennobled and wise disabled character in pop culture, think of Forrest Gump, played by Tom Hanks, titular character of the 1994 film.

To return to Hartley's view of reciprocity, it is important to note that Radio's personality was, according to Hartley, "revealed" through the kindness of the football team and coach (2009a, 154). She does not mention, or seem to believe, that it was enabled or created through interaction with others; instead, it seems an innate part of Radio, waiting to be enjoyed by those around him if only they would give him a chance. This belies Hartley's overall aim to place "transformative" relationships at the center of social cooperation. Radio is not presented in her account as a "transformed" character, even if some supposedly innate aspects of his personality were revealed through social interaction. His "transformative" effects on others, meanwhile, are limited to reminding them of virtues *already commonly held*; he provides lessons that could likely have been encountered elsewhere. The official tagline of *Radio* is: "*His* Courage Made *Them* champions" (2003, emphasis mine). This articulation reveals that the focus of the film (which Hartley does not attempt to mitigate or contextualize) is clearly the benefit given to the abled community through its interaction with Radio.

Hartley's depictions, especially of Radio, and their connection to the "magic Negro" trope can be reinforced by reference to a further trope, this time linked directly to stereotypical views of persons within the disability community: the "supercrip."[89] Eli Clare critiques the notion of the "inspirational" disabled person, the "believe-it-or-not

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[89] Goffman refers to this trope in the following way: "Each time someone with a particular stigma makes a spectacle of himself by breaking a law, winning a prize, or becoming a first of his kind, a local community may take gossipy note of this; these events can even make news in the mass media of the wider society" (1963, 27). Recall also my description in chapter one of the young girl profiled in *Physical Culture* magazine who "swam her way" out of paralysis.

disability story" (1999, 2). Clare refers to this as "supercrip crap" (2). Clare understands the "supercrip" trope to uphold the inferiority of disability and the superiority of the abled body; the view relates the idea that "disability and achievement contradict each other and that any disabled person who overcomes this contradiction is heroic" (8, cf. Ware 2002, 144). Others have noted the constancy of these images in the media (Riley 2005; Ware 2002). Diane De Vries, subject of Gelya Frank's multi-year ethnographic studies, was the "poster child" of many charities as the result of her swimming despite lacking limbs (Frank 2000). De Vries and Clare both register deep unease with the trope, and Clare describes the way he has internalized the trope. Taking the figure of the supercrip into consideration, Radio appears more one-dimensional than ever. "His courage" which "made them champions" is an unbelievable feat; Radio must be a *hero* to participate in that kind of achievement.

Important work has been done on the issue of black oppression that has been picked up to great benefit within disability studies. I am thinking specifically of the work of Frantz Fanon, which, alongside work done on the oppression of women by Sandra Bartky, features prominently in James Charlton's discussion of the workings of false consciousness (1998). He notes that those who are abled and those who are disabled are both contributors to the notion that the disabled are fundamentally powerless and needy. Writes Charlton: "when blatantly pejorative attitudes are not held, people with disabilities often experience a paradoxical set of 'sympathetic' notions like the courageous or noble individual" (1998, 51). Charlton emphasizes the importance of contestation in response to these attitudes; he encourages "demanding recognition, respect, and responsibility" (54). Demands like this are a key part of what seems to be missing from Hartley's account of reciprocity, which begins with the assumption of fundamental asymmetry by definitional fiat. Charlton emphatically rejects the circular logic of equating disability with inferiority (68). He argues that the "worth" of persons with disabilities "is reduced to cost-benefit analysis" (70). This rings true when it comes to widespread notions of mutual advantage in social contract theory, as Hartley herself argues (2009a, 141-143). And, if reciprocity collapses into mutual advantage and relies upon stereotypes regarding the disabled, it is also true of reciprocity as Hartley has conceived of it.

Perhaps Hartley's vision of reciprocity is merely a way to maintain and police the boundary between "ability" and "disability," a way to reinscribe the binary from within relationships. Elizabeth Spelman's essay "'Race' and the Labor of Identity" spells out the work that must be done by persons oppressed because of their race precisely in order to uphold the notion that whiteness is superior (2002). She argues that this invisible work is a type of "acclamation on demand" and involves supporting the *feeling* of superiority enjoyed by whites (339). In the case of the trope of the supercrip, or the champion football players in *Radio,* it is clear that the acceptance or internalization of these ways of comparing abled and disabled achievement is a labor of identity. Clare's desire to climb mountains, which he explicitly troubles even while enjoying it immensely, reinforces the importance and meaning of this achievement along with aspects of ableism.

Now that the above tropes have been described and briefly explored, I hope to have made the case that Hartley's chosen ideals of cooperation with the disabled, as represented by her depictions of Sesha, Leo and Radio, have unfortunate connections to traditional prejudices against the disabled. Let me briefly summarize some of the main points. Think of the classroom: there, everyday challenges, including disobedience, *could* be viewed as a result of inadequate accommodation; yet, given Hartley's ideal types, disobedience among the disabled all too easily appear as a character flaw, especially if overtures of friendship had already been extended to them from other classmates or from a teacher. This is particularly true given an educational context which already supports this interpretation (Cook, 2004). Think of morals: Hartley's examples perpetuate the stereotype that those who lack intellect are innocently ethical, serving as a reminder of genuine human spirit; this ethical nature is not even construed as wisdom, but as simplicity (Carlson 2010, 24, 29). Think again of the character of Forrest Gump and the depiction of his gentle reminders to those around him about what is of value in life; his parallel is Radio.

Through Radio, Hartley perpetuates the stereotype of what Eli Clare calls the "supercrip." Even further, Radio's image reveals that jocularity seems to be *expected* of the mentally disabled (Radio is clearly depicted as a good sport, "happy to be included in whatever is going on"). These stereotypes inevitably meet with foils in real life because the disability community is a heterogeneous group of singular individuals with unique histories, personalities, preferences, and quirks. No particular characteristics ought to be used as reasons to deny or to afford persons with disabilities a position in a scheme of justice—in just the same way as these characteristics among the abled are not used to mete out social goods and benefits.

Hartley, of course, is not unaware that the disability community includes unkind individuals. For example, she speaks of an autistic woman named Donna Williams, "who found direct or emotional communication painful and debilitating as she was growing up…because of her behavior, Donna was considered uncooperative and sometimes disruptive." But Hartley goes on to say that "Donna was misunderstood" and that "it was not that she could not communicate or that she did not want to communicate." Instead, "she just could not [communicate] in the typical manner, at least *not yet*" (2009a, 156, emphasis mine). While this narrative would seem to exonerate Hartley of some of the claims I make against her, her "not yet" implicitly denies that Williams may simply be, or become, a quiet person who does not enjoy regular interaction. Not knowing Williams, I must concede that Hartley may be right and that her personality may have been hidden by those around her. I do not concede, however, the more significant theoretical point: that every disabled person should be expected to (at least eventually) be cooperative in a way opposed to Williams' relatively "uncooperative" behavior – or that their value or social worth depends on cooperative behavior. I maintain that Hartley's theory lends itself to the unrealistic and unfair expectation that all disabled persons are either already sociable in the way she describes, preconceived through contractualist values, or that they can or should be nurtured *until* they are sociable in that way. The idea that persons are justly open to exclusion pursuant to failures in sociability is extremely objectionable.

In "Justice for the Disabled: A Contractualist Approach," Hartley anticipates some of my arguments. She writes: "Some may think that, in my account, the contributions that can be made by those with severe mental disabilities are 'uncomfortably derivative' and *a mere matter of what those with severe mental impairments can do for others by engaging in relationships with them*" (2009b, 29, emphasis mine). She softens this objection by responding that while "those with disabilities are often cast as noncontributing burdens on others," in fact "individuals with severe mental disabilities do provide others with benefits, which is itself important to recognize" (29). While Hartley is correct that the contributions of persons with disabilities are often undervalued or hidden, in her narratives they are shown acting merely as helpers to the abled, and seem to be one-dimensional persons most notable for their virtuous character. Hartley goes on, to assert that it is the "cooperative relationships" which "are themselves important to contractualist society," and repeats her commitment to mutual respect, along with mutual trust and support (29). Yet, multi-dimensional "cooperative relationships" are missing from her examples. Instead, contractualist values stand in their place; these are set as the goal of such cooperation and already delimit these relationships.

As I indicated at the outset, Hartley's account aims to demonstrate the potential inclusiveness offered by contractualist theory, one thread within the much larger liberal tradition of social contract theory. Yet, Hartley does not deal adequately with historical systems of oppression affecting the disability community and the place of filmic images she uses in their perpetuation. Like one-dimensional images of black characters in Hollywood films, the stereotypes implied in her narratives figure the mentally disabled individual as an accessible other who reflects already-valued social behaviors.

Hartley's move to revivify core values of contractualism in order to include the claims of members of the disability community is based on a demeaning view of disability; that is, the differentiation of reciprocity from mutual advantage results in the reversion to common stereotypes and tropes regarding persons with disabilities. This support for homogenizing and limiting images of persons with mental disabilities undermines her stated aims (2009a, 142-3; 2009b, 29). Reciprocity and mutual advantage more generally appear to support a binary between "abled" and "disabled" and, when carried out within the context of this binary, these structures link to negative stereotyping of persons with disabilities.

Because Hartley is aiming to include persons with disabilities, we are given more information about the disabled subject than about the abled subject in liberal contexts. But, the images we are given, of the supercrip, the Magic Negro, and opportunities for moral education *through* the disabled body *for* those who are abled, are limiting and disappointing. We also see that disability is still constructed by way of lack – this time, lack within cooperation that the abled subject does not experience. In other words, while both subjects are figured as cooperative, the primary liberal subject is *abled* and therefore fully cooperative while the disabled subject is *other* and cooperative in a limited way.

Possibilities for Transformed Theorizing

In my discussion so far in this chapter, I have dedicated my effort to finding the figure of disability within liberal contexts and discussing the limiting way disability appears in Hartley's political schemes. I do not wish, however, to argue that liberalism cannot accommodate difference or be more inclusive of persons with disabilities. For that reason, I now turn to two theoretical points of view, within the liberal tradition, which I argue are more transformative than Hartley's and represent a significant improvement upon her view.

I start with Anita Silvers' three-pronged distinction among and classification of strategies used to respond to difference, which she suggests in order to minimize confusions and avoid over-generalizations when discussing the disability community.

These are 1) differences that should be denied, 2) differences that should be mitigated, and 3) differences that should be embraced (Silvers 2009, 169). Differences that should be denied are those that are "illusory," i.e. prejudices which are attributed wrongly to inherent traits (171). Differences that should be mitigated are those that are related to what has been called "impairment"; for example, deafness. These also include differences arising from historical injustice, such as actual differences (like those in pay or education) attributable to misconceptions regarding ability (173). Differences that should be embraced are those related to talent (and capability sets). Talent, as we shall see, is a central idea in Silvers' notion of justice (184). To this I add the reminder that those who embody difference should be celebrated, taking the idea from Marsha Saxton, who notes that "we in the disability rights community resist the notion that our humanness can be evaluated and then reduced to a flawed gene" (Saxton 2000, 161). Building in the responsive structure of embracing differences rejects the spread, generalization, and synecdoche associated with stigmatizing practices. Silvers argues that responding to difference in social and political settings should involve the use of all three strategies (170).

The third of these, "differences which should be embraced," is representative of a provision and an attitude she believes is missing from accounts of justice built by Rawls and Martha Nussbaum (Silvers 2009, 169). A central test case for Silvers can explain her objections to both of these theorists, while at the same time showcasing the intuition behind her contribution of "justice for talent" as it applies to disability. On Silvers' view, commonsense notions of justice would reject the type of outcome represented by the Supreme Court's decision in *Board of Education of the Hendrick Hudson Central School*

District v. *Rowley* (1982). In that case, the Court held that Amy Rowley, a deaf elementary student at a public school, should not be given an interpreter in a public classroom (although she did receive tutoring and therapy) (Silvers 2009, 180). This decision was representative of parts of (then current) EHA legislation (the Education For All Handicapped Children Act, passed in 1975), but not its "mainstreaming" ethos; furthermore, Silvers notices that today's ruling legislation (the Americans with Disabilities Act) does not uphold the spirit or intent of the decision (184-6). Rowley maintained a "B" average without an interpreter, which met or even exceeded baseline expectations for classroom performance among her peers (180-3, 187). Rowley, then, performed better, on average, than some of her hearing classmates. Because of her performance, there was no need, in the Court's majority opinion, for further public expenditure on Rowley's behalf (181). This is despite the fact that Rowley could understand only around 50 percent of classroom proceedings, including instructions from the teacher. Had she been given an interpreter, Silvers presumes that she could have outperformed her classmates in accordance with her potential (180).

Here, the problem is that a "baseline" or "threshold" notion of equality as it was applied in this case does not conform to what most persons, Silvers argues, would believe is just – that Rowley be provided with an interpreter (Silvers 2009, 183). The "equal treatment" given to Rowley did not ensure justice in her case, because her *talent* was not considered and her difference was not embraced (180, 184). Rowley's case shows why a focus only on the two strategies of mitigating or ignoring difference can lead to unjust results (197). Note, also, that her disability was not fully mitigated; it was, instead, mitigated to a baseline degree necessary for what the Court considered "normalcy."

Writes Silvers: “assimilation and compensation” merely “take justice to be a matter of advancing outliers to normalcy” (192).

Silvers points to another issue in Rawlsian liberal theory which I have not, as yet, considered. She argues that Rawls’s theory of justice, with its difference principle of extra social support for the “worst off,” would lead to the same conclusion that the Court reached in Rowley’s case. Because Rowley was not the “worst off” in the classroom – she outperformed some of her peers – she is not the appropriate recipient of extra social expenditure (Silvers 2009, 187). Silvers finds the notion of the “worst off” generally troubling in the case of persons with disabilities. She argues that this principle leads to jockeying for position among the disadvantaged and results in an unhelpful hierarchy, one that accords benefit to being seen as less advantaged than others. Thus, an already vulnerable class is fragmented (179, 194-7). She writes:

> Theories of justice aimed at mitigating the disadvantage of the worst off face difficulties in accounting for disapprobation [of the intuitive] sort. Focused on deficiency, they neglect Amy and those like her whose losses, however unfair, do not depress their wellbeing drastically (187).

For Silvers, it is wrong to suppose that “different ways in which people can be very badly off must be commensurable” (179), or that some individuals cannot be both better and worse off, like Amy Rowley (187). Beyond these worries, Silvers also has concerns about Nussbaum’s capabilities approach, which invokes thresholds and baseline notions (182); Silvers believes this approach would have to support the Court’s decision in *Board of Education* v. *Rowley* (181). On her view, capability theory views justice merely as “equality of basic outcomes,” although it does have the strength of a baseline requirement, regardless of what resources and social support are necessary (182). Silvers argues, however, that there is no obligation to assist the disabled in exceeding "benchmarks" "so their opportunities….equal those of nondisabled people" (183). This drawback of Nussbaum's view is significant for persons with disabilities, as is the drawback of the notion of the "worst off" that Rawls offers.

For Silvers, justice for talent means that "social support" should be provided for exercising talent, which "engenders personal benefits by cultivating individuals' incentive and self-esteem" (2009, 192). Impediments to this ideal "impoverish productive cooperative social relations" (192). She does not see this as a challenge to liberalism's basic commitments, but rather a refinement and reminder of what those commitments really mean: "preference for talent seems patently acceptable to justice and is a principle endorsed by both proponents and opponents of race-based affirmative action [for example]" (191). Silvers wants to revitalize the cooperation that political liberalism is founded upon, and her comments regarding justice for talent bring to the fore a further project. Silvers and Francis both articulate a notion of "justice through trust," which "calls for principles aimed directly at facilitating cooperative interaction among different kinds of people rather than among people who are the same" (Silvers 2009 192-3; Silvers and Francis 2005). Silvers' commentary on justice for talent, together with the reminder provided by justice through trust – that diversity is vital to collaborative democracy – assist the move past mere mitigation of difference to embracing difference (Silvers 2009, 184).

I appreciate Silvers' contributions to liberal theory and now would also affirm Eva Kittay's contribution in her liberal scheme of "justice as care." Key to the discourse of the "ethics of care" is the contention that autonomy, rendered in traditional liberal theory as accomplishing key acts without significant assistance, must be replaced or transformed as the central characteristic of personhood (Kittay 2001, 570). This theory is applied to questions of vulnerability and how to justly treat those with disabilities. These efforts, generally, are geared toward recognizing the flaws in common notions of both autonomy and dependency. Given these insights, theorists like Kittay wish to recast the role of the "dependent"—including individuals with disabilities—and open up space for a responsive ethic (570). Tied to this aim is that of recasting the role of the care-giver and providing social support to them in an attempt to mitigate the impact of biased views of the meaning of that support (573). "Justice as caring" is the expression of the responsive ethic that Kittay outlines.

Kittay brings the experience of raising her daughter, Sesha, to bear upon the issue of what is owed the cognitively disabled in a just liberal society. Kittay and her partner were already committed academics at the time she gave birth to Sesha. Upon discovering that Sesha could never share in what Kittay and her partner most valued (for the purposes of this discussion, we could even say that Sesha could not share in Kittay's conception of the good as she conceived it at that time), Kittay began to undergo the life-changing experience of raising Sesha and recognizing her unique conception of the good. She criticizes liberal notions of personhood for being unable to treat her daughter as a citizen of any country (2001, 567) or as a subject of justice (574) or as a person (568). In other words, the traditional liberal subject excludes Sesha. She finds this untenable and, additionally, counter-intuitive, arguing that all feel the pangs of injustice when we hear stories of the abuse or neglect of the dependent and persons with disabilities, including those with cognitive difference (558).

Kittay writes: “constructed only as a problem, Sesha and other developmentally disabled persons appear to have no claim to the aids and supports that they need to live and live well” (2001, 567). But Sesha does not have to be a problem; justice as caring can treat her as a person. This is because justice as caring acknowledges that “being a person has little to do with rationality and everything to do with relationships to our world and to those in it” (568). Kittay argues that liberal notions of personhood must be overhauled in light of this recognition if we are to successfully extend justice to the disabled. On Kittay’s view of justice as caring,

> being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one’s own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him or herself (568).

For Kittay, it is clear that Sesha is able to enjoy her own conception of the good, and fulfills the above sense of personhood. She enjoys music and laughter and the people she knows and loves (cf. Hartley 2009, 151). On Kittay’s view, focusing on her deficiency is unjust, and “only by considering her in the fullness of her joys and capacities can we view her impairments in light of her life, her interests, her happiness—and not as projections of her ‘able” parents or of an able-biased society.” But, as mentioned above, it is only through the appropriate social support for family care and care workers, along with social support for Sesha herself, will help expose the fullness of her personhood and allow focus to be reoriented away from Sesha’s differences (Kittay 2001, 567).

For Kittay, “justice as caring” can open up the opportunity for society to support diverse ways of living. She writes: “those who have developmental disabilities require more supports than those without these impairments. However, they also provide different and rich opportunities for relationships and experiencing new ways of seeing the world" (2001, 567). This outcome, however, is threatened by society's bias against dependence. On Kittay's view, independence is a "fiction," which

> turns those whose dependence cannot be masked into pariahs, or makes them objects of disdain or pity. It causes us to refuse assistance when it is needed. It encourages us either to deny that assistance to others when they require it or to be givers of care because we fear having to receive care ourselves. In acknowledging dependency, we respect the fact that as individuals our dependency relations are constitutive of who we are and that, as a society, we are inextricably dependent on one another (2001, 570).

For Kittay, then, an overhaul of the liberal conception of personhood is required. The over-emphasis on rationality in that context, she argues, is problematic because it leaves out significantly vulnerable populations and denies them justice rightly deserved (2001, 562-5). For Kittay, social interdependence renders us all vulnerable, and it would be a mistake of hubris to forget or deny "the independent animals we are" (2001, 576).

Importantly, Kittay's work can point to the *stigma* of dependence (recall here Garland-Thomson's view of disability as a "pervasive cultural concept") which has an easily overlooked effect on dependency workers and their dignity and flourishing, and which in turn (if unattended to or unmitigated) has deleterious effects upon the dependent themselves and their social and political opportunities (2001, 571; cf. Goffman 1963, 20-23). Kittay is a rich resource on the topic of dependency and care, and my limited overview of some of her key ideas in no way exhausts her insights. Kittay's fundamental critique of the notions of independence and dependence separate her view from that of Christie Hartley. She avoids the problem of asymmetry that Hartley encounters by way of the transformative view of subjectivity she brings to bear on all persons, not simply persons with disabilities.

Eva Kittay, who articulates justice as caring, and Anita Silvers, who articulates justice for talent, both make important steps toward the inclusion of the disability community in accounts of justice while simultaneously fighting stigma and refusing synecdoche. While liberalism is haunted by the exclusion of persons with disabilities, more transformative views are available, and the work of Kittay and Silvers represents those possibilities.

Conclusion

This chapter represents a political interlude in my project, one which I undertook quite deliberately in order to understand the way that disability and ability are opposed to each other and constructed in a liberal context. I found that in traditional Rawlsian liberalism and the heritage of that liberalism, just as in the case of bioethics, disability tends to be interpreted as lack and a strong boundary line between "ability" and "disability" is policed and maintained.

Bioethics and liberal discourse inform each other (e.g. Carson 1994, Loughlin 1995, Pauer-Studer 2006). The transhumanist utopias I consider in this project are not only biologically but also politically outlined; for instance, Bostrom imagines a world of wide access to technologies and new political and moral possibilities opened up as a result of cognitive enhancement (Bostrom 2004, 2008). Traditional liberalism and transhumanism mimic each other by positing a fantasy subject that is *not* dependent and that can *choose* without limitation; this subject is cooperative, rational, and atomistic. This fantasy is detached from interpersonal realities and the contingencies of social and political life; the focus in both these discourses on atomism and individuality obscures fundamental human interdependence. In both locations, the disabled subject is illicitly constructed as uniquely dependent and limited.

I have employed the cultural model, along with the concept of stigma, to better understand the construction of disability and its appearance in multiple contexts. While disability need not be a negative signifier, it is often assumed to be such, and to connote naturalized characteristics of negativity and lack. But all bodies are open to stigma; human differences are equally vulnerable to stigmatization and so the “abled” subject is not so much “abled” as “temporarily able-bodied” by way of social circumstance (TAB, cf. Brueggemann *et al*. 2001).

CONCLUSION

TRANSHUMANIST UTOPIAS IN CONTEXT

In this project, I challenged views in bioethics and political liberalism that implicitly or explicitly questioned the existence and value of persons in the disability community. I traced the borders of the social acceptance of particular bodies and iterations of the bio-political question: who should live? I investigated the fantasies of transhumanism and exposed the ableist assumptions and heritage which drive and shape it. My motivation, here, was to track the denigration of dependence, difference, and the body, alongside the over-valuation of the avoidance of death, longevity, and intelligence (of a particular kind) in the literature of bioethics. In the course of these pages, I uncovered and exposed one debate in which bigoted and prejudicial attitudes are expressed and fed: the enhancement debate. My main focusing question was: what desires or wishes do transhumanist utopias represent, and what can these utopias teach us about ableism in bioethical contexts?

In carrying out my project, I was committed to understanding disability in such a way that would recognize the centrality of society's responsibility to make a place for, respond to, and attend to persons and their needs by revisiting the terms of philosophical debate in bioethics, the provision of medical care, political institutions, and institutional barriers of all kinds.

Transhumanist strategies reinscribe disability onto the body, ignoring its social contours and construction. As exemplified in the work of Bostrom and Savulescu, transhumanism views the current human body through the lens of risk, and views biotechnology through the lens of choice. The risk that the human body encounters is often conceived of as the risk of disablement, including disablement through aging, illness or accident. For these thinkers, then, the disabled body is uniquely linked to limitation, risk, and ultimately, death. In contrast to this body, I argue, transhumanist utopias focus on an ideal subject, one which would experience no restriction with regard to pleasures, choice-making, or opportunities—the techno-liberal subject, a subject whose future is mediated by the choice to use technology. This fixation on a utopian version of what the human subject should be comes at the expense of already-existing persons.

Each section of the preceding pages represents an engagement with the ways in which meanings and definitions of disability are built and sustained in various social, political, and philosophical contexts—that is, a variety of "locations" of disability were explored. In chapter one, I investigated a history of enhancement technologies, which is also a history of how illness and deviance, and therefore disability, have been defined against changing conceptions of health. In chapter two, I call into question the implicit naturalization and biologization of disability inherent in Julian Savulescu's suggestion that negative genetic selection is not only a desirable "human enhancement" technique but also a moral obligation. This naturalization process is also a feature of genetic counseling practices and bioethical debate regarding what parents owe children when contemplating childbirth, and feeds the development of disability as risk in enhancement discussions. I attempted to delineate and work from a position which seeks reproductive justice and is pointedly critical of the deeply ableist context in which pre-natal testing technology is developed, employed, and recommended by the medical community to women and parent(s) who are expecting. Finally, in chapters three and four, I discussed disability within a variety of political contexts, both practical and theoretical.

I now linger to offer a few further reflections on transhumanism and transhumanist utopias. Most importantly, I suggest that for the transhumanist, positive and negative eugenics are linked together. While these "strategies" of enhancement are often tackled as separate, Peter Singer explicitly acknowledges their connection (see chapter one) and transhumanists implicitly acknowledge their connection (see chapter two). Transhumanism continually treats the two modes as co-extensive: to rid the world of disability *is* to enhance the human. Recall that Savulescu claims that we must enhance or go extinct, and that his preferred mode of enhancement is genetic selection (selection against marked bodies). Transhumanism seems to here enact a *reversal* of the feminist insight that subjectivity is interconnected and persons are significantly interdependent; transhumanists perversely acknowledge the importance of intersubjectivity when they implicitly claim that for any single person to be enhanced, all must be "enhanced" (culled). This is the heart of the linkage between positive and negative eugenics—enhancement seems to require, for the transhumanist, the rejection of disability and embodiment generally as risk and limitation. This is posed as necessary for the realization of enhancement for the individual and even in order to save the world (Savulescu 2009).

As I indicated at the outset, transhumanist literature is written by white men and seems directed toward their specific concerns, with little regard to its potential ableist, sexist, and racist impacts. This is especially clear in my case study, negative genetic selection. Meanwhile, there is a masculinist "tint" to much bioethical literature written on enhancement (e.g. concern about shortness of stature) and this orientation extends to transhumanism. In many ways, transhumanism is an expression of its setting in bioethics, and bioethics is in turn influenced by transhumanism. In the social milieu of prenatal testing, one receives the impression that reproduction would be perfected if women were not involved at all—the womb is a risky place for the fetus to gestate. Transhumanist argumentation transforms all embodiment into risk—recall Bostrom's imagery of the paper hut, and Savulescu's treatment of procreative beneficence as a risky game of Wheel of Fortune. The fetus is transformed into a site of risk, and autonomous "reproducers" should embrace their role as risk managers in order to stave off undesirable outcomes.

Transhumanism sees freedom as the freedom to make choices, and the freedom to make choices as positioned as a route to bliss and happiness. Transhumanism extends the prerogatives of humanism instead of calling its boundaries into question; transhumanism seeks a broader field of action, a secure future, not transgressed boundaries and transformative hybridity. Transhumanist enhancement is simply a romantic dream of endless autonomy. "Better" and "best" for the transhumanist references social prejudices without questioning them. Finally, the "freedom" of choice-making is opposed to the "risks" of disability and embodiment; transhumanism reinforces illicit boundary lines between disability and ability. Because transhumanist visions of the future do not question stigmas, these visions serve to reify them.

In conclusion, I offer a suggestion for further philosophical reflection on the issues that were brought up in the course of this project. A revised version of "enhancement" could focus on the revision of political and social circumstances, seeking justice for those with disabilities and acceptance of diverse forms of embodiment. Cost-and-benefit analyses connected to the bio-political question of who should live must be challenged, and appropriate housing, transportation, schooling, and medical care must be sought. These would be true "enhancements." Enhancement can be made an expression of care.

We should *seek* augmentations—political, social, and technological—that bridge the gap between the body and individual life goals *as articulated* by those upon whom the suggested technology would intervene; this makes enhancement an expression of care, and would resemble neither positive nor negative eugenics. We should *reject* enhancement strategies which rely, for their desirability, on the connection of a proposed technology to maximized, optimized autonomy for a future human, a future human whose details are constrained by existing prejudices and whose happiness depends on added capabilities and unencumbered choice-making rather than complex interdependence.

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