

The Genetic Zeitgeist of Generation Z
Entanglements of Reproductive Ethics in the Near Future

by
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Introduction

Part I-New Waves in Reproductive Medicine

Scholars have long studied the coevolution of technology and culture. When work is eased by technology, new work emerges—and new work brings a new way of life. Consider the wheel: one can imagine that its invention simultaneously alleviated the burden of transporting materials *and* spurred trail building. The wheel changed daily life and, thus, culture.

Today, as inventions are increasingly changing the methods and outcomes of reproduction, we face the coevolution of technology and humans themselves. Cultural evolution need not rely only on what people do, but also on who they are genetically. To the extent that genetic variation corresponds to qualitative difference in human characteristics, reproductive practices that influence which genes occur in society also sculpt society in socially relevant ways. How, for example, might biotechnological selection for males change the dynamic between the sexes? How might the screening out of those at risk for heart disease affect health care? When we manipulate who is born, we modify social practices and attitudes.

Social change is uniquely direct when effected by reproductive technologies that allow for genetic selection, as the taste of societal soup largely depends on its constituent ingredients. Other medical innovations that transform society do so in a more roundabout way. Take the invention of Penicillin in 1942: millions of people with access to the antibiotic were cured of potentially fatal illnesses (“The History of Penicillin”). Lifespan increase resulted in demographic change, which caused other

pragmatic and perceptual changes in turn (Wilmoth 2000). But Penicillin is a reactive solution—it kills existing bacterial infections and has nothing to do with their occurring in the first place. Such a drug contrasts with reproductive technologies in its locus of intervention. The latter deals with problems at their source, censoring problematic genetic material and propagating its more favorable counterparts. In influencing genetic composition, reproductive technologies dictate who we are in an essential, irreversible way; their development and utilization must be closely monitored for this reason.

Another reason for vigilance has to do with the current state of genetics. Genetic research is progressing at an unprecedented rate, and reproductive technologies are flourishing alongside it. This is not to say that genetic understanding unilaterally informs reproductive possibilities: there are biological and physiological realities, like gestation time and womb size, that constrain our ability to fashion reproductive technologies solely out of genetic knowledge. But a new command of genetics is playing a significant role in the development of reproductive technologies, especially those involved with genotype-based selection.

The phenomenon responsible for such advancement in genetics is referred to as next-generation sequencing (NGS hereafter). Compared to previous sequencing techniques, NGS is a faster, and thus cheaper, method of determining the genome of an organism (the mechanisms and consequences of NGS are thoroughly discussed below; the technology is merely introduced here to contextualize modern genetics for the non-scientist reader). The efficiency of NGS permits elaborate comparison of genetic material, and promises to support abundant discoveries relating to genotype-

phenotype correlation. To anticipate the extensive mapping of molecular-level genes to human qualities is no longer imaginative. Similarly conceivable are the reproductive technologies this information might give rise to. If genotype-phenotype correlations are available to the common procreator, offspring qualities may be less randomly determined and more deliberately selected. The near future of reproduction, therefore, is one of great decision making.

Of central importance to the ethical questions herein is the extent to which decisions of soon-to-be parents (proto-parents hereafter) require guessing. Because genetic information assumes the (simplified) form, “genotypic property *X* correlates to phenotypic property *Y*,” genetic selection is subject to a disconnect between the intention of a selection decision and its actual result. And yet many proto-parents would choose not to implant an embryo implicated with, say, a two percent risk of developing multiple sclerosis (the logistics of pre-implantation diagnosis are discussed with *in vitro* fertilization in the next section). That proto-parents may act on low genotype-phenotype correlations—thereby systematically selecting against certain potentially important genes—suggests a need for bioethicists to regulate genetic information and research.

More broadly, bioethicists must establish criteria that can guide a principled segregation of reproductive choices we ought, or ought not, to make for ourselves. Given that there will be (and arguably already are) a subset of reproductive options whose availability risks social harm, the freedom of the individual must be balanced with the benefit of the society she inhabits. In the playing field of reproductive ethics, players in different positions interact constantly; the decisions of proto-

parents, medical practitioners, institutional health care providers, and policy makers not only impact one another, but also determine whether or not prospective offspring will exist, and what they will be like. Longstanding questions in medical ethics surrounding patient autonomy will be critical in assessing future reproductive choices: when is a practitioner justified in withholding information from a patient? When is a patient deemed competent to make a decision, and is competence an ethically sufficient condition for his total autonomy?

Further questions are unique to the reproductive choices that NGS may soon enable. Current bioethical concerns regarding prenatal screening and selective abortion do conceptually overlap with concerns we can anticipate for the future; but the magnitude of genetic information that NGS promises makes these concerns even more numerous and pressing. Should insurance companies incentivize customers to screen out prospective children whose genes indicate a costly malady? How might encouraging the negative selection of a particular medical condition shape its social perception? Does a fertilized egg have moral status? If not, the person it might become certainly does; how do proto-parents' selection decisions influence the quality of life their children will experience?

I will address questions of this nature through a sequence of case studies. Each case is a phenotypic quality that either is genetically detectable today, or is expected to be in the near, NGS-defined future. The first two cases, Tay-Sachs disease and sex, appear in the "philosophical context" section of this chapter and serve to elucidate some of the general moral concerns tied to genetic selection. Tay-Sachs disease is a degenerative condition that kills its victims in early childhood; it

represents a class of diseases that induce immense suffering for patients and families and inhibit any substantial cognitive development—its negative selection is relatively uncontroversial (“Tay-Sachs Disease”). Similarly, it is relatively uncontroversial that non-medical selection *for* sex is morally impermissible: there are few convincing bioethical counters to the argument that sex selection is an intervention void of intrinsic benefit and, instead, harmful to the nuclear family and society alike.

The next three case studies are more ethically ambiguous and comprise chapters two, three, and four. Spina bifida represents a class of diseases that are severely disabling but need not discount the possibility of a fulfilling life. The negative selection of spina bifida is highly disputable; discussion will ensue about the right to live regardless of condition, and about the shortcomings of society in accommodating the disabled. Selection against type II diabetes (T2D) incites bioethical conflict for a different reason. While a reduction in T2D would drastically cut health care costs around the world, it is confounding and morally problematic that genetic T2D propensity alone could dictate who is born. And because certain ethnic groups are at greater risk for T2D, a negative selection practice would have disproportionate demographic impacts. Attention deficit/ hyperactivity disorder (ADHD) is the final case study. Unique moral concerns surrounding ADHD selection involve the trait’s well-documented correlation with certain positive qualities: though inattention and hyperactivity can be disabling in the context of contemporary society, these neurologically-based conditions come from the same genetic variations that often grant ADHD possessors unique creativity and insight

(Sherman 2012). Of course, these considerations only graze the surface of the moral arguments for and against spina bifida, T2D, and ADHD screening.

Because of the diversity of moral concerns they raise, these five phenotypic traits provide structure for a rich ethical analysis of anticipated reproductive technologies. Cultural change stemming from NGS technology need not be resisted; indeed, it should be sought with a firm grasp on morality.

Part II-Biotechnological Context

This section briefs the reader on the current state of reproductive biotechnology and backdrops the philosophically normative focus of my project. Only through assessing contemporary genomic technologies and reproductive practices do I (partly following others) envision how the former might revolutionize the latter. And of course, the strength of the basis for imagining a reproductive revolution is proportional to the urgency of addressing its associated moral concerns: the information herein serves to both contextualize and legitimize the ethical analyses of subsequent chapters. I begin with an abridged chronology of relevant reproductive landmarks.

Amniocentesis—whereby analysis of maternal amniotic fluid can indicate fetal genetic abnormalities—became popular in the 1970s (Press 2008). Concurring with *Roe v. Wade* in 1973, the advent of amniocentesis led to widespread selective abortion of fetuses implicated with conditions like Down syndrome, Tay-Sachs, and spina bifida (Press). Meanwhile, Louise Brown became the first baby to be born via *in vitro* fertilization (IVF) in 1978 (“The World’s First...”). IVF immediately grew in popularity for proto-parents experiencing fertility problems, as well as for same-sex couples (“IVF History...”). As more and more genotype-phenotype correlations were discovered through the 1980s, prenatal tests were made to illuminate new risk factors and thus created new justifications for selective abortion (Press). The 1990s saw the emergence of selective implantation—IVF’s alternative to selective abortion—as companies like Natera and Genesis began to offer pre-implantation genetic diagnosis (PGD) for proto-parents pursuing IVF (“What We Test For...”). In tandem, the

American Board of Genetic Counseling was established in 1993 as the accrediting service for genetic counselors (for whom the young PGD industry created high demand) (“American Board...”). To this day, no legislation has specified which genetic risk factors may or may not justify selective implantation or abortion; however, regulatory commissions have formed internationally to oversee companies that provide PGD. The Human Fertilization and Embryology Authority, for example, publishes a list of several hundred “sufficiently serious” genetic conditions to which PGD clinics in the United Kingdom must limit their screening (“PGD conditions licensed...”).

The 1990s also saw the development of next-generation technologies with science fiction-evoking names like “massively parallel signature sequencing” and “DNA nanoball sequencing” (“DNA Nanoballs...”). The innovation of such methods is their ability to process vast quantities of genetic information at low (and decreasing) cost. When the Human Genome Project was completed in 2001, accomplished only by “*first-generation*” sequencing, the significance and potential of NGS technology was undisputable. Unveiling the human genome already carried vast medico-social implications; the notion that NGS could achieve inexpensive personal genome sequencing spawned novel biomedical research arenas and bioethical debate topics (“Genetic Variant...”). In response to widespread anxiety about the publicity of genetic information, Congress passed the Genetic Information Nondiscrimination Act (GINA) in 2008; predictably, GINA prohibits employers and insurers from treating their respective employees and customers differentially on the basis of genetic constitution (Press). Amidst much political and philosophical

discourse, proto-parents have increasingly utilized IVF and PGD. In 2012, between one and two percent of all American babies born had been conceived *in vitro*; of these, five percent had been tested with PGD (this percentage does not account for the embryos that tested positively—presumably, these were never implanted) (“Clinical Summary...”). While these statistics represent the highest IVF rates to date (with the possible exception of 2013 rates, which have yet to be published), there is reason to believe IVF could become an extremely popular reproductive procedure in the near future (“Clinical Summary...”).

This claim comes from three premises: the cost of whole-genome sequencing will decline, the cost of IVF will decline, and proto-parents will prefer selective implantation to selective abortion. The relevance of this last premise has to do with recent efforts to sequence entire fetal genomes during the first trimester of pregnancy: whole-genome sequencing may soon be possible prenatally, but it will appeal more to proto-parents as a comprehensive pre-implantation screen (Yurkiewicz 2014). We must not forget that proto-parents seek PGD and prenatal testing for the very purpose of detecting genetic abnormalities and procuring the opportunity to possibly discard the implicated embryo(s). Such discarding, of course, occurs either during pregnancy as an abortion, or before pregnancy (during the IVF process) as the destruction of the Petri dish-residing embryo(s) at issue. Whereas abortion is invasive, discarding an embryo *in vitro* is not; whereas abortion requires proto-parents to “start over,” discarding an embryo *in vitro* typically only means that another embryo in the dish will be implanted instead; whereas selective abortion requires a “yes or no” decision, selective implantation theoretically allows for as

many options as there are embryos. Thus, even disregarding the relevant political and religious ideologies, selective implantation is in many ways more desirable than selective abortion; and one or the other potentially accompanies any procreative course that involves genetic testing. The relative appeal of selective implantation importantly figures into to how I envision the future popularity of IVF.

Proto-parental draw to selective implantation over selective abortion is only one piece of the equation, however. In the United States, IVF and PGD cost around \$12,000 and \$3,500, respectively (IVF is actually considerably cheaper in some countries, but still prohibitively expensive for the average family) (“PGD Costs”). Accordingly, the relative desirability of selective implantation has little impact on mainstream reproductive pursuits today. But IVF is expected to become more affordable as the necessary technology is streamlined, and as more physicians pursue reproductive endocrinology to meet the demand (Skoch 2010). In the United States, only 40 reproductive endocrinology fellowships are available each year; the American Board of Obstetrics and Gynecology sets this number and is under increasing pressure to open more fellowships. A Newsweek article entitled “Why is IVF so Expensive in the United States?” cites reproductive specialist Elan Simckes as saying, “just as there has been a price adjustment in other medical fields, it needs to happen in the fertility field” (Skoch). The article goes on to describe how most cutting-edge medical procedures ultimately come down in price via increased competition: in the case of Lasik surgery, the combination of more ocular specialists and improved technology has decreased the cost of the procedure from \$12,000 to

\$1,500 since the early 1990s (Skoch). Similarly, increasing demand for IVF will likely bring down the price.

Offering *why* exactly this demand might increase is my final task in explaining the plausibility of an upcoming IVF era. Put simply, the blossoming of NGS technology will make whole-genome sequencing and pre-implantation screening affordable and informative. IVF and PGD will include extensive mapping of embryonic genotypes to their phenotypic correlations, and proto-parents will have the opportunity to use this knowledge to inform their implantation decisions. Of course, to the extent that bioethics constrains research and medical protocol, certain genetic correlations may not be studied, let alone tested for in PGD. Yet current, mainstream utilization of genetic testing suggests how highly proto-parents value deliberate reproductive decision making: if the next generation is at all like this one, many proto-parents will embrace whichever new, NGS-facilitated reproductive options are bioethically sanctioned (and perhaps some that are not).

Thus far, NGS technology might seem farfetched or intangible to the non-scientist reader. I discuss the basic technical foundations of NGS below in order to make the technology seem more concrete, if no less miraculous. To begin, genetic material is the common thread that unites all organisms on Earth: unicellular protists and whales alike have DNA consisting of the same four constituent nucleotides (particular molecules). What makes species and individuals unique is their specific arrangement, or sequence, of nucleotides—for within a sequence, functional units called genes dictate the beholder's innate characteristics (phenotypes). The structure of DNA was discovered in 1953, and microscopic organisms were first sequenced in

their entirety in the early 1970s (Pillsbury 1997). The most effective sequencing method from this era, capillary electrophoresis (CE), is still used today for certain purposes (though NGS is rapidly phasing it out) (“An Introduction to Next...”). The premise behind both methods is that DNA exists as two complementary strands (i.e., each nucleotide on one strand corresponds and is chemically bonded to its complementary nucleotide on the other strand). Thus, reacting a single-stranded template with a sufficient quantity of all four nucleotides forms a complementary strand, which is easily interpreted to reveal the template sequence (“The Order of Nucleotides...”). The complementary strand does not form continuously, however: prior to the reaction, technicians have altered some of the nucleotides to stifle elongation, and the addition of one such nucleotide creates a fragment (“The Order of Nucleotides...”). After all the fragments form and are sorted by length, their constituent nucleotides—having been initially labeled by fluorescent dyes—are read by their degree of fluorescence (the necessity of labeling explains why the sequence cannot be interpreted directly from the unlabeled template stand) (“The Order of Nucleotides...”). Putting the resultant fragmented sequences in order and taking the complement yields the original template sequence.

Given that even small bacterial genomes contain millions of nucleotides, sequencing without NGS is extremely tedious (“An Introduction to Next...”). For reference, *H. influenzae* contains 1.8 million base pairs (complementary nucleotides) and took one year to sequence; the human genome contains 3.2 *billion* base pairs and required over a decade of international collaboration between 100 laboratories to sequence (Pillsbury). The time-intensive aspect of CE is that only “a single or a few

DNA fragments” can be processed at once (An Introduction to Next...). Thus, the core novelty of NGS is its ability to process millions of fragments “in parallel” (i.e., simultaneously); but for this incomparable reading rate, NGS functions similarly to CE (“An Introduction to Next...”).

Importantly, bioinformatics (the branch of biology concerned with information processing) has progressed such that the rapid data production from simultaneous fragment sequencing may be analyzed without significant delay (“An Introduction to Next...”). And the associated expenses, often measured in dollars per base pair, have “plummeted”: in 1996, CE sequencing cost \$1/ base pair; in 2008 and 2013, NGS cost \$0.0002 and \$0.000006, respectively (Niedringhaus 2011). Today, whole human genotyping costs around \$20,000—less than twice the cost of IVF in the United States (Niedringhaus). Research aiming to bring personal genome sequencing below \$1000 is currently underway, suggesting that prices could be utterly insignificant within decades (Niedringhaus).

Efficient sequencing has fundamentally changed genetic research. Before NGS, genotype-phenotype correlations were found by targeting specific genes thought to play a role in the pathology of a disease of interest. For example, researchers studying the genetic underpinnings of breast cancer might zero in on a gene that regulates breast cell proliferation; the DNA of breast cancer patients would then be analyzed—at great time and labor costs—for the presence of a mutation in this gene (“Five Years...”). The success rate of such research is impeded by the low probability that a gene predicted to correlate with a disease actually does (“Five Years...”). The human body is so complex that effectively, there are infinite ways a

biochemical process can malfunction and trigger disease: in the breast cancer case, thousands of genes play a role in the regulation of cell growth and any one (or any combination) of their variants could instigate cancerous proliferation (“Cell Proliferation...”).

NGS-facilitated genome-wide association studies (GWAS) resolve this problem by eliminating the need to guess and check (“GWAS Fact Sheet”). In GWAS, the genomes of two large populations—one with and one without a condition of interest—are analyzed and contrasted. The more unique a particular gene variant is to the afflicted population, the better its candidacy as a genetic risk factor for the condition (“GWAS Fact Sheet”). In this manner, GWAS identify genetic correlations at a much higher success rate than do “guess-and-check” studies; the former have led to the discovery of thousands of risk factors for multifactorial traits like type two diabetes and prostate cancer (“GWAS Fact Sheet”). Of course, the extent of sequencing necessary for GWAS is only feasible with high throughput NGS technology (“An Introduction to Next...”). That NGS permits GWAS contributes to the widely shared view that efficient sequencing has revolutionary implications for the future of human medicine, among other biologically based disciplines.

At this point, I have fully outlined the claim that IVF will be drastically more widely utilized in the near future than it is today. As the cost of NGS continues to drop, new genetic markers will surface and proto-parents will seek more comprehensive testing for their prospective children. Testing will be accomplished inexpensively by embryonic whole-genome sequencing and subsequent screening for many undesirable genetic markers. Though such testing may ultimately be possible

prenatally, proto-parents will pursue IVF preferentially for two reasons. First, the associated expenses will drop to some extent as demand increases and more specialists enter the field. Next, the idea of selective implantation will appeal to more proto-parents than the idea of selective abortion. Although coital conception often results in healthy embryos, the criteria for “healthy” will narrow as genetics pervade preventative medicine and proto-parents approach the reproductive process more deliberately. IVF and embryo sequencing will lend proto-parents increased—albeit far from complete—control over who joins the family. Reproductive practice therefore will increasingly involve what I call the “decision room,” in which proto-parents assess their early embryos’ genetic risk factors (up to two dozen embryos can be retrieved at one time for IVF) and make an informed implantation decision (“IVF”).

Part III-Philosophical Context

How might we determine productive moral lenses through which to view the social-scientific interplay described in the previous section? This sort of question lies at the core of bioethics, where contemporary medical technologies and practices are evaluated on the basis of their compatibility with and promotion of health, for individuals and society alike. Bioethicists, then, must consider what constitutes health, and how various technologies and practices should be utilized for its attainment or preservation. Which (if any) moral theories might illuminate a philosophically productive route for bioethical consideration? The traditional moral theories of consequentialism and deontology boast absolute applicability: their respective tenets allegedly provide a procedure for evaluating moral action in any imaginable circumstance. Bioethical literature uses metaphors of elevation to differentiate these “high” theories from more narrowly applicable “mid-level” guidelines such as “do as a virtuous person would do,” or, in health care, “facilitate patient autonomy” (Arras 2013). In turn, mid-level guidelines are organized and contextualized by moral views like virtue ethics, principlism, and pragmatism. Compared to high theory, these views leave more room for interpretation in ethical analysis. Yet their proponents claim they may be more responsive to detail and may better guide moral decision making overall (as universal application of high moral theory results in countless absurd conclusions). A moral theory that is too abstract struggles to gain traction in a practical field like bioethics; and yet a moderate degree of abstraction is widely considered essential for framing practical situations in terms of ethical ideals.

Taking a third position, anti-theorists contend that even mid-level views are too “blunt,” upon their application to practical situations, to provide an adequate moral framework for action guiding (Arras). Practical situations are unique in morally relevant ways: when human actors in these situations appeal to any sort of moral theory for guidance, they are most often misled. Thus, anti-theorists scrutinize the particularities of a given case, and assume that no moral theory can account for the “ineradicable untidiness” of those particularities that require moral attention (Arras). Whereas consequentialists and deontologists use theory to inform their moral judgments, anti-theorists (who I will later refer to as pure casuists) use paradigm cases. Assessing moral concerns in a past case, similar to the one at hand, may indeed be informative; but when no sufficiently similar paradigm case exists, the anti-theorist is less prepared to evaluate the moral concerns of the present case. This problematic deficiency of moral guidelines in anti-theory, combined with the problematic inflexibility in high theory, explains why mid-level views dominate contemporary bioethical literature. I will elaborate on some of these mid-level views following a brief summary of high theory, as the former developed in direct response to (and retains some features of) the latter.

Consequentialism and Deontology

The two canonical and opposed high moral theories are consequentialism and deontology. Consequentialism was developed most systematically by Jeremy Bentham and John Stuart Mill in the late eighteenth and early nineteenth centuries (Sinnot-Armstrong 2011). The theory attributes all moral value of an action to its consequences, so that the moral character of an act is measured solely by its contribution to a resultant state of affairs. Classic utilitarianism, the most recognized

strain of consequentialism, is hedonistic in that the quality of a consequence is measured by the pleasure it provides. Faced with two choices, a moral actor elects whichever of the two promises consequences with maximal pleasure and minimal pain. Thus, an infinite number of moral answers hinges on only one tenet; the consequence with the highest pleasure to pain ratio (compared to its alternatives) corresponds to the moral action.

Coincidentally for this project, one of the classic thought experiments used to criticize utilitarianism has to do with organ donation. Referred to as “Transplant,” the hypothetical situation contains five dying patients, each of whom could be cured by the transplant of a different organ, and one healthy patient who embodies each of these organs (Sinnott-Armstrong). While it seems morally repugnant to dissect the healthy patient and harvest her organs to save the five people, such transplants are *prima facie* morally required by classical utilitarianism. In pursuit of the greatest good for the greatest number, utilitarianism cannot easily justify keeping the healthy patient intact. Thought experiments like Transplant demonstrate the importance of individual rights and offer what many consider to be intuitive reasons for deontological arguments.

Largely attributed to Immanuel Kant’s moral postulations toward the end of the eighteenth century, deontology holds that morality is measured by the integrity of the intentions behind one’s moral agency (Alexander and Moore 2011). The extent to which one upholds her moral duties—instead of the pleasure to pain ratio in the consequences she instigates—determines morality. Consulted on the Transplant case, a deontologist would claim there is a moral duty not to sacrifice the healthy patient,

no matter the fate of the other five. Deontology thus often coincides with moral intuition, preserving individuals' rights by restricting the moral agent to "right," duty-upholding action, instead of "good," consequence-optimizing action that may marginalize some individuals in the name of utility for others.

Of course, a deontological ethics has limitations of its own. It is most vulnerable to criticism regarding the ambiguity of duties. Granted a moral agent has a categorical imperative to fulfill her duties, how might she identify what these duties are? If there are duties that exist beyond the scope of moral intuition, it is unclear how we might discover, let alone uphold them. Additionally, moral agents may conflate duties with preferences: they may justify action on the basis of deontological necessity when, in fact, the action was motivated by morally indefensible reasons. Kant's claim—that a moral agent must will a maxim to be universally adopted if that maxim is to represent a moral duty—does ensure that duties are situated in the context of humanity. But ambiguity remains in the event that a moral agent has multiple, conflicting duties (While Kant claims that no two duties can actually conflict, this notion is widely criticized) (Hart 1998).

In a theoretical attempt to resolve such apparent conflicts, deontologists have differentiated between active and passive duty fulfillment (or neglect) (Alexander and Moore). Consider a case regarding the contentious bioethical issue of euthanasia: when an unconscious patient's life has been long sustained only by cardiopulmonary devices, his guardian faces both a duty not to kill, and a duty, say, not to squander his life savings on a confirmed medically futile treatment. A deontologist may claim that by authorizing the physician to passively discontinue the cardiopulmonary device—

instead of to actively administer an intravenous toxin, for example—the guardian would not be neglecting his duty not to kill. A consequentialist, however, would view such a distinction between active and passive killing as morally irrelevant, given that death results, in this case, both from action and omission. Death of the patient would be one consequence to be weighed against the others (e.g., the ability of the younger guardian to afford to live decently) in a cost-benefit analysis of the guardian's various decisions.

Similar to the criticism that deontology provides no account of which duties we are to uphold in an apparent conflict, classical consequentialism bears the epistemological problem of maximal utility calculation. Given all of the consequences of an action, and all of the largely unquantifiable pleasure-to-pain ratios of each consequence, an actor will rarely have epistemic access to the decision supported by utilitarianism. Even if the moral value of an action did, in fact, rely on its consequential pleasure-to-pain ratio, such an incalculable criterion would be unhelpful in practical fields like bioethics in which moral judgments are particularly constrained by time.

It is evident why contemporary bioethics does not strictly adhere to high moral theory. The central tenets of consequentialism and deontology are too general to cleanly overlay the complexity and nuance of bioethical issues. Yet high theory is far from dead: lines of argument related to utility and duty are regularly incorporated into and adapted for mid-level principles. One example of such adaptation is seen in the concept of autonomy.

In an influential book entitled *Principles of Biomedical Ethics*, Tom Beauchamp and James Childress argue for the indispensability of patient autonomy: they claim that an emphasis on autonomy is necessary to resist paternalism, which pervaded standard medical practice at the time (1979) (Arras). The notion of protecting the self-sufficiency of a moral agent is unmistakably reminiscent of Kant. Left to his own devices, a patient may make a morally unjustifiable decision; yet to interfere with his ability to decide—for Kant—neglects a duty to protect his independence. This emphasis Kant places on the moral agency of individuals nicely reflects the contemporary, anti-paternalistic conception of autonomy described in *Principles of Biomedical Ethics*. Beauchamp and Childress' principlism thus exemplifies the partial utilization of high moral theory for the construction of a pluralistic, mid-level view.

Like deontology, consequentialism significantly influences contemporary bioethics. Indeed, patient autonomy may be understood not as respect for individual moral agency, as discussed above, but instead as a rule that promotes the greatest good. Rule-utilitarianism, attributed to John Stuart Mill, equates moral action with following a rule whose observation tends to yield the highest consequential pleasure-to-pain ratio (Sinnott-Armstrong). Some contemporary bioethicists define autonomy as directly opposed to paternalism; they argue for autonomy on the basis of a rule that paternalistic medical practice generally causes poor outcomes. This view concedes that paternalistic practice may immediately benefit the patient, but denies that paternalism has a moral role in medicine. Observing a rule against paternalism, neo-

consequentialist bioethicists argue, improves medical practice and policy by fostering the greatest good (Gert 2005).

A consequentialist perspective is also seen in genetic modification literature. Upon ethical consideration of DNA alteration, consequence-minded bioethicists emphasize the macro-scale, ecological and social upshots of such biotechnology. A common argument against genetic modification in agriculture, for example, is that genes for pesticide- or cold weather-resistance may ultimately disturb the biotic balance of ecosystems (“GM Crops...”). Regardless of its extent of empirical support, this argument concerns the long-term preservation of the greatest good; it employs distinctly utilitarian logic in weighing higher, modification-induced crop yields against their corresponding ecological harm.

Literature on human genetic selection uses consequentialist elements as well. Whether or not to pursue the prenatal (or pre-implantation) diagnosis and negative selection of a particular trait depends on both genetic and social consequences. If a mildly disabling trait is linked to genes that (in other genotypic contexts) code for positive qualities, a neo-consequentialist bioethicist may discourage this trait’s negative selection, claiming that the long-term elimination of this gene from humanity would cause more harm than the elimination of the mild disability would cause good. Additionally, the screening of mildly disabling or merely non-preferred traits may have harmful social implications. If, say, it became the norm for proto-parents undergoing IVF to screen out embryos possessing a gene linked to early-onset balding, the perceived inferiority of baldness might be exacerbated. To the great extent that normalized medical practices sculpt cultural attitudes, we can imagine that

routine selection against early-onset balding genes might contribute to bald people's social marginalization. This argument carries even more weight when the trait considered for screening is socially contentious. Consider a future in which detecting certain genes associated with homosexuality is technologically possible, while screening on account of such detection is legal and often pursued. The increased stigmatization of homosexuality that would result—combined with diminishing numbers of homosexuals on whose backs the stigma must be carried—provides grounds for a forceful consequence-minded argument against this case of genetic selection.

A final example of consequentialist concerns in human selection literature has to do with social disparity. If genetic selection, based on a broad range of trait types, becomes technologically possible and legal, families with the financial means to pursue selection will see increasingly “superior” genotypes (i.e., genotypes with fewer risk-conferring alleles) in every generation. Science fiction writing on this topic often depicts a society in which participation in selection renders people so elite that their genetically traditional counterparts, left in the dust, may be considered another race altogether (Niccol 1997). These dystopias of science fiction, albeit not imminently dangerous, remind bioethicists that reproductive technologies must be both accessible and regulated. The consequentialist- and deontology- inspired concerns described above do not nearly exhaust the list of examples of high theory in bioethics; they serve only to foreshadow some of the arguments I will assess in the case studies that follow.

Tay-Sachs Selection

What kind of moral insight might result from applying high theory to the Tay-Sachs case? Let us first return to classical, non-adapted consequentialism and deontology (as opposed to high theory-*inspired* views) to address the question. A consequentialist would weigh the potential good of selectively implanting an early embryo identified to possess the Tay-Sachs genotype against the potential harm. Recall that the majority of Tay-Sachs-afflicted children experience normal development for six months, and then rapidly and painfully degenerate until they die by age four. Given the minimal pleasure and deep suffering associated with such a life, and given the emotional burden placed on the child's parents and relatives, a classical utilitarian would take the expectedly low pleasure-to-pain ratio (relative to that ratio in the consequences of alternative decisions) as moral grounds for selecting not to implant a Tay-Sachs embryo.

As a thought experiment, consider a set of proto-parents who desire to implant this embryo, expecting their experience parenting a severely disabled child to reap valuable personal growth. A utilitarian view would deem this decision morally justifiable only if the parents' growth were expected to outweigh the prospective child's suffering—an unlikely case for a disease of this degenerative nature. Even if the proto-parents somehow knew their benefit would outweigh the child's harm, a consequentialist account could only justify the implantation within the moral sphere of proto-parents; whereas consequentialist physicians, institutional health care professionals, and policy makers would find the implantation immoral on the grounds that bringing someone with Tay-Sachs into the world induces more (medical, fiscal, and social) harm than good. All things considered, members of every moral sphere

could justify the negative selection of a Tay-Sachs-implicated embryo by classical utilitarianism.

A unanimous decision regarding the Tay-Sachs case would not likely be reached among deontologists, as deontology leaves some room for a moral agent to interpret how her duties apply to the world. For example, a deontologist's metaphysics of personhood is a critical factor in determining whether or when she may have an abortion; only if fetuses are persons does her duty not to kill apply to an abortion decision. If personhood initiates with fertilization, as some deontologists believe, then the practice of IVF is ethically impermissible (Sullivan 2001). Recall that IVF requires fertilizing multiple eggs: on a conception of personhood so broad as to include zygotes, the inevitable destruction of a small number of these zygotes conflicts with the duty not to kill. Thus, a world solely inhabited by Kantian deontologists who also view zygotes as persons would exhibit the "natural" frequency of Tay-Sachs, as no (currently available or foreseeable) genetic intervention could be utilized to reduce its occurrence.

On a metaphysics of personhood that excludes zygotes, IVF is not inherently impermissible. Instead of disobeying a duty not to kill, then, proto-parents pursuing IVF face a duty not to knowingly cause profound suffering: arguably, it is a deontological wrong to knowingly carry a Tay-Sachs-implicated embryo to term and produce a severely disabled and painful life. Indeed, it may be universally willed not to commit such a wrong. Given that Tay-Sachs is reliably diagnosed at the early embryo stage, a world solely inhabited by Kantian deontologists who do *not* consider selective implantation murder would be void of Tay-Sachs. So within the moral

sphere of proto-parents, deontology suggests two disparate actions (non-intervention if early embryos are persons, and negative selection if they are not); in turn, these actions result in two distinct outcomes: a “natural” Tay-Sachs frequency and a great reduction in Tay-Sachs cases, respectively. In emphasizing the right instead of the good, deontology permits these two resulting scenarios (albeit not simultaneously), instead of the one scenario derivable from a classical utilitarian account.

Kantian deontology also has different implications for the various moral spheres of medicine. To the extent that particular moral agents have particular duties, one’s professional role in the medical world impacts his moral obligations. This complicates the Tay-Sachs case substantially: for example, is a physician’s duty to respect the autonomous decision making of his patients ever ethically overridden by a duty to prohibit certain wrongs? If so, physicians with broad conceptions of personhood would not facilitate IVF for proto-parents pursuing it. If, however, a physician’s duty to respect patient autonomy always trumps other duties, only overarching medical policies may restrict patient choice.

While it is difficult to postulate what exactly deontology requires of policy makers and institutional health care professionals, we can be sure that deontological action in these moral spheres is not framed by an aim to promote the greatest good for the greatest number. Thus, a policy allowing the negative selection of Tay-Sachs could not be based on the argument that a world with fewer Tay-Sachs patients has a higher pleasure-to-pain ratio. Instead, negative selection could be legalized on the grounds that proto-parents should be able to minimize predictable suffering. It is unlikely a deontologist-sanctioned policy would *mandate* negative selection,

however, as deontology places great value on individuals' rights. Likewise, institutional health care professionals writing insurance policies under a Kantian ethic would not compromise patient rights in the name of the greatest good. A deontologist-sanctioned insurance policy would not, for example, provide fiscal incentives for undergoing IVF and negatively selecting Tay-Sachs. While such a policy might reduce medical resources associated with the disability, it mainly appeals to the consequentialist argument that resources saved may be used for other goods. And given their emphasis on individuals' rights, deontologists are more likely than consequentialists to devise a policy guaranteeing that if born, Tay-Sachs patients receive high quality care regardless of their imminent death; whereas a consequentialist policy might not devote as many resources to patients with early-lethal diseases.

Evidently, the Tay-Sachs case is more complex under deontology than it is under consequentialism. Because the classical utilitarian account exclusively pursues the greatest good, utilitarian actors in every moral sphere share roughly the same obligations. But a deontological focus on duty and patient autonomy diversifies the obligations of actors in various moral spheres. While it is unclear whether the duty to respect patient autonomy always supersedes duties to prevent wrongs, it is critical that physicians, institutional health care professionals, and government policy makers act in accordance with what is *right* (as defined partly by their social role), not merely with what anticipates the best consequences. In short, a consequentialist stance generally endorses negatively selecting against Tay-Sachs embryos, while a deontological view takes this intervention to be either a violation of a duty not to kill,

a compliance with a duty to prevent suffering, or a decision that must be delegated to those whom it affects directly.

Many difficulties associated with applying high moral theory to the Tay-Sachs case are avoided with mid-level views. Recall that mid-level views replace abstract high theoretical tenets with relatively concrete moral principles to be used as guidelines for action (Arras). With several guiding principles instead of only one or two broad tenets, mid-level views are more finely attuned to the issues that affect bioethical decisions. Of course, contemporary bioethics' widespread use of looser theoretical frameworks represents a tradeoff: in adopting views that are somewhat malleable and can thus provide insight on nuanced issues, mid-level bioethical outlooks sacrifice the perceived epistemic confidence that high theory affords the moral agent. In other words, the more values an agent must juggle, the more ambiguous the morality of her possible actions. Yet this ambiguity is a necessary byproduct of doing ethics in a field with such emotional and technological complexities; one measure of an apt mid-level bioethics is its ability to minimize its own nebulae and impart clear action guidance.

Principlism

Principlism, discussed previously as a mid-level view with isolable deontology-inspired features, has become the mainstream bioethical framework since its initial articulation in the 1979 *Principles of Biomedical Ethics*. Beauchamp and Childress propose four principles—autonomy, beneficence, nonmaleficence, and justice—whose observance reveals moral action in medicine (Arras). An important divergence from high theory in principlism is the explicit recognition that these principles warrant differential interpretation based on social context. Beneficent

medical practice in end-of-life care, for example, requires pursuing the goods specified by any religious beliefs held by the dying patient. One may therefore think of beneficence as an often-reached-for tool in principlist bioethics that is sharpened by patients' values; instead of an ultimate truth like the utility principle in classic utilitarianism, beneficence is a guiding principle, often contextualized by the desires of a given patient.

Beneficence is importantly distinct from nonmaleficence: while the former requires a moral agent (typically the physician in principlist discussion) to do good, the latter requires her to do no harm. An example from a hospital ethics manual exemplifies the difference: by watching an assistant botch a minor procedure and inflict unnecessary pain on a patient, a physician meets the conditions for nonmaleficence but does not meet the conditions for beneficence (the physician is not harming the patient, but also is not acting in the patient's best interest) (Riddick 2003). Like beneficence and nonmaleficence, the principle of justice is specified by those to whom it applies. With regard to bioethical policy and resource distribution, Beauchamp and Childress write that "need is the basis for the individual's claim to any basic good" (Beauchamp and Childress 2001). A just policy, then, maximally accommodates the varied needs of the people affected by it. The American Medical Association's code of ethics, largely built upon principlism, prohibits non-medical criteria for measuring need, such as "ability to pay...obstacles to treatment, patient contribution to illness, and use of past resources" (Riddick). Thus, in maximally satisfying patients' needs, a policy that reflects the principle of justice must first determine need with the appropriate criteria.

The principle of autonomy is perhaps the most frequently invoked principle in contemporary bioethics. As discussed earlier, it was adapted from Kant and emphasized in *Principles of Biomedical Ethics* to address the paternalism that pervaded medicine when the book was written. While Beauchamp and Childress do not unconditionally condemn paternalism, they maintain that paternalist practice is rarely justifiable. Beauchamp and Childress define informed consent and competence at length; their detailed account of autonomy and the issues surrounding it prevalently guides medical practice today and serves as a reference point in bioethical literature. As the paradigm mid-level view, principlism is scrutinized by bioethicists for its advantages and inadequacies; in turn, such deliberation has helped formulate alternative mid-level bioethics.

Bioethical Pragmatism

One such alternative is bioethical pragmatism, a theory that limits (but does not reject) the value of Beauchamp and Childress' principles. Bioethical pragmatists contend that alongside principles, practical, context-dependent information provides moral guidance on bioethical issues. Considered alone, principles are too abstract to be of use in nuanced medical decisions; a moral appeal only to principles is subject to the same conflicting and ambiguous conclusions that follow from appeals to high theory. And yet principles are indispensable: without some moral ideals to blend with the particularities of a case, the dead-end problems associated with anti-theory and pure casuistry emerge. In virtue of being a mid-level view, bioethical pragmatism does not follow pure casuistry in abandoning a moral framework altogether. Instead, it represents a middle ground between pure casuistry and principlism; it argues a moral agent must consider both concrete information and ideals to infer moral action.

Bioethical pragmatism is simply the adaptation of traditional, philosophical pragmatism for bioethics; the bioethical variety is only unique in focusing the broader pragmatist view on issues in medicine (often those concerned with physician decision making). Given the close phylogeny of pragmatism and bioethical pragmatism, I will briefly discuss the former to elucidate the latter.

The tradition of pragmatism is tied to the United States, as John Dewey and others first developed it here. With regard to the tension between foundationalism and naturalism, pragmatism is importantly naturalist in replacing “the *a priori* metaphysics of moral principles” with those principles’ experience-derived, information-dependent properties (Moreno 1999). Naturalism rejects the foundationalist view that certain essential beliefs are intrinsically defensible—that these beliefs form our epistemic foundation and therefore must support all less essential beliefs (Moreno). Alternatively, naturalism posits that beliefs come from human experience, within the confines of nature; so any hierarchy of beliefs must be constructed empirically. In this spirit, pragmatism holds that certain methodologies of scientific research offer productive models for moral inquiry (Fins 1999). A moral unknown reflects a scientific unknown in that ethicists and scientists alike must utilize assumptions—the facts and principles that constitute their working beliefs—as platforms for intellectual progress. While straightforward answers may be unattainable, pragmatists contend that the best approach in ethics, as in science, is to methodically employ experience-derived knowledge and beliefs to pursue unknowns or to resolve dilemmas.

Bioethical pragmatists go on to argue that moral problem solving in medicine is an experiential process that involves details-based hypothesizing, testing, and evaluating; in accounting for information unique to the case at hand, this process of inquiry tends to yield the most appropriate moral recommendation (McGee 1999). Conversely, relying too heavily on theoretical frameworks (e.g. Beauchamp and Childress' principles) neglects to account for information relevant to a given case, or moral inquiry. Even if principles are adapted to the particularities of a case—as in the above example, in which beneficent care of a religious patient entails pursuing the goods specified by his beliefs—they may be inadequate starting points; the particularities may not be best understood in terms of the four principles. In a case whose patient is a murderer, for example, perhaps appealing to a principle of forgiveness (brought to the fore upon considering the patient's history) is more relevant to the case's moral complexities. Yet the four principles are useful in problem solving to the extent that they apply aptly to the case at hand. If the particularities of a case are such that special attention to the principle of autonomy is required, then autonomy is a proportionately significant guide for moral judgment. Bioethical pragmatists thus claim that values contribute to moral inquiry without grounding it staunchly. Pure casuistry and abstract theorizing are both inadequate: a middle ground most effectively identifies a moral solution.

So far the pragmatism discussion has focused on the moral sphere of physicians—on “clinical pragmatism” (Fins). But how might bioethical pragmatists judge an issue in the public realm? Reverting to the Tay-Sachs case may prove explanatory: in considering the moral spheres of institutional health care professionals

and government policy makers, one can imagine a pragmatic approach utilizing the *general* features of the Tay-Sachs case to design a moral policy on selection, just as a clinician would utilize the details of a particular Tay-Sachs case to determine a moral route. Note that the public realm's version of this process may retain the pragmatist method of experiential inquiry by combining case-specific information with consideration of relevant theory. The particularities would include, among others: 1. Tay-Sachs is an "early lethal" disease that causes its victims to suffer; 2. Many proto-parents wish to detect and select against Tay-Sachs; and 3. Tay-Sachs patients incur high health care costs compared to those incurred by healthy children. It is apparent that a policy permitting the negative selection of Tay-Sachs would *prima facie* satisfy the principles of beneficence (due to 1.), autonomy (due to 2.), and justice (due to 3.). Is principlism therefore a sufficient framework for moral judgment? A bioethical pragmatist would say "no" on the methodological grounds that principlism lacks pragmatism's crucial process of inquiry. The particularities map neatly to the four principles here, but they will not in every case. To ensure productive moral inquiry in less neat cases, a pragmatist must consider details and values simultaneously—not in the values-first order of principlism.

The following hypothetical example further explicates the uniqueness of pragmatist methodology: returning to the moral sphere of physicians, consider a couple pursuing IVF for their first time. Each proto-parent is an Ashkanazi Jew and has had cousins or siblings test positive for the Tay-Sachs mutation. If both proto-parents carry the Tay-Sachs allele (a likely scenario), then each of their prospective children has a 25 percent risk of receiving two implicated alleles and suffering the

condition. Yet the couple is adamant about not sequencing the genomes of the early embryos they produce, nor screening for Tay-Sachs by simpler, targeted technologies. Upon strong encouragement to test given the significance of the risk, the proto-parents become frantic and tearful, imagining the tests might be done against their volition. At this point, a clinical pragmatist realizes that her original hypothesis—“if proto-parents understand their likelihood of passing on Tay-Sachs, then they can be entrusted to pursue testing or selection accordingly”—has been put into question. How highly should she prioritize her moral commitment to preventing Tay-Sachs-related suffering? She might decide that the particularities of the case justify allocating more weight to the principle of autonomy than to the principles of beneficence and justice. Because the proto-parents feel very strongly and still have a 75 percent chance of bearing a healthy child, it may be ethical to value their freedom of choice over the best interests of the prospective child and the health care system from which he might draw a disproportionate amount of resources. This moral judgment demonstrates the important but limited role of Beauchamp and Childress’ principles: by contextualizing ethical protocol within the facts of the case, the physician can both identify which principles are relevant and determine which of these to prioritize. Bioethical pragmatists claim that by applying the four principles from the start, a principlist physician overlooks the particularities of the case and cannot reap their integral moral guidance.

Bioethical pragmatism and naturalist ethics more generally are often criticized for inviting moral relativism: by emphasizing the context of a moral problem, the pragmatist view posits a methodological standard but not a theoretical standard by

which to test a proposed solution (McGee). Instead of framing this objection as a failed interpretation of naturalist ethics, many pragmatists embrace this kind of moral relativism with the conviction that there is no alternative (McGee). Indeed, as a product of eschewing *a priori* morals and emphasizing context-sensitivity, moral relativism is quite common in contemporary bioethics: principlism and even utilitarianism embody it to lesser degrees. Thus nearly inevitable, moral relativism does little to reduce the credibility of bioethical pragmatism as a strong approach to bioethical problem solving.

Virtue Bioethics

Another alternative to principlism is virtue bioethics, a clear-cut derivative of virtue ethics. Here I will treat virtue ethics as a mid-level view, despite some controversy on the matter, on the basis that virtue is a fundamentally pluralistic concept. When virtue ethics is adapted to a particular discipline (such as bioethics), the concerns unique to that discipline may refine what counts as virtuous. This flexible capacity of virtue ethics attunes it to bioethical issues in a manner that deontology and utilitarianism cannot follow. Granted the conclusions reached by employing high theory largely depend on moral agents' concerns, the tenets of high theory *themselves* may not be adjusted to suit those concerns—only the interpretation of the tenets may vary; whereas in virtue ethics, the maxim “do as a virtuous person would do” may be modified in ways that do not interfere with the theory's essence (that morality lies in the character of the agent, not in the quality of his action). In reproductive bioethics, for example, the maxim might state, “do as a compassionate parent would do,” where compassion is not merely instantiating a virtue, but instead providing moral guidance in its own right (McDougall 2007). Note that while

making the theory more apt for reproductive guidance, the “compassionate parent” substitution (among many others) retains virtue ethics’ defining property, that an actor’s character determines the morality of her actions.

This aspect of virtue ethics is unshared by high theory: the tenets of deontology and utilitarianism cannot be amended without a fundamental divergence from the theories as originally defined. Imagine changing the utility principle, for instance, from “act to maximize pleasure and minimize pain” to “act to maximize intelligence and minimize unintelligence” in the context of reproductive ethics. Moral conclusions would follow that would unlikely be drawn from the original utility principle (e.g., genetic selection against all cognitive disorders is permissible). While utilitarian actors may interpret what counts as pleasure and pain, they cannot make substitutions for pleasure and pain in the utility principle without altering the essence of classical utilitarianism. This is all to suggest that virtue ethics satisfies an important condition of a mid-level view: it may be adapted for fields like bioethics and used there productively; whereas often, the universality and abstraction of high theory makes it unfit for manageable application.

The substantive articulation (if not origination) of virtue ethics traces back to classical Greek philosophy. Aristotle posits the best life is one of *eudaimonia*, or flourishing, and that a person may achieve *eudaimonia* by exercising virtue and practical wisdom (Kraut 2010). The theory claims that developing a virtuous mindset and using it to practice moral behavior is instrumental to happiness; indeed, virtuous character is a necessary condition for *eudaimonia*. A fundamental distinction in Aristotle’s ethics is that between virtue and practical wisdom. While virtue entails a

certain moral energy, practical wisdom involves the appropriate harnessing of this energy (Kraut). A quite self-explanatory term, practical wisdom is the insight that allows an agent to assess a moral problem before determining a virtuous course of action. Aristotle's practical emphasis resonates with ethical pragmatism in this manner; virtue ethics and pragmatism's ability to contextualize ideals in reality may explain their common and fruitful use in bioethics.

In reproductive bioethics, virtue theory asks what a virtuous person (typically a parent, proto-parent, or physician) would do in the face of a given reproductive decision. The morality of this decision is based on personal character, not deontological rightness or consequence optimization. The sort of character that constitutes virtue in a reproductive setting, then, must be clarified by the virtue theorist. Rosalind McDougall writes that a virtuous parent embodies "acceptingness," "committedness," and "future-agent-focus." She claims that these three virtues underlie moral reproductive decisions when Aristotelian *eudaimonia* is the ultimate pursuit. Articulating virtues as "character traits conducive to human flourishing," McDougall contends it is in the best interest of proto-parents—and their prospective children—to make reproductive choices in the spirit of the ideal parent (who exemplifies acceptingness, committedness, and future-agent-focus).

McDougall goes on to assess the moral permissibility of a real case in which a couple pursuing IVF sought sperm from a genetically induced deaf man so as to bear a deaf child. While there is no reason to doubt these proto-parents' committedness (indeed, the deliberate nature of their reproductive decisions suggests a strong commitment to the prospective child), their future-agent-focus and acceptingness are

put in question (McDougall). With regard to future-agent-focus, the proto-parents fail to appreciate the constraints that deafness would place on their child's opportunities. Even if deafness would grant the child access to the deaf community and its unique advantages, the disadvantages of not being able to hear are countless and potentially traumatic; McDougall explains that the proto-parents place insufficient weight on the flourishing of their future child. Lastly, this reproductive decision demonstrates a lack of acceptingness: in acting on a preference for their child to be deaf, the proto-parents suggest they might not accept "any old" baby, or the tendencies and interests he might develop. Of course, virtuous parents need not accept emergent features of their children's lives, like unhealthy habits, that "inhibit flourishing"; but possessing proper hearing abilities is not such a feature (McDougall). By invoking this IVF case, McDougall shows that the application of virtue ethics to reproductive issues can be philosophically informative.

It is less clear whether virtue ethics can guide reproductive decisions for institutional health care professionals and government policy makers. While most of the virtue-based bioethical literature focuses on the moral spheres of physicians and proto-parents, a fuller assessment of virtue theory's aptness for bioethics must consider use of virtue in public policy construction. Stephen Holland explains why simply asking what a "virtuous legislator" would do is an inadequate translation of virtue ethics to the public realm (2011). First, public policies built upon this criterion will inevitably conflict with some personal policies maintained by truly virtuous physicians and proto-parents. The necessary generality of a public policy, albeit one designed by a virtuous legislator, likely precludes the possibility that the course of

action it dictates will align with the moral course of action for every person, regardless of her circumstances. Another reason Holland claims we may not simply ask, “what would a virtuous legislator do?” is this approach’s subjection to an inescapable objection, namely that we might just as well ask, “what would a Kantian or utilitarian legislator do?” For virtue theory to operate in public bioethics, it must have merits unshared by rival theories (note that such a condition in personal bioethics requires less critical attention, because the merits of virtue theory are more obvious on the personal level—it is clearer there how virtue ethics may provide valuable moral insight). Holland goes on to propose a way virtue theory might be salvageable for public-realm bioethics, but he himself is unconvinced of its viability. Appeals I make in subsequent chapters to bioethical virtue theory are therefore limited to the scale of individuals.

Confucian Bioethics

Some scholars claim that important contributions to virtue theory were made independently of classical Greece in the Confucian tradition of China (Yu 2013). Just as virtue theory holds that practicing virtue brings the individual overall health, Confucianism posits the core values of *ren* and *yi* (often translated as “humanity” and “righteousness,” respectively) as the key to healthy societal life (Fan 2011). Much of the moral-behavioral advice Confucius and his followers provide in *The Analects* is given on the grounds that such conduct instantiates *ren* and *yi*—quite similar to the notion, in virtue theory, that a moral decision is one that a virtuous person might make (Brooks and Brooks 1998). But unlike virtue theory, Confucianism offers one comprehensive account of the world and is based on a specific set of metaphysical convictions. Central to Confucianism, for instance, is the notion of *qi*, or “vital

energy,” which fills the living individual and emanates from her body upon death; *qi* is forever recycled, so the *qi* lost from someone’s passing will go on to vitalize someone or something else (Fan).

In Hong Kong, a group of intellectuals has recently applied the Confucian tradition to bioethics. The literature of this group explicates “Confucian bioethics,” an approach which they argue both corrects problems in mainstream Western (principlist) bioethics and better represents East Asian people. In *Toward a Confucian Bioethics*, Ruiping Fan explains that East Asian culture is heavily influenced by the Confucian tradition, even if people do not consciously “identify” with Confucianism (Fan). Accordingly, a Confucian approach to bioethics aligns more closely with many East Asians’ values than the Western approach does. So practically, Confucian bioethics is beneficial; Ruiping Fan argues that theoretically, too, the Confucian approach is conducive to ethical medical practice. Whereas Western principlism puts too much weight on patient autonomy, Confucian bioethics advocates a decision-making process directed by the patient, his family, and his physician together (Fan). This communitarian approach rejects the notion that a patient’s needs must always take precedence in virtue of his being ill or vulnerable: a physician or family exhibits *ren* and *yi* in meeting the patient’s demands only to a point, after which they neglect their own needs in a manner incongruent with *ren* and *yi*. The Confucian view holds that in putting all its eggs in the patient autonomy basket, mainstream Western bioethics overlooks the autonomy of those who care for the patient (namely the physician and the family).

Confucian bioethics has much to say with regard to issues surrounding end-of-life care. In assessing a patient near death, a Confucian would not typically make the medical “futility judgment” needed to justify passive euthanasia (expediting death by “withholding or withdrawing” treatment) (Fan). This is due to a firm belief in the body’s ability to heal itself. But importantly, Confucians do not endorse “aggressive medical treatment” because such intervention on natural human processes is not compatible with *ren* and *yi* (Fan). Thus, a Confucian medical guardian would not likely consent to withholding life-sustaining treatment from the patient in her charge; but neither would she consent to a highly invasive operation on the patient, even if the operation could have a significant positive impact on the patient’s health. The body is not to be underappreciated in its self-healing power. And its inevitable failure is not to be dreaded or greatly resisted, given the eternal reutilization of *qi*. On these grounds, Ruiping Fan and other Confucian bioethicists claim that many decisions for medical intervention demonstrate distrust in the body and the universe at large. In turn, such decisions reflect divergence from *ren* and *yi*.

In abstaining from unnecessary medical intervention, a Confucian bioethicist would be unlikely to support Tay-Sachs selection, at least in the manner of selection of interest here (via pre-implantation diagnosis). What a Confucian bioethicist would do in a decision room scenario is irrelevant: more illuminating for this thought experiment is the notion that a Confucian bioethicist would never *be* in this kind of decision room, having chosen coital conception due to a fundamental disagreement with IVF. Even if a homosexual or an infertile, heterosexual couple pursued IVF (ethically justifying the decision on the grounds, say, that having a child provides

unique opportunities to practice *ren* and *yi*), the couple surely would not have their embryos sequenced. It is one thing not to trust the body's natural abilities, under a Confucian metaphysics, when coital conception is clearly impossible; not to trust that any given embryo will develop into a healthy infant, however, is to stray too far from *ren* and *yi*. While similar to contemporary virtue theory in basing morality on personal character, the Confucian approach is reminiscent of Kantian deontology. Reproductive decisions are ethical when they exhibit *ren* and *yi*, for the Confucian, but *ren* and *yi* are partially defined by a comprehensive metaphysics. The faction of deontologists who object to IVF view zygotes as persons and thus cannot justify their destruction; and similarly, Confucian bioethics objects to IVF for the procedure's discordance with the Confucian metaphysical conception of the human body. I will not pursue Confucian bioethics in the body of this paper, yet I find works like *Toward a Confucian Bioethics* to be valuable reminders to think critically about Western bioethical assumptions.

Without the metaphysical parameters of Confucianism, Western virtue bioethics raises concerns that may be addressed by reproductive decisions like the negative selection of Tay-Sachs embryos. Of course, selecting against Tay-Sachs is not intrinsically morally permissible; rather, such selection is permissible on the grounds that a virtuous person would tend to pursue it. Indeed, it seems virtuous not to induce suffering by bringing a child into the world with an early lethal condition—especially given that the child's suffering and demise would also translate to his family's feelings of extreme anxiety and loss. In a less personal sense, selecting against Tay-Sachs may be virtuous in preemptively alleviating a great burden on the

health care system. If caring for a severely disabled child requires a disproportionately large sum of resources, and if such a child's existence may be prevented harmlessly in the decision room, then a virtuous proto-parent would take steps (e.g., IVF and embryo sequencing) to ensure her infant is not severely disabled in this way.

Of course, coital conception also seems virtuous when a commitment to love the child unconditionally underlies this reproductive decision. But the technological and social context of reproduction must be taken into account in employing Aristotle's practical wisdom: a virtuous person must consider available reproductive technology and its capacity to positively impact his family and society alike. Those who understand virtue conceptually but cannot channel this understanding into virtuous action lack practical wisdom; their resulting moral blunders, Aristotle suggests, make it impossible for them to achieve *eudaimonia*. In the near-future world this paper anticipates, perhaps avoiding IVF and embryo sequencing will *necessarily* demonstrate an absence of practical wisdom. How could a truly virtuous person ignore the reliable information provided by reproductive technology, if this information may be utilized (via selective implantation) to avoid definite harm? To be sure, this line of argument is more convincing with regard to the Tay-Sachs case: it is less clear whether a virtuous and practically wise proto-parent would tend to select against less severe traits. Even within the Tay-Sachs case, it is less clear which decisions virtue bioethics might inform for the moral spheres of institutional health care professionals and policy makers. As discussed above, virtue bioethics emphasizes the character of individuals in their small-scale decision making; the

insight virtue bioethics might provide in the public realm is substantially more speculative, and thus I will resist exploring it.

Feminist Bioethics

The feminist bioethical outlook is discussed last—but certainly not least, given the indispensability of the feminist perspective on reproductive issues—to end this theoretical section (after which I delve into the main case studies on genetic selection). Feminist bioethics emerged alongside modern bioethics itself in the latter half of the twentieth century, originally criticizing mainstream medical practice for neglecting the needs of women and other marginalized groups (e.g., ethnic and religious minorities, the poor, etc.) (Donchin 2012). Even today, many feminist bioethicists believe mainstream medical practice, guided by principlism, problematically assumes that all patients are “generic individuals” and warrant identical treatment (Mahowald 2006). In reality, feminist bioethicists argue, patients have distinct social statuses. Physicians must be sensitive to the impact of social marginalization (be it economic, psychological, or otherwise) on their patients in order to avoid perpetuating such marginalization.

Carolyn McLeod represents this position in her writing on women’s self-trust (McLeod 2002). For Beauchamp and Childress’ principle of autonomy to be useful, McLeod claims, physicians must be careful not to do anything that might instill self-doubt in their patients. To the extent that medical treatment (particularly that surrounding reproduction) can deflate women’s self-confidence, female patients’ reproductive decisions are not actually autonomous. This criticism of the mainstream conception of autonomy is subtly distinct from the more common criticism that patient “consent” is often misinformed and coercive: even if a patient is fully

educated and unforced in her decision making, she must also possess a firm sense of self-trust in order to make an autonomous decision. McLeod explains that physicians have an obligation to cultivate—and certainly not thwart—self-trust through their verbal and medical interactions with female patients (McLeod).

In *Women and Bioethics*, Mary Mahowald articulates another important theme in feminist bioethics—a theme common to the ideology of all social justice movements: she writes, “justice is served when unprivileged groups are imputed special privilege to compensate; this entails their input having weight proportional to the effect a decision will have on them” (Mahowald). Today, Mahowald implies, the leverage women have in personal- and policy-level medical decisions does not match the influence those decisions have on women’s health. Correcting this imbalance requires having more female representatives in politics and on bioethics committees; it also requires adequately funding research and procedures relating to conditions unique to women, such as cervical cancer and certain contraceptive methods (Mahowald). In the moral sphere of proto-parents, feminist bioethicists would likewise want to ensure that proto-mothers have proportional input in a given reproductive decision. After all, they are the ones who will endure pregnancy and bear the child.

Protecting the rights of proto-mothers encompasses a more recent discussion in the literature, regarding the negative impact of reproductive technology on how society perceives women’s bodies and the infants they produce. With countless reproductive options, and with pressure to utilize technologies like IVF and pre-implantation screening, feminist bioethicists explain how current reproductive

medicine objectifies women. A woman's value must not be measured by her capacity to give birth to healthy, talented, or attractive children—such criteria are neo-Darwinian and morally irrelevant to the woman's worth. Accordingly, a condition for reproductive technology to be ethical is that it empowers women, rather than commodifying them as mere “vessels” for reproduction (McLeod 2007). This feminist bioethical issue is of particular concern here, as I navigate the nebulous waters of choices and moral permissibility with respect to reproductive technology.

The question remains whether feminist bioethics would tend to deem it empowering or objectifying for women to pursue the technologies necessary for Tay-Sachs screening. Given the severity of Tay-Sachs, it seems that actively avoiding the presence of the disorder in one's children better represents female liberation than oppression. Especially for Ashkanazi Jewish women who may be carriers, preventing a profound emotional and financial burden through IVF and embryo sequencing seems in line with feminist concerns. In pursuing negative selection of Tay-Sachs, women are asserting their freedom to dictate their life routes and to avoid immense, unnecessary obstacles. This freedom seems to outweigh the risk that selecting against Tay-Sachs could contribute to female objectification: while pressure to select for and against a range of other traits could certainly make women feel inadequate and perpetuate patriarchal norms, selecting against Tay-Sachs is not likely as discrediting. It seems that ensuring women have a baseline understanding of biology is most important, so that producing Tay-Sachs-implicated embryos is understood to be a matter of genetic chance, rather than personal inadequacy.

One might notice that most of the moral perspectives discussed in this section relay concerns that tend to mesh well with the negative selection of Tay-Sachs, making it a relatively uncontroversial case. Yet moral accounts with restrictive metaphysics, like Confucian bioethics and some varieties of deontological ethics, take issue with genetic intervention more broadly. Before closing this chapter, I introduce sex selection as a form of intervention that poses moral concerns for virtually all bioethical outlooks. The widely-held convictions that proto-parents should be free to select against Tay-Sachs but barred from selecting for sex thus become controls in my philosophical experiment: as relatively uncontroversial selection cases, Tay-Sachs and sex provide a theoretical foundation on which the reader may conceptualize the ethical issues surrounding spina bifida, T2D, and ADHD selection. Of course, Tay-Sachs selection is discussed extensively herein and contributes most to this foundation; but sex selection is an urgent bioethical issue and its mention, while brief, can only enhance the reader's conceptual preparation for subsequent chapters.

Sex Selection

Sex selection is currently accomplished through a variety of practices, ranging from PGD to selective abortion to post-birth abandonment or infanticide (“Gender and Genetics” 2014). The central moral qualm about sex-selective practices is their underlying motivation: very often, the reasons proto-parents would prefer a child of a particular sex (typically male) has to do with problematic social attitudes and institutions favoring this sex. Stemming from antiquity and remaining a reality in many regions of the contemporary world, a male child protects the social and economic viability of his family. Particularly in China and India, where overpopulation limits resource availability, many proto-parents pursue sex selection

in its various forms due to perceived and/or real disadvantages associated with having a female child—and, conversely, not having a male child (“Gender and Genetics”). Yet from a bioethical perspective, such sex selection represents a misplaced intervention: cultural preferences for males should be addressed and mitigated, not perpetuated by continued selection against female embryos. At stake in *addition* to qualitative gender inequality are concerns associated with divergence from an approximately equal ratio of men and women. One such concern is the well-documented correlation between surplus men and increased criminal activity. In a 2007 study of the impact of China’s one-child policy, Edlund et al. report that “every one percent increase in the sex ratio results in a six percent increase in the rates of violent and property crime” (Edlund et al. 2007; Brooks 2013). Parallel to the rising male-female ratio, China is suffering sharp increases in “gambling, alcohol and drug abuse, [and] kidnapping and trafficking of women (Brooks). The preservation of an approximately equal male-female ratio is therefore of chief bioethical concern.

Interestingly, the United States is one of the only countries in which sex selection—for the purpose of “family balancing”—is legal (Sidhu 2012). Yet the moral permissibility of steering the gender constituency of one’s children through PGD is difficult to defend. First, it may be argued that a proto-parent who cares strongly about the gender of her child (or the collective gender make-up of her children) is pursuing parenthood with misplaced priorities. The reader might recognize this type of argument from the above discussion on Rosalind McDougall. Indeed, McDougall explicitly objects to sex selection on the grounds that a virtuous parent’s acceptance of her child must not be contingent upon the child’s sex; for

breaching the parental virtue of “acceptingness,” McDougall contends, sex selection is impermissible (2005). Others argue that sex selection for the purpose of “family balancing” is a dangerous step down the slippery slope of genetic enhancement. This argument is not without merit: Jeffrey Steinberg, the leading U.S. sex selection specialist, advertised in 2009 that his clinics could provide eye and hair color selection (Sidhu). If selection on the basis of a theoretically neutral trait like sex is socially accepted, or even taken as a reproductive right, it becomes difficult to argue that selection for traits like eye and hair color should be prohibited. And yet surely, selecting for certain neutral or positive traits could contribute to a loss of human diversity and to increased socioeconomic disparity based on the costliness of non-medical PGD testing. These parental virtue and slippery slope arguments reflect a wider sentiment in the bioethics literature—manifested in most countries’ reproductive policies—that sex selection is morally unacceptable.

Despite some bioethical endorsements of sex selection for non-medical reasons, sex mirrors Tay-Sachs in that the moral concerns surrounding its selection are largely uncontroversial in the bioethics literature. Yet the technology exists for PGD to detect traits that, as criteria for proto-parents’ selection decisions, are considerably more academically contentious than Tay-Sachs and sex. As I explore unique concerns that entangle the negative selection of spina bifida, T2D, and ADHD, the reader may think back to the Tay-Sachs and sex discussions for conceptual recalibration.

Spina Bifida

Keeping Tay-Sachs in mind as a relatively uncontroversial case for negative selection, we are prepared to examine the ethical questions surrounding the negative selection of less severely disabling traits. Such traits that do not entail early death, and that do not necessarily preclude a rich life experience, are considerably more controversial in the reproductive screening debate. These traits also tend to exhibit more complex genetic profiles. Unlike Tay-Sachs, for which an implicated embryo will necessarily develop the disorder, the less severe traits discussed herein do not have completely reliable genetic markers (to be sure, severity need not inversely relate to genetic complexity). This is because the etiology of such traits is multifactorial: genetic propensity and environmental dynamics alike play into the odds that an individual will develop a given complex trait. For complex traits, then, proto-parents will only have percentage probabilities to work with in the decision room.

This epistemic challenge represents one reason that screening for complex traits can be more controversial than screening for genetically simple ones. In selecting against a mere risk, however great it may be, proto-parents are selecting against an embryo that could develop into a clinically normal person (IVF itself also necessitates discarding excess embryos that may be genetically benign). One can imagine that the possibility an embryo could develop normally might be a low-priority factor in a *lassiez-faire* decision room. Comparatively, the quantified risks associated with an embryo would play a much larger role in the implantation

decision. The practical reality that proto-parents might act on information regarding risks of any magnitude will play into ethical discussion on genetic screening; should the strength of a genotype-phenotype correlation dictate its inclusion in PGD tests?

Another reason that screening out complex traits requires more ethical deliberation is that they tend to vary in severity. Traits with complex genotypes do not lend themselves to “all-or-nothing” phenotypes the way that simple Mendelian (i.e., dominant and recessive) traits do. And of course, environmental factors may lessen or amplify the genetic risk. We can anticipate that even as NGS affords the discovery of many genetic markers for undesirable traits, proto-parents still will not be able to predict the severity of the trait; the percentage probability, based on genetic markers, is merely the chance a trait will manifest at all—to any degree. On a biochemical level, many undesirable traits develop because the body lacks or is deficient in a critical protein (Sturm 2013). If the gene that codes for this protein is identified *in vitro* to be mutated, then the risk of the implicated embryo developing the associated trait may be assessed. But it is unlikely, given the level of genetic understanding we anticipate for the near future, that geneticists will be capable of accounting for the full butterfly effect instigated by the mutated gene: perhaps the body compensates by utilizing an alternative biochemical pathway; or maybe a small concentration of the critical protein is still translated (i.e., produced), thereby allowing the original biochemical pathway to proceed at a lower efficiency. Such scenarios would effectively make the undesirable trait more moderate; we can just as easily imagine other scenarios that would make the trait more severe. These biological variables, combined with environmental variables (e.g., chemical exposure,

diet, stress, exercise, etc.), make the degree of severity to which a trait will manifest impossible to predict *in vitro*. Arguably, this epistemic barrier provides a case for limiting the information available to proto-parents. If proto-parents are inclined to act on a non-comprehensive risk assessment, then perceptions and biases outdo concrete medical information in influencing who is brought into the world. Much is at stake; spina bifida, a disorder exhibiting a wide range in severity case-to-case, is discussed below to further delineate genetic questions regarding the epistemic barrier, and also to pursue several other ethical inquiries.

Spina bifida falls into a category of birth defects called neural tube defects, which occur in one or two out of every 1000 births (“Spina Bifida”). Thus one of the more common birth defects, they are characterized by malformation of the spinal cord or brain during embryonic development (“Spina Bifida Fact Sheet”). Spina bifida represents a subset of neural tube defects in which the neural tube does not fuse properly around the spinal cord; it occurs once every 2000 births (“Spina Bifida Fact Sheet”). An asymptomatic form of the condition called spina bifida occulta is independent of this statistic: up to one third of the entire population possess it (“Spina Bifida”). The one-in-2000 refers instead to spina bifida cystica, which encompasses meningocele and myelomeningocele (“Spina Bifida”). Meningocele is less severe, and, unfortunately, less common; the majority of spina bifida cystica cases are classified as myelomeningocele and are accompanied by any combination of orthopedic problems, partial paralysis, incontinence, and mental retardation (importantly, mental retardation does not occur in most spina bifida cases) (“Spina

Bifida”). Patients with myelomeningocele always exhibit a bulging sac of fluid and nervous tissue toward the base of their spines (“Spina Bifida”).

The etiology of spina bifida is complex, in that genetic and environmental factors are implicated. Associated with a deficiency of folic acid, spina bifida may result both from deficient maternal folic acid intake, and from genetic mutations that impair the mother’s ability to decompose folic acid into important derivative compounds. At least three gene mutations are likely associated with spina bifida: mutations in genes called *CFL1* and *MTHFR* disrupt the folic acid pathway, and a mutation in a gene called *VANGL1* prohibits proper neural tube development (Kibar et al. 2007). Delving much further into the biochemistry would be irrelevant for the purposes of ethical analysis. It is crucial, however, that spina bifida is currently mapped to certain genetic mutations: we can reasonably conclude that NGS will be used to determine other risk factors. In turn, a broader understanding of the risk factors will provide a basis for the calculation of the probability that a given embryo will develop spina bifida. Spina bifida thus becomes a trait on which proto-parents could potentially base implantation options in the decision room.

We can imagine that many proto-parents would be inclined not to implant a spina bifida-implicated embryo. After all, the opportunity to discover embryos that possess risk factors for traits like spina bifida is largely what drives genetic testing. Given that the majority of spina bifida cystica cases involve myelomeningocele, proto-parents have reason to believe that a baby born with spina bifida will suffer severe disability. More specifically, proto-parents can expect an afflicted child to be orthopedically impaired or partially paralyzed, thereby excluding her from many

mobile activities. Additionally, a child with myelomeningocele will live with the aforementioned fluid sac on his back. These inevitabilities, combined with the possibilities of incontinence and mental impairment, engender a major disadvantage for myelomeningocele patients. On top of this physical disadvantage is the extra effort required for someone with myelomeningocele to accept herself and achieve psychological health: unable to integrate fully with her clinically normal peers, she is subject to intense, potentially insurmountable feelings of inadequacy. Another disadvantage is economic, as myelomeningocele patients will have added health care expenses and will likely earn a lower income—assuming they can work at all—than their clinically normal counterparts. These disadvantages explain why many pro-parents would actively avoid implanting an embryo whose genome includes spina bifida risk factors. Indeed, selecting against spina bifida (even via contemporary practices of prenatal screening and selective abortion) is well intended and (arguably) an ethical choice in many instances.

However, disability rights activists offer forceful ethical arguments against the negative selection of traits like spina bifida. Marsha Saxton, an outspoken figure in the disability rights movement, has spina bifida herself and believes the mainstream perception of disability is built upon false assumptions. While she submits that spina bifida is a negative trait, Saxton claims that intrinsically, spina bifida is not nearly as negative and disadvantageous as it is made to be in the context of our insufficiently accommodating society. Contrary to mainstream attitudes that shape bioethical policy, the physiological impairments of people with traits like spina bifida are not

the primary source of disability: instead, “the [societal] oppression is what’s most disabling about disability” (Saxton 1998).

What does this oppression entail? Saxton contends that society believes disabled people necessarily endure lower quality lives than their clinically normal counterparts. This notion is perpetuated by systematic discrimination of the disabled. Because disabled people are considered pitiable, they are not fully accepted in society: they are denied opportunities not because of their actual physical or mental limitations, but because of the exaggerated perception of these limitations (i.e., that they relegate disabled people to a morally distinct, incompletely relatable class). The perversity of this situation is elucidated upon considering individuals in Saxton’s position, for example, who possess full cognitive faculties but moderate physical disabilities. Though there are real differences between such disabled individuals and clinically normal ones, it is difficult, if not impossible, to construct a sound argument that these differences are morally relevant to the value of each group.

That there are no morally relevant distinctions between someone with a typical case of spina bifida and someone whose neural tube happened to develop properly shows how both types of people exist on the same level. Both of their lives have the potential to be rich and meaningful; individuals with spina bifida have just as much at stake as those without it. Of course, the moral status of individuals with severe mental impairment is more controversial. I will not pursue whether or not such individuals are capable of experiencing life to the fullest, in the way Saxton argues that primarily physically disabled people are. But spina bifida is not typically accompanied by severe mental impairment: as mentioned above, most patients are of

“normal intelligence” (“Spina Bifida Fact Sheet”). It is therefore necessary to consider the degree to which a functional mind provides the capacity to achieve a good life experience. This is not to say that spina bifida patients have no physical functionality whatsoever; but considering the value of a functional mind is a critical step in analyzing the ethical permissibility of screening out spina bifida-implicated embryos.

The most severely affected spina bifida patients are quadriplegics. To what extent are these individuals capable of fulfillment solely via mental functionality? Such a measurement is difficult, given the variability of patients’ social environments. It is plausible, for example, that a quadriplegic with a loving and supportive family may find satisfaction; whereas it is exceedingly unlikely that another quadriplegic, whose family rejects and chastises him, may find similar satisfaction. This speaks to the significance of the treatment of disabled people as a determinant of their welfare. In turn, one’s treatment of the disabled is largely dictated by the prevalent attitudes of the culture in which she is socialized. Saxton claims that American culture promotes an off-base perception of the disabled experience. Though she does not say so explicitly, we may extrapolate from Saxton’s general views that she believes negative, external perception of a quadriplegic is more damaging to his psyche than is his actual paralysis. He is not intrinsically inferior in a moral sense, but he is made to *feel* inferior. A vicious cycle ensues: artificially unhappy disabled people instantiate the societal notion that disability precludes happiness. This notion, Saxton explains, is precisely what makes physicians and proto-parents feel warranted in selecting against and aborting implicated embryos.

Here, I transition into considering the ethical implications of a near future in which the societal attitude that Saxton criticizes persists, and negative selection of spina bifida remains unregulated. As IVF and pre-implantation sequencing become increasingly affordable, more proto-parents will have the opportunity to identify and discard embryos whose genomes contain spina bifida risk factors. Selecting against spina bifida will be so logistically convenient and socially accepted that the vast majority of proto-parents will be unable to resist. Even if they understand that the diagnosis is only a risk, that the risk may be considerably reduced by maternal folic acid supplementation, and that people with spina bifida are very rarely cognitively impaired, proto-parents will be disinclined to implant an embryo marked with spina bifida—especially considering the likelihood that another one of their embryos will not contain risk factors for spina bifida, or any trait as allegedly disabling. *Laissez-faire* spina bifida screening (in the context of an IVF era) will simply result in a significant decline in the number of people born with spina bifida. But should the presence or absence of spina bifida risk factors really determine who is brought into the world?

An individual with spina bifida has innumerable features, only one of which is spina bifida. Granted that spina bifida involves real disadvantages, affected people who must cope with them still develop unique personalities and interests. Just as an albino individual may have vibrant internal attributes, someone with spina bifida may have any number of advantageous qualities. Arguably, most of what defines an individual with spina bifida is utterly unrelated to the disability itself. Take Marsha Saxton as an example: she is articulate, compassionate, driven, and, incidentally, has

spina bifida. Perhaps her experience with the condition helped cultivate her positive attributes, but she presumably would have possessed them either way. It seems odd how much weight is assigned to spina bifida, compared to other traits, in the judgment of who might be a nice addition to the family or to the world. Part of the explanation, of course, is that traits such as articulateness and drive are less tangible and thus cannot be mapped to genotypes as reliably as can phenotypes like spina bifida. Without genetic markers, a trait receives no attention in the decision room.

A common concern regarding the advancement of reproductive technology is that it conduces social stratification. More (costly) options for proto-parents mean more ways that the wealthy can further isolate themselves from the poor. And this isolation entails an eerie permanence, as it is founded on genetics and may be intensified through subsequent generations. Bioethicists who voice the stratification concern explain that when wealth-based distinctions are built into the genome, class advantage is determined from birth in a new and profound way (Silver 1998). As mentioned in the last section, science fiction writers like Gattaca's Andrew Niccol have even imagined a scenario in which the genetically elite gradually form a distinct race of people (the implications for the lesser race being predictably dire).

However, the more immediate scenario that I anticipate in this paper involves readily affordable IVF and embryo sequencing. By no means will such technologies be limited to the wealthiest proto-parents if the procedures come down in price as much as they are expected to. Just as personal computers were once inaccessible to the middle class and are now ubiquitous, so too will reproductive technology become available across socioeconomic lines. The social stratification concern is not

alleviated in this scenario, but it has less to do with cost and more to do with education and the deliberateness of family planning.

Today, approximately half of all pregnancies in the United States are unintended; of these, approximately 40 percent terminate in abortion and approximately 60 percent result in a birth (“Unintended Pregnancy in the U.S.” 2013). These data allow for the rough estimate that over 25 percent of all births in the United States result from unintended pregnancy. We can surmise that even if IVF and embryo sequencing were affordable today, at least one quarter of births would be products of coital conception. Due largely to educational deficit and failure to employ contraceptives, a disproportionate number of the women who give unintended birth are below the poverty line and/or representative of ethnic minorities: if the statistics above hold in the anticipated era of affordable IVF and embryo sequencing, social stratification could indeed increase. But if 75 percent of births were planned, and IVF were the mainstream reproductive route, the upper *and* middle classes would diverge from the lower class (as opposed to the common science fiction scenario in which the socioeconomic elite diverge from everyone else). Theoretically, people who were not genetically selected via IVF would comprise the least privileged 25 percent of the national population. It remains a frightening prospect that the other 75 percent would gradually shed themselves of socially undesirable traits, while their less privileged counterparts would appear increasingly deformed.

This picture of exacerbated social inequality derives from a *ceteris paribus*-scenario in which IVF and embryo sequencing are inexpensive and readily accessible. It is therefore useful for considering how reproductive technological advancement

alone might influence society. Yet the impact of many variables will fill in the details of this oversimplified picture—perhaps even rendering it unrecognizable. One variable is the extent of sex education in poor communities. Because the use of contraceptives is politically charged, adolescents in socially conservative school systems have less access to information that would reduce the occurrence of unintended pregnancy (Collins et al. 2002). Indeed, whether or not teens learn contraceptive strategies besides abstinence is directly related to their likelihood of effecting or enduring pregnancy inadvertently (Collins et. al.). The reader is undoubtedly familiar with these correlations; of interest, here, are the implications of weak sex education curriculums for adolescents who live in the IVF era. If the majority of planned pregnancies are accomplished by IVF, unintended pregnancy will become that much more disadvantageous for parents and (if carried to term) their babies. This is because unintended infants will not have been selectively implanted: unlike their *in vitro*-fertilized counterparts, they will not have been filtered by whichever traits society finds desirable. To the extent that thorough sex education reduces the incidence of unintended pregnancy, people unexposed to contraceptive methods will more often parent unselected and “problematic” children. Access to a *complete* education, not just any education, becomes a factor in social stratification hypotheses.

But the expansion of reproductive technology could very well alter health curriculum writers’ attitudes. If the disadvantage of unintended pregnancy and random conception becomes overwhelming, perhaps socially conservative school systems will succumb to the changing times and adopt a more involved sex education

program. Surely, the inability to genetically select that accompanies unintended pregnancy will instill new fear in parents of teenagers: the idea that their adolescents' sexual activity could manifest in a reproductive route lacking the benefits of IVF will make many parents nervous. This anxiety may provide the impetus to influence politics and, by extension, public school sex education curriculums.

With regard to IVF and social stratification, an analogous variable to sex education is abortion. Like sex education, attitudes about abortion are intertwined with religion and politics. State laws that determine the relative ease or difficulty of obtaining an abortion have to do with insurance coverage, parental notification, waiting periods between one's initial interview and her actual procedure, a mandatory viewing of the fetal ultrasound, and more ("State Policies..."). Logically, states that uphold strict abortion laws will contribute most to social stratification in an IVF era: in these states, more unplanned pregnancies will result in the birth of an infant whose early embryo was not selectively implanted. But just as we can imagine public school systems evolving with communities' IVF-influenced values and enriching sex education, we can imagine that the mainstream utilization of IVF and embryo sequencing might loosen abortion policy. Compared to conservative-minded perceptions of abortion rationale today, a pregnant woman in the IVF era may seem quite warranted in desiring to abort an unselected fetus. Having missed the opportunity to weed out any undesirable embryos, she may garner special sympathy; accordingly, her ability to pursue abortion may improve as the relevant legal inconveniences are lifted. Albeit a morally twisted path to more lenience in abortion policy, this is a plausible one.

Alternatively, socially conservative ideologies may not be so malleable. Examples abound of instances in which biotechnological advancement fails to budge political stances grounded in religion. Biologists' continued difficulty funding stem cell research—due to the political fragility surrounding fetuses—represents one such instance: while very promising for a variety of medical therapies, stem cells are considered, by many, to be impermissible research items (“The Stem Cell Debates” 2012). It is entirely possible that the anticipated reproductive revolution will have no impact on abortion policy or the extent of sex education in schools. The question remains: would rampant IVF and embryo sequencing establish a greater moral responsibility to improve abortion and sex education than that responsibility exists today? Would efforts to save women from having to birth unselected babies perpetuate ethically problematic views of which traits justify negative selection? Regardless, we can be sure that the politics of abortion and sex education will influence the way IVF and embryo sequencing contribute to social disparity.

The last variable discussed herein—health insurance policy—may actually mitigate the social stratification associated with reproductive technology. Recall that approximately 25 percent of annual births in the United States are unplanned (these are the 60 percent of unintended pregnancies that are not terminated). I have discussed how NGS technology promises to aid in the determination of multitudes of genetic correlations between genotypes and undesirable traits (which tend to be medically expensive). It is thus foreseeable that health insurance providers may offer fiscal incentives for proto-parents who pursue IVF and select against embryos implicated with expensive traits. Effectively, it may be unaffordable to reproduce

without selective implantation: if genetic selection lowers health care expenses astronomically, failure to select may be proportionately, and prohibitively, expensive.

The 60 percent of inadvertently pregnant women who ultimately give birth forego abortion for a variety of reasons. But we can expect more women to opt for an abortion if paying for unselected children's insurance premiums becomes unfeasible—especially because women below the federal poverty line are five times more likely than women above this line to experience an unplanned pregnancy (“Unintended Pregnancy in the U.S.”). The extreme financial burden of raising an unselected child may make abortion considerably more appealing to pregnant women, even despite moral opposition they may have to the procedure. In turn, the risk of social stratification would diminish: the percentage of unplanned births would drop to virtually none, disassociating undesirable traits from low socioeconomic standing. Undesirable traits would not disappear from society, but they would spawn from fallible genetic risk assessment rather than from the poor neglecting to choose IVF.

Health insurance policy, as a variable influencing the social stratification risk in reproductive technology, contains many variables of its own. The above scenario is therefore speculative and functions to illustrate one way that the exacerbation of socioeconomic disparity may be avoided. But what moral problems would this scenario involve instead? First, it is nearly impossible to ethically justify coercive abortion. Yet the vast majority of inadvertently pregnant women would need to terminate their pregnancies in order to stay financially afloat. In this case, criteria for free and informed consent, the cornerstone of contemporary medical ethics, are not fulfilled: a woman's formal consent to abortion is void of substance if economic

pressure leaves her no other choice (Shrader-Freschette 2002). Women who view the fetus as a person, or whose ideological community considers abortion impermissible, would be particularly traumatized if they had to undergo abortion by economic necessity. Such a scenario seems unacceptable, and unjustified by the consequentialist notion that eliminating unplanned births will reduce overall suffering (by saving the health care system money). To contextualize the flaw in this scenario, effectively forced abortion would contradict the values of pro-life and pro-choice proponents alike.

Another morally problematic feature of the “elevated insurance premiums” scenario involves the definition of an undesirable trait. Insurance providers will only save money if proto-parents select against traits that are medically expensive, but the degree of this expense must be somewhat arbitrary, and measuring this degree must be quite a fallible enterprise. While actuaries dedicate their careers to such inquiries and use time-proven methods, the line between expensive and inexpensive traits will never be ascertained precisely. And the genetic risk assessment must be accounted for: how similar are the price tags on an embryo with a 20 percent spina bifida risk versus an embryo with an 80 percent late-onset cardiomyopathy risk? Assuming that a spina bifida patient, afflicted throughout life, requires more medical appointments and health care resources than does an elderly patient who develops a weak heart, perhaps the lower probability that the first embryo will develop spina bifida balances with the higher probability that the second embryo will develop the (less costly) heart condition. One can envision the muddiness of embryo pricing and the inevitably

arbitrary lines that insurance providers would establish, thereby significantly influencing the next generation solely via economic speculation.

The crux of this concern is that the insurance provider's threshold for negative selection is very unlikely to match that proposed by the average bioethicist (if she even believes devising such a threshold is morally appropriate). A policy requiring proto-parents to select against embryos implicated with spina bifida, for example, may be economically beneficial while simultaneously morally impermissible. One task of reproductive bioethics is therefore to intervene before personal and economic interests encourage morally problematic medical practices.

In this chapter, I have discussed several features of spina bifida relevant to the question of whether or not implicated embryos should be screened out. As with all multifactorial traits, spina bifida will only be predictable with great uncertainty. Many proto-parents, however, will be disinclined to implant an embryo tagged with *any* degree of spina bifida risk. In its typical manifestation, the trait imparts real disadvantages on those who possess it. But as Saxton urges us to appreciate, these disadvantages would diminish considerably were the public to reform its prevailing attitude that people with spina bifida necessarily lead poorer quality lives. That spina bifida generally spares cognitive function—and can produce people like Saxton—suggests that living with spina bifida need not preclude meaning and contribution. The latter portion of this chapter discusses how sex education, abortion ideology, and health insurance policy might influence the social disparity that could accompany widespread practice of IVF and embryo sequencing. While elevated insurance premiums for unselected children could reduce social stratification, they would

unavoidably introduce new injustices (e.g., pressure to abort, and to reproduce by health insurance-dictated selective implantation). The spina bifida analysis provides a flavor of the moral complexities that entangle an anticipated era of increased genetic selection.

Type II Diabetes

The spina bifida discussion touches on the friction between the value of prospective life, regardless of anticipated cost, and the utilitarian notion of screening out embryos (with risk factors for medically expensive traits) to cut health care costs. Here, this ideological clash is further explored through an assessment of type 2 diabetes mellitus (T2D hereafter). T2D is pertinent to utilitarian considerations because it is a great burden on developed countries' health care systems—and an increasing burden on those of developing countries (“National Diabetes...” 2011). In a time of insufficient medical resources and increasing demand, billions of people in need of health care could theoretically benefit from reducing the occurrence of T2D. And reducing T2D may be accomplished through IVF and embryo sequencing: in addition to the currently understood T2D risk factors, we can expect that NGS technology will enable the discovery of many more. Of course, T2D is a multifactorial trait and is largely induced by environmental factors that promote unhealthy habits (“National Diabetes...”). But to the extent that genetic factors reflect a propensity for T2D, selective implantation may help to reduce future T2D cases.

This chapter raises ethical questions surrounding the negative selection of T2D-implicated embryos. On one hand, T2D is a global epidemic that consumes medical resources like few other conditions do. On the other hand, T2D onsets in adulthood, does not necessarily reduce quality of life, and may be alleviated more effectively by addressing the environmental risk factors. The ethics of societal T2D

management are tied to practical considerations: many fewer people would develop T2D if agricultural subsidies were reformed, highly caloric foods were taxed, and everyone had access to nutritional and culinary education; yet it may be logistically easier, and perhaps an interim solution, to devise insurance policies that discourage proto-parents from implanting T2D-tagged embryos (Bener et al. 2005). I assess the ethical permissibility of this latter scenario with in mind the social and medical particularities of T2D.

T2D was distinguished from type 1 diabetes mellitus (T1D) in 1935 (Sattley 2008). Previously, the two forms of diabetes had been conflated due to their shared physiological trademark: an elevated concentration of glucose in the bloodstream (Sattley). The respective biochemical causes of increased glucose are what make T1D and T2D pathogenically distinct. T1D involves an innate incapacity to produce insulin, a hormone that normally lowers the blood-glucose concentration following food consumption (Alex et al. 2013). Whereas in T2D, somewhat reduced insulin secretion is compounded with dysfunctional insulin receptors: any insulin secreted has little or no impact on blood-glucose concentration (Prentki 2006). T2D cases involve varying degrees of inhibited secretion versus receptor malfunction (Prentki).

Excessive consumption of carbohydrates desensitizes insulin receptor cells over time; accordingly, over 80 percent of type 2 diabetics are overweight or obese (“National Diabetes...”). T1D pathogenesis has comparatively (many) fewer environmental risk factors. More deeply grounded in genetics, T1D may be predictable by embryo sequencing sooner than T2D. But only 5 percent of American diabetics are afflicted with type 1; these T1D patients only account for 8 percent of all

health care expenditure for diabetics in the United States (Dall et al. 2009). In contrast, 92 percent and \$225 billion per year support American T2D patients (Dall et al.). This value includes direct costs (mainly hospitalization and medication) and indirect costs (primarily due to patients' inability to work); the direct costs "account for more than 1 in 5 health care dollars in the U.S." (Yang et al. 2013).

Unfortunately, the T2D epidemic is not unique to the United States, or even to developed countries. China and India each house more than four times as many diabetics as does the U.S., and global expenditure on T2D is approximately \$504 billion—between 10 and 20 percent of all global health care expenses (Hirschler 2013). These statistics demonstrate why I zero in on T2D instead of the more genetics-based T1D: while both forms of diabetes significantly burden individuals, only T2D significantly burdens nations. Ethically, there is more at stake in reducing the occurrence of T2D, rather than T1D, through selective implantation.

The genetic profile of T2D provides foundation for subsequent deliberation on screening. Recall that genetic markers are most productively discovered through genome-wide association studies (GWAS), in which entire genomes belonging to people who possess a condition of interest are overlaid with clinically normal genomes. The resulting discrepancies become genetic markers for that condition; and the frequency of a discrepancy is proportional to its reliability as a genetic marker ("GWAS Fact Sheet"). GWAS have identified dozens of genetic markers for T2D, the most significant one being a mutated TCF7L2 gene. This gene, along with most of the other genes implicated in T2D predisposition, is thought to inhibit insulin secretion (as opposed to insulin receptivity) (Ali 2013). But impaired receptivity is

certainly an integral component of T2D: one explanation is that genetic factors tend to impact secretion and environmental factors tend to impact receptivity (Ali). Another explanation is that geneticists simply have yet to discover the genetic markers associated with insulin receptivity (Ali).

Indeed, our understanding of T2D genetics is far from comprehensive: only 10 percent of the trait's "observed heritability" (i.e., the actual proportion of T2D possessors whose children develop T2D) may be accounted for by currently known genetic markers (Ali). And the observed heritability is significant: 40 percent of people with one afflicted parent develop T2D, and 70 percent of people with two afflicted parents develop T2D (Ali). Of course, environmental factors play a substantial role in these trends; but as NGS technology advances and simultaneously drops in price, GWAS are expected to identify many new genetic correlations with T2D (Inamura and Maeda 2011). In turn, the observed heritability will be better accounted for by genetic markers than it is today. A better-defined picture of T2D genetics could plausibly make negative selection an effective method for reducing the occurrence of the disease.

What makes T2D etiology particularly complex is that some genetic and environmental risk factors are intertwined. Obesity, for example, is directly influenced by excessive eating and insufficient exercise, but indirectly influenced by physiological qualities like gustatory inclination for sweets and low resting metabolism (Ali). Given the strong link between obesity and T2D, we can imagine that a complete T2D risk assessment for a sequenced embryo might incorporate genes loosely associated with obesity.

Another complication in measuring T2D risk is the influence of the maternal environment on the fetal epigenome (Ali). Recall that whereas the genome refers to DNA sequence, the epigenome refers to the regulation of the transcription—and thus the functional manifestation—of that sequence. Albeit incompletely understood, fetal epigenetics are believed to contribute to a prospective child's T2D risk (Ali). They may be conceived as hybrid, genetic-environmental factors that selective implantation will not be able to correct for. To an even greater degree than spina bifida, T2D necessitates uncertainty in assessing the risk of an early embryo: because T2D commences in adulthood, any gene that influences environmental interaction (as in the example of taste preference for sweets) may contribute to T2D risk. And again, fetal epigenetic risk factors cannot be mitigated by selective implantation. The high degree of uncertainty in attempting to screen out T2D adds a layer of ethical ambiguity to this diabetes alleviation route. The lack of T2D genetic markers becomes a criterion for implantation and admission into the world; and yet the presence of T2D genetic markers does not guarantee the development of T2D by any means.

A large (and growing) number of T2D markers also exacerbates the problem of gene linkage, and the inadvertent negative selection of potentially critical genetic material. The basis for this concern is that the proximity of two gene sequences is proportional to the probability that these sequences will be inherited together (McClellan 1997). During fertilization, genes from each parent intermix by moving between maternal and paternal chromosomes. But the genes have no agenda: chromosomes are fragmented randomly, so that physically proximate genetic material

is more likely (than distant genetic material) to remain in the same fragment (McClellan). This means that if a T2D marker lies near essential DNA on a parental chromosome, both sequences will tend to stick together in the offspring genome. The fear is that in systematically discarding embryos implicated with genetic markers for T2D, we could simultaneously deprive subsequent generations of genetic material whose role in human functionality has never been researched, let alone understood. Granted, the vast majority of our genome is non-coding and has no impact on our lives: the likelihood that a T2D marker happens to be linked to a critical sequence is low. But this likelihood increases as new markers are discovered and selected against. The pickier we become in choosing an embryo worthy of implantation, the greater the chance that a discarded embryo's unworthy genes will be linked to others with unappreciated significance.

Another consideration in the ethics of T2D screening involves racial differences in the frequencies of genetic markers for obesity and insulin resistance (McCormack and Grant 2007). While environmental variables account for much of the observable T2D demographics, it is widely believed that genetic predisposition plays a role as well. In 2011, the Center for Disease Control reported that respectively, 9.2 and 9.3 percent of Hispanics and blacks had diabetes, compared to 5.6 percent of non-Hispanic whites; put another way, Hispanics and blacks are, respectively, 1.7 and 1.8 times more likely than non-Hispanic whites to develop T2D (Lawrence et al. 2009; "Diabetes and African-Americans" 2011). These statistics are undoubtedly related to the disproportionate number of minority members occupying lower socioeconomic brackets: lack of access to nutritious food and education are,

ultimately, the greatest risk factors for T2D. But more and more GWAS suggest that a portion of this demographic disparity may result from innate genetic differences. Just as people of European descent are more likely to develop multiple sclerosis, people of indigenous American and African descent are more likely to develop T2D (“National Diabetes...”).

Such correlations raise the question of how certain T2D risk factors came to inhabit the genomes of particular ethnic groups. The “thrifty gene hypothesis” proposes that gene variants we associate with T2D risk today were once advantageous—they facilitated early humans’ need for flexible adiposity (fat reserve) based on the fluctuating scarcity and abundance of food (Hales and Barker 1992). In the context of contemporary America, however, copious calories relegate “thrifty” genes to disadvantageous T2D risk factors.

If insurance providers incentivize the negative selection of T2D-implicated embryos, we can expect that proto-parents representing ethnicities more prone to T2D will have more screening to do. In a Hispanic couple’s decision room, for example, there might be fewer financially viable embryos to choose from (compared to those choices available to a non-Hispanic white couple). Admittedly, it seems bizarre to suggest that limited implantation possibilities would represent a moral injustice: there are no such decision rooms today, and even proto-parents who choose IVF do not fully sequence their embryos’ genomes. But reproductive justice is always somewhat relative to current technology. Consider the practice of selective abortion: it would be absurd, a century ago, to claim a mother’s right to abort a fetus diagnosed with Down syndrome via amniocentesis—prenatal diagnosis only began in the nineteen seventies

(Press 2008). Yet today, many believe that mothers should have the option to abort upon learning a diagnosis like Down syndrome. Likewise, the ability to select among a slew of embryos might be considered a reproductive right in the anticipated IVF era.

Would insurance incentives to discard T2D-tagged embryos then create problematic, race-based limitations? If contemporary geneticists are correct in attributing certain genetic T2D risk factors to Hispanics and blacks, many proto-parents representing these groups will be systematically stripped of some of their implantation candidates. It is unclear how many Hispanic or black embryos would tend to remain in the running. *Any* routine reduction in implantation options, however, might be considered unjust—especially given the discrimination and disadvantage that Hispanics and blacks already endure in the United States. Granted, genetic propensity for T2D is a real, inherent disadvantage; it is not socially constructed disadvantage like skin color or language of origin, and thus there is arguably no ethical violation in a policy that disproportionately impacts certain ethnic groups. But this logic may be too simple. Recall that feminist bioethicists like Mary Mahowald claim that ethical health care policies must compensate for the societal marginalization of minority groups (2006). If we are to acknowledge the disadvantages imposed on many American blacks and Hispanics, we must not implement disfavoring policies, no matter how effective and racially blind they may be. This general argument suggests that pre-implantation screening for T2D would be unethical: it would negatively impact ethnic groups who should be helped actively, not burdened further.

The arguments I have raised thus far relate to what we know and expect to find out about specific T2D genetics. Moving away from technical considerations, I discuss more abstract ones regarding the permissibility of T2D screening as a state- or insurance provider-sanctioned disease management strategy. It is first important to understand the health care incentives that have been employed, controversially, within the last several years. Financial penalization as a disincentive for unhealthy habits is no longer a hypothetical tactic: in 2011, 10 percent of U.S. employers charged higher insurance premiums for employees who smoked cigarettes or were clinically overweight; approximately half of all employers are projected to follow suit by 2016 (Mincer 2011). And the legality of such policies has become more inclusive under President Obama's Affordable Care Act (ACA): health insurance providers may require smokers to pay up to 1.5 times the non-smoker rate (Mincer).

Companies frame these policies as catalysts for healthy behavior rather than punishments, some offering free smoking cessation workshops and gym access (Mincer). Also, employees who present a doctor's note stating that it is extraordinarily difficult or medically unwise for them to quit smoking or lose weight are exempt from paying the elevated rate (Mincer). Yet many regard any policy with differential premiums as morally problematic; perhaps the most salient argument representing this view is that the poorest people, who are most likely to smoke and exceed a healthy weight, are most burdened by paying extra for problems largely beyond their control. Limited access to nutritious food and health education certainly contribute to impoverished people's disproportionate consumption of fast food and tobacco. Additionally, stress associated with financial difficulty promotes impulsive

choices, namely the use of relaxants like hypercaloric foods and cigarettes (Abraham 2012). To what degree is it then morally appropriate to hold the poor accountable for smoking or being overweight?

Proponents of elevated premiums contend that holding employees responsible for their health represents no injustice if employers do their part. Free or subsidized health workshops and nutritious food options, for example, are said to allow employees to pursue their health aspirations in the workplace (Mincer). Of course, the 6.6 percent of Americans who are unemployed would not have the benefit of employer-sponsored health programs (Hill 2014). Even if raising premiums for smokers and the overweight is effective overall in promoting healthier habits, this strategy risks harming the most socioeconomically vulnerable among us. But this issue could be resolved, conceivably, if well-managed fitness and smoking cessations programs were available to everyone.

The question arises whether raising premiums for smoking and body mass index is comparable to raising premiums for the failure to screen for T2D. If so, the arguments surrounding the former will inform our moral conception of the latter; if not, new arguments that apply more aptly to T2D screening must be developed. With regard to their similarities, smoking, being overweight, and possessing genetic risk factors for T2D all constitute potential expenses to the health care system that are somewhat avoidable. These expenses are not entirely avoidable, because even taking measures to counter the risk (e.g., quitting smoking, eating healthily, and exercising) might not prevent the onset of the originally foreseeable medical complications (e.g., lung cancer, heart disease, and T2D).

The differences between smoking and being overweight on the one hand, and possessing T2D risk factors on the other, have to do with personal agency. One might intuit that smokers and the overweight have more agency: most people in these categories (exceptions being those whose excess weight results from metabolic disorders) could conceivably quit smoking or lose weight; whereas people with T2D risk factors cannot rid themselves of these DNA sequences. However, we must not overlook proto-parents' agency. In the anticipated IVF era, it will be much easier for proto-parents to select against T2D-implicated embryos than for the average smoker to quit, or for the average overweight person to lower her body mass index to a clinically normal level. If insurance premiums are raised, not for all people who possess T2D (this would be clearly morally problematic), but for those who were not *screened* for T2D, then proto-parents will have considerable agency in avoiding higher premiums. In this vein, selecting against T2D risk factors is fundamentally distinct from quitting smoking or losing weight. The former requires proto-parents to proceed with IVF, entailing a month-long maternal hormone treatment and a few extra visits to the obstetrician; whereas the latter requires smokers and the overweight themselves to counter the overwhelming inertia propelling their risky habits.

Many contemporary arguments against elevated premiums are thus unfit for application to questions of pre-implantation screening. Surely, signing on to a particular reproductive route requires less willpower than transforming one's everyday lifestyle. The argument that qualifying for the standard insurance rate is too difficult, then, loses considerable force when the subjects change from smokers and the overweight to proto-parents. Even the notion that impoverished people suffer the

greatest blow from differential premiums is weakened (though not fully discredited) when applied to T2D screening. Recall the premise of this notion: poor people are not only susceptible to smoking and being overweight, but they also possess little resources to aid in the reversal of these conditions. But T2D screening in the IVF era would require no such reversal. Assuming the costs associated with IVF are subsidized, financial insecurity need not prohibit the IVF route; instead, eligibility for the standard health insurance rate would strongly incentivize it. Granted, as discussed in the previous chapter, the poor tend to receive less sex education and incur more unintended pregnancy. A higher rate of coital conception would be the barrier between some poor people and their qualification for standard premiums. Comparing the respective barriers between T2D screening and smoking cessation or weight loss becomes a question of which social programs are more feasible in the United States: education on and access to contraceptives—or a complex interplay of nutritional and anti-smoking curricula, increased (geographic and fiscal) access to nutritious foods, and decreased access to cigarettes? Such an involved question exceeds the scope of this paper; however, there is reason to believe that reducing unintended pregnancy is a relatively simpler endeavor (especially in the IVF era, which would see additional political will to reduce unintended births and thereby avoid unnecessary health care costs). In sum, the main ethical argument against charging smokers and the overweight extra for health insurance holds less gravity when applied to T2D screening. Given the anticipated reproductive revolution, we can expect that people with fewer resources will more easily pursue IVF than avoid the overconsumption of calories and tobacco.

This is not to say that policies requiring differential, selection-based premiums are exempt from moral skepticism: instead, I only suggest that such policies may be less problematic than currently-employed ones based on highly engrained conditions (smoking and being overweight). Indeed, selection-based policies neither sidestep the technical concerns elucidated in this chapter (high uncertainty, gene linkage, and racial disparity), nor do they dodge the broader concerns discussed in the previous chapter (pressure to abort and the general risk of misaligned moral and economic values).

Another concern is that incentivizing T2D screening represents a misplaced intervention. Why attempt to reduce the occurrence of the disease eugenically, and with ethical ambiguity, when environmental risk factors have a greater impact on T2D development anyway? It seems illogical to manage T2D through genetic intervention before addressing the every-day issues that transform predisposition into condition. As mentioned above, the rise of hypercaloric diets and the decline of active lifestyles have caused and continue to aggravate a global obesity epidemic, claiming millions of lives via weight-related complications like T2D (“National Diabetes...” 2011). Surely, we are morally obligated to tackle the underlying issues. But corporate interests make change difficult: processed food industries rely on corn subsidies and divert subsidization from nutritious vegetables, fruits, and grains (“For a Healthier Country...” 2012). In turn, all that many people can afford to eat are processed foods rich in calories and void of nutrition. We can imagine that processed food industries would like nothing better than for reproductive technology to peacefully resolve the destruction their products are causing; this way, business

would remain lucrative and external criticism would subside. But this scenario is unrealistic: embryo sequencing and selective implantation—even despite the wealth of new genetic discoveries expected to come out of NGS—will not make humans immune to the danger of hypercaloric diets anytime soon. It would be absurd, then, if incentives for selecting against T2D risk factors were to be implemented while double cheeseburgers and large sodas remained the cheapest items on the block.

The management options become either focusing exclusively on the environmental T2D risks, or working to thwart both the environmental and genetic risks at once. Given that the ethical concerns I have raised call into question the permissibility of selection-based insurance policies, the first option seems preferable. Yet we must not forget that the existing T2D epidemic is morally unacceptable: inordinate numbers of people are burdened financially and physically, often dying early and indecently; and the health care system is strapped for resources. Concerns born from the notion of a selection-based policy therefore must be weighed against those pertaining to the status quo. To the extent that genetic intervention could reduce the occurrence of T2D, the moral issues surrounding such intervention must not be considered independently. In a utilitarian sense, the harm done by institutional incentives to screen against T2D stands in relation to the good established by reducing the particularly T2D-predisposed population.

This is a case in which bioethicists must delve deeply into the science in order to produce a meaningful policy recommendation. The permissibility of incentivizing T2D screening largely depends on the specific proportion of overall T2D risk that is genetic. This proportion cannot be quantified with precision, but it must be

approximated closely before a screening policy is sanctioned. As relayed above, only 10 percent of observed T2D inheritance has been linked to genetics at this point in time. This number is sure to rise with NGS-facilitated discoveries, but it may never rise sufficiently to warrant a systematic reduction (via negative selection) of people genetically predisposed to T2D. Or, perhaps, the magnitude of the T2D problem makes 10 percent quite enough. The threshold above which fiscally encouraged T2D screening is permissible must be estimated by blending each ethical component together and tasting the result. Many of these components, of course, are grounded in genetic statistics; another critical component has to do with how effective the reduction of environmental T2D risk factors is in lowering T2D occurrence. If the political will exists to reform the food system such that people adopt healthier diets, for example, it may not be necessary to manage T2D by genetic intervention.

This chapter discusses a diverse, albeit non-exhaustive, list of factors relevant to the ethics of T2D screening. The disease is defined by its proliferation alongside the unhealthy habits of our time, and by its consumption of 20 percent of U.S. health care dollars (Yang et. al.). Its genetic risk factors are tied up in those of obesity, and other components of its overall risk are believed to be epigenetic in nature; today, T2D is difficult to predict independently of its environmental risk factors. Because of the growing number of DNA sequences that geneticists are associating with T2D predisposition, gene linkage—the tendency for proximate genetic material to be inherited together—introduces the dangerous possibility that we could inadvertently screen out important genetic material if it exists near a T2D risk factor. T2D screening also risks disproportionately affecting certain minority

groups, especially blacks and Hispanics, who are believed to possess more T2D risk factors than their non-Hispanic white counterparts. Following this examination of T2D markers' technical qualities, I contrast current insurance penalties for smokers and the overweight with the hypothetical penalty for neglecting to select against T2D-tagged embryos; the penalties employed today seem to be harsher than the hypothetical one, as quitting smoking and losing weight require more resources than does opting for IVF (if the cost of this procedure declines as expected). Finally, I discuss the importance of addressing public health issues that conduce environmental T2D risk factors. This approach is more direct than genetic intervention, but it may be ethically imperative to attack the environmental and genetic foundations of T2D simultaneously, given the severity of the epidemic. While I provide no specific resolutions, the reader can see how one would go about assessing the moral permissibility of T2D screening.

Attention Deficit/ Hyperactivity Disorder

Both spina bifida and T2D affect the body more than the mind: cognitive impairment only accompanies spina bifida on occasion, and T2D has no mental component at all. Yet many traits whose genetic markers could conceivably warrant negative selection mainly impact the mind. In this chapter, I introduce moral concerns unique to the prospect of screening for mental conditions via analysis of attention deficit/ hyperactivity disorder (ADHD). The nature of this trait is such that preventing its occurrence through genetic intervention invites a rich moral discourse. Like T2D, ADHD incurs significant and mounting expenses in the United States; many of the concerns raised in the previous chapter thus carry over to this one (“ADHD, Data...” 2013). But I avoid dwelling on the same questions of insurance incentives, here, for there is novel ethical terrain to explore. ADHD is classified as a mental illness; its genetic risk factors influence brain chemistry, and some are shared by clinically distinct mental conditions (Silver 1998). Even more than spina bifida, ADHD engenders debate regarding the inherent versus contextual quality of its associated disability. Its cases have risen steadily for the last couple decades, but its genetic and environmental risk factors have remained relatively constant: might ADHD then have something to do with evolving norms for mental aptitude (Campbell and Eisenberg)? Investigating the ethics of ADHD screening requires disentangling this condition’s objective and perceived properties. While both types of properties are relevant to the screening debate, public perception is malleable and medical pathology is not: to the extent that these two aspects of ADHD may be

viewed in isolation—as well as understood in relation to one another—the ethical inquiries herein may be better informed.

The etiology of ADHD is multifactorial, with the genetic factor comprising an estimated 76 percent of the total risk of developing the trait (Collingwood 1995). All of the dozens of implicated genes impact neurotransmission—the movement and concentration regulation of neurotransmitters, or small molecules that facilitate communication between nerve cells (neurons) in the brain (Stufflebeam 2008). More specifically, the gene variants (polymorphisms) linked to ADHD affect neurotransmitters called dopamine, norepinephrine, and serotonin (Stufflebeam). What makes ADHD risk assessment so complex is that each implicated gene has multiple and distinct polymorphisms linked to ADHD vulnerability (Collingwood). The DRD4 gene, for example, has “more than a dozen known polymorphisms” whose conferred risks may be amplified or suppressed by polymorphisms of *other* ADHD-related genes (Winstead 2000). Contemporary research has yet to parcel out and quantify the risk associated with all of these combinations; that many ADHD patients possess entirely different (relevant) genetic compositions, however, is well documented (Doyle et al. 2005). NGS technology promises to help clarify the genetic etiology of ADHD by high-throughput comparisons ADHD- and control-populations’ genomes. We can expect that as time progresses, the susceptibility statistics relayed to proto-parents in the decision room will become increasingly more reliable.

Yet even the most comprehensive genetic risk assessment will not account for the estimated 24 percent of total ADHD risk unrelated or indirectly related to genetic predisposition (Collingwood). Prenatal environmental factors comprise the majority

of this risk. Recall that the epigenome refers not to one's complete set of genes (this is the genome), but instead to one's unique pattern of expressing and silencing these genes. When toxins come in contact with a fetus through maternal smoking, or through other deliberate or involuntary chemical exposure, the fetal epigenome is subject to modification that impacts neurotransmission (Thapar et al. 2007).

Perinatal factors form another subcategory of non-genetic ADHD risk. Studies that control for genetic and prenatal environmental risk factors have demonstrated that premature and underweight birth both significantly increase the chance an infant will develop ADHD (Brooks 2012). On the other hand, studies report that the use and duration of breast-feeding alleviate ADHD risk (Brooks). Just as maternal consumption of folic acid supplements reduces the odds of neural tube defects and spina bifida, breast-feeding may counter existing ADHD susceptibility.

The remaining—and most primitively understood—subcategory of total ADHD risk has to do with genetic-environmental interplay, “whereby genes operate by influencing sensitivity or response to environmental adversity” (Thapar et al.). In the diabetes chapter, I exemplify this form of risk through the hypothetical patient whose genetic inclination for sweets causes him to succumb more often to gastronomic temptation. Analogous gene-environment interaction is thought to impact the onset and course of ADHD (though such interaction is more temporally constrained than it is for T2D, as ADHD typically onsets much earlier in life). Evidently, risk factors that are not purely genetic play a significant role in ADHD etiology. Yet the role of genetics is roughly three times as great; all evidence

suggests that IVF-era selection against embryos marked for ADHD could not only be possible, but also “successful.”

As touched on above, the variety and interrelation of the causes of ADHD make for an elusively defined trait. Children may be clinically diagnosed with ADHD if they exhibit the five “essential features” spelled out in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (“Diagnostic Criteria...” 1995). In brief paraphrase, a child must be particularly inattentive and/or hyperactive-impulsive; symptoms must occur before age seven; symptoms must occur in multiple settings; symptoms must impair social or occupational behavior; and symptoms are not better accounted for by another mental condition (“Diagnostic Criteria...”). The DSM further classifies ADHD into a primarily inattentive form, a primarily hyperactive-impulsive form, and a combined form (“Diagnostic Criteria...”). While these guidelines facilitate the identification of millions of ADHD patients, many of whom then receive invaluable assistance, they are too simplistic for the bioethical investigation at hand. What is at stake in screening out ADHD-implicated embryos depends on what exactly ADHD entails—and a five-piece list does not do justice to the readily observable variety among clinical ADHD patients. Without attending to the disconnect between the standard conception of ADHD and the vast array of phenotypes huddled under the trait’s clinical umbrella, we risk problematically conflating a wealth of morally relevant human characteristics—and the genes conferring at least some of these characteristics are surely worth keeping in the gene pool.

The concept of an endophenotype may help to ground these ideas. Whereas a phenotype is the ultimate functional manifestation of the genotype, the endophenotype is an intermediate functional manifestation. Researchers are investigating ADHD endophenotypes to resolve the problem of “genetic heterogeneity” within ADHD cases (Doyle et al.). If ADHD is conceived not as a blanket psychosocial phenomenon, but instead as the confluence of different biological phenotypes (endophenotypes), then the genotypic (and phenotypic) variety exhibited by different ADHD patients may be explained. An innovative paper by Alysa E. Doyle and other psychologists posits certain cognitive properties that may be considered endophenotypes of ADHD. One endophenotype candidate is called “delay aversion,” and refers to the tendency to forego greater rewards in exchange for lesser ones that are more immediately accessible (Doyle et al.). Delay aversion is related to the DSM’s impulsiveness criterion, but being an endophenotype, the former has a more direct biological foundation than the latter does. Specifically, delay aversion is thought to result from “dysfunction in the meso-limbic-cortical branch of the dopamine system”—a particular neuronal pathway involved in dopamine transmission (Doyle et al.). Doyle et al. explain that delay aversion is an endophenotype by virtue of its “co-occur[rence]” with some (but not all) ADHD cases. And importantly, this endophenotype is not unique to ADHD: it occurs both in clinically normal individuals and in individuals afflicted by other dopamine-related mental conditions. That different ADHD cases comprise different endophenotypes suggests that ADHD may be more aptly characterized as several disparate conditions. Just as psychology once lumped together the conditions now known as bipolar

disorder, major depressive disorder (simply “depression” hereafter), and dysthymia, we can imagine that modern neurological research will draw meaningful divisions within ADHD.

What moral concerns arise from this definitional transience? Essentially, some ADHD subtypes could be more appropriate to select against than others. The basis for this prospect of morally preferential selection lies in the various harmful and valuable traits associated with ADHD. If one ADHD subtype is highly correlated with a “comorbid” disorder (e.g., depression), and another subtype is highly correlated with a constructive quality (e.g., adventurousness), perhaps we should respond differently to their respective pre-implantation diagnoses (Silver). Perhaps, even, an ADHD subtype is linked in nearly equal proportion to comorbidity and unique ability: how might we assess the permissibility of selecting against an embryo conveying this subtype?

A closer look at the relationship between ADHD and other traits might help contextualize these questions for the reader. With regard to comorbidity, an estimated 50 percent of ADHD patients suffer from distinct, clinically recognized problems like anxiety, depression, obsessive-compulsive disorder, and certain learning disorders (Silver). Of course, ADHD itself is the underlying source of associated difficulties for many of these patients. Poor academic performance and social inaptitude, for example, can severely impede a child’s flourishing and trigger depression. Yet many clinical disorders seen in ADHD patients (depression included) are not merely secondary to ADHD; in such patients, the disorders are said to be truly comorbid (Silver).

One generally accepted explanation for comorbidity involves shared genetic risk factors. The genetic markers of ADHD and depression, for instance, have 10 percent overlap (Mick and Faraone 2008). Accordingly, ADHD and depression likely share endophenotypes related to abnormal neurotransmission. The question of interest to our ethical inquiry is whether the 10 percent overlap might be confined to one or two isolable ADHD subtypes (instead of permeating ADHD as a whole). Imagine an embryo implicated with a depression-affiliated subtype, and possessing no genetic markers for “redeeming” ADHD-related qualities (discussed shortly): if any ADHD screening is morally justifiable, it is certainly so for this embryo. For implanting this embryo would likely set up the resultant child and his parents to navigate the obstacles of ADHD *alongside* those of depression; and likely, no genes would offset these disadvantages by conferring valuable, ADHD-related traits. This hypothetical case would represent the negative extreme of ADHD subtypes—whereas the positive extreme might consist of a subtype characterized by mild and treatable symptoms, combined with special ADHD-related qualities. Selecting against this latter case seems quite difficult to justify: one might even argue this subtype is more advantageous than not.

The prevailing theory behind positive, ADHD-related qualities has to do with human evolution (Campbell and Eisenberg). While inattention is conceived as such in the contemporary classroom, researchers believe the gene variant linked to inattention was (naturally) selected for 45,000 years ago (Campbell and Eisenberg). This variant affects a dopamine transmission gene called DRD4; it bestows what is called “scanning behavior,” an attention style that allowed hunter-gatherers to scan

their environment in lieu of zeroing in on a particular feature within it (Campbell and Eisenberg). Anthropologists Benjamin Campbell and Dan Eisenberg demonstrate the advantage of this DRD4 variant through a study of the Aarial people in Kenya, who live either in settled villages or nomadic tribes. According to the study, nomadic Aarials with the DRD4 variant are less underweight than their counterparts who lack it; and predictably, settled Aarials with the DRD4 variant are *more* underweight than their counterparts who lack it (Campbell and Eisenberg). Thus, one of the more significant ADHD risk factors is simultaneously crucial to nomads' survival.

Yet proto-parents pursuing IVF and embryo sequencing will not be nomadic, and the DRD4 variant is just as detrimental to contemporary schooling as it is beneficial for tasks like hunting and maintaining vigilance in the wild. With regard to ADHD screening, then, one might argue that the DRD4 variant is solely utile as an indicator for negative selection. But it seems premature to discount genetic material on the grounds that it interferes with success in socially constructed features of the world. Such constructs—the confines of a classroom, standardized tests, ubiquitous emphasis on verbal skills—have existed, relative to the DRD4 variant, for an exceedingly small portion of human history. And the modern education style alone does not explain the explosion of ADHD cases diagnosed over the last decade. Some researchers believe that excessive television watching and video game playing have sapped children's attention spans, often exacerbating genetic predispositions and cultivating clinical ADHD (Klass 2011). The DRD4 variant and contemporary society may be incompatible, but eradicating the former to accommodate the latter seems morally dubious. The preferred course of action might be to identify and

amend societal practices that promote ADHD, thereby accommodating more fundamental human qualities ahead of our transient (and possibly misplaced) values.

Recall from the previous chapter that “thrifty” T2D risk factors are also believed to have gained prominence in the human gene pool through natural selection. Yet there are morally relevant differences between thrifty genes and DRD4. While thrifty gene variants are only valuable for glucose metabolism, the DRD4 variant—along with other ADHD markers—confer advantages that extend beyond scanning behavior. Ever-accessible calories make thrifty T2D genes utterly useless, but regimented education and digitized entertainment do not exhaust ADHD markers’ value. This claim derives from the well-documented notion that ADHD imparts alternative, not inferior, qualities. The cognitive tools permitting a child without ADHD to study intently for an exam, for example, might correspond to the immense creativity with which an ADHD-possessing child plays the fiddle. Likewise, the physical restraint a child without ADHD maintains through a long class period might correspond to the hyperactivity with which an ADHD-possessing child excels on the hockey rink. In this vein, scholars have hypothesized—based on their subjects’ habits and personalities—that such geniuses as Albert Einstein and Wolfgang Amadeus Mozart possessed ADHD (Zaslow 2005). Moreover, the percentage of professional athletes with ADHD is twice that of the rest of the population (8-10 percent versus 4-5 percent) (Dutton 1998). It would thus be misguided to claim that ADHD-related traits are purely detrimental. Whereas thrifty T2D gene variants have no purpose beyond their outdated physiological one, ADHD

risk factors have not depreciated; ADHD has merely become an impediment to success in certain dispensable institutions of contemporary society.

Perhaps, however, some such institutions deserve more credit. Take the paradigmatic elementary school classroom: children learn through a combination of oral lessons and hands-on projects; many thrive this way and prepare themselves for the next level of academic stimulation. If the classroom is an environmental risk factor for ADHD, then, it is certainly not so for every student. Compare the classroom to a T2D risk factor like fast food consumption: whereas no one benefits nutritionally from fast food, millions benefit socially and academically from their experiences in the classroom. Perhaps the classroom should not be dismissed simply as an arbitrary, ADHD-aggravating construct; conceivably, the same classroom dynamics implicated in the recent surge of ADHD cases might be of great educational service to many children. If so, an attempt to reduce the occurrence or burden of ADHD through education reform might make learning more difficult for students with standard cognitive styles. Consider a fourth grade class which, in an effort to accommodate students with attention problems, replaces silent reading blocks with teacher-led reading and intermittent discussion: the students without attention problems might have been better challenged reading independently. Given this conflict, the prospect of morally sound ADHD screening is revitalized. If classroom-style education is effective for the majority of students but incompatible with ADHD, then perhaps ADHD screening is morally justifiable: the harm in selecting against the positive qualities associated with ADHD is offset by the good in protecting clinically

normal students from academic stifling imposed by their ADHD-afflicted counterparts.

Of course, this argument is not convincing and overlooks the ideal solution: increasing individualized support within the classroom so that each student may learn at her own pace. If we are to embrace people with ADHD for their cognitive uniqueness, we must accommodate their educational needs from an early age; otherwise, the special qualities for which they are known will have little chance of developing. Not to mention that unique qualities aside, children with ADHD deserve a proper education like anyone else. While special education is nothing new, it is often underfunded and could undoubtedly improve to satisfy more ADHD students' needs ("Understanding Special Education..." 2009).

I have discussed why negative selection against ADHD is morally problematic— especially if societal ADHD aggravators like excessive television watching are not curbed first, or at least concurrently. The remainder of this chapter concerns the responsibilities of physicians and proto-parents in dealing with genetic ADHD markers and all they entail. Even if theoretical arguments reduce the moral permissibility of ADHD screening, moral work remains to be done in reflecting on what should come of ADHD in the seemingly inevitable IVF era and its epitomic decision room. Questions abound regarding which genetic information physicians should relay to proto-parents; what constitutes proto-parents' reproductive rights given our biotechnological capabilities; and how proto-parents should go about selection decisions in an ethically attuned way. For it may be that despite the aforementioned dangers of ADHD screening, it would be morally unacceptable for an

IVF-era geneticist to withhold from proto-parents information pertinent to ADHD risk. And likely, it would be unacceptable for a geneticist who *does* communicate ADHD risk factors to prohibit proto-parents from basing their selection decisions on them.

Regardless of how much genetic information proto-parents receive, they will only reach morally responsible implantation decisions through thoughtful deliberation on the implications of selecting for or against the genetic markers at hand. Yet proto-parents will undoubtedly bring unfounded biases and perceptions into the decision: a task of reproductive bioethics may be to establish guidelines for how much and what kind of genetic insight physicians should convey to proto-parents. While too little information could frustrate proto-parents' ability to make an informed choice, too much information could thrust onto them a degree of responsibility they are prone to mishandle.

The circumstances that warrant withholding relevant information from medical patients are highly contested in the bioethics literature. As discussed in the introduction, Beauchamp and Childress codify the principle of autonomy in a rejection of widely accepted paternalist practices that were routine in medical care at the time of *Principles*' publication; autonomy has since become the basis of Western medical ethics. In turn, more recent bioethicists like Carolyn McLeod criticize the autonomy principle—as it is often implemented, at least—for being a moral façade behind which patients' decisions are tied up in externally imposed feelings of self-doubt. Bioethicists point out even more commonly that patients must be fully informed and unpressured in order to make truly autonomous decisions. Such

literature thus provides a picture of what true reproductive autonomy might entail; yet it is unclear which decisions should be made *possible*, let alone autonomous, for proto-parents in the anticipated IVF era. As a revolutionary means of genetic marker discovery, NGS technology promises to create screening options more numerous, precise, and cheap than may be beneficial for society. If proto-parental autonomy requires access to all of these options, an expansive definition of paternalism may be helpful in conceptualizing the harm that could result from an IVF era in which autonomy remains the precedent.

To elaborate, paternalism—the interference with a person’s autonomy for the sake of her welfare—might be reconceived so that “welfare” encompasses her immediate interests as well as her broader interests as a society member (Dworkin 2010). We can imagine that a proto-mother who would not knowingly implant an ADHD-implicated embryo might also lament a new generation void of the unique, positive qualities associated with ADHD. Justified paternalism would not, of course, entail occasional mandated implantation of ADHD-implicated embryos; rather, justified paternalism would underlie a bioethical policy prohibiting physicians from testing for—and thus preventing proto-parents from selecting against—genes linked to ADHD. Such a policy would help reproductive medicine avoid a “prisoner’s dilemma” scenario by ensuring proto-parental cooperation (Kuhn 2009). In the context of widespread ADHD screening and negative selection, it would be socially difficult for proto-parents not to follow suit and select against ADHD-tagged embryos: neglecting to do so could place one’s prospective child at a relative disadvantage. In this way, screening for ADHD and not screening for ADHD (when

many proto-parents are) both would constitute morally problematic reproductive decisions. Perpetuated by competition and preventable through cooperation, the outcomes of pervasive ADHD screening reflect those in the “prisoner’s dilemma”: just as it is in the prisoners’ best interest to make a slightly incriminating confession, it is similarly in proto-parents’ best interest to forego ADHD screening despite the small chance of begetting a child with the trait. For laissez-faire ADHD screening and negative selection could result in a mass-reduction of human diversity. If we conceive of this diversity loss as frustrating the broad interests of proto-parents, who have a stake in the next generation by virtue of bearing it, we can conceive of a policy that requires physicians to withhold ADHD-related genetic information from proto-parents as a form of justified paternalism (in the inclusive sense of the term explained above).

To be sure, I do not mean to discredit proto-parents’ moral agency. However much genetic information physicians withhold, proto-parents will still have many more reproductive options than are available today. After all, the reason IVF is expected to become the mainstream reproductive route is because it offers proto-parents more influence over who joins the family. Paternalistic withholding of genetic markers therefore does not exempt proto-parents from considering the implantation options they do have with the utmost moral integrity. It seems imperative that IVF-era reproducers are versed in at least vaguely systematic ethical thinking; the IVF process might include an introduction to Rosalind McDougall’s conception of the “virtuous parent,” for example. If proto-parents are urged to embody “acceptingness,” “committedness,” and “future-agent-focus,” their

implantation decisions may be that much more ethically informed (McDougall 2007). And McDougall's guidelines represent just one method of thinking about reproductive responsibility: we can imagine that IVF-era hospitals will enlist ethicists to devise patient-accessible guidelines of a similar variety. Ultimately, proto-parents must be trusted to make thoughtful implantation decisions; without this trust, our societal trajectory must be actively shifted away from the establishment of IVF and embryo sequencing as popular reproductive practices.

Before closing this chapter, I return to ADHD and paternalism to suggest one way a geneticist (or an overseeing bioethics committee) might determine which markers to share with or withhold from proto-parents. Recall that "ADHD" is likely a conglomeration of subtypes that we have yet to disentangle—but which NGS-facilitated discoveries may soon make genetically discernible. Just as certain genetic markers are correlated with ADHD, we can imagine that subsets of these markers might be correlated with ADHD subtypes. Perhaps a geneticist should only share ADHD-related markers with proto-parents if an embryo is implicated with one of the more severe subtypes: for instance, one defined by extreme social withdrawal, comorbidity with depression, and the absence of positive ADHD-related qualities. Arguably, it would be morally reprehensible *not* to inform the proto-parents about this embryo.

But what of a subtype lacking positive ADHD-related qualities and characterized only by mild inattention? To argue that this subtype should be conveyed to proto-parents—and thus subject to negative selection—is to argue that the only major ethical deterrent to ADHD screening is the association between

ADHD and certain positive qualities. But surely screening on the basis of mild inattention is inappropriate even without the risk of inadvertently selecting against favorable qualities. Screening a mild subtype risks perpetuating the stigma surrounding ADHD, reducing human diversity untenably, and instigating “runaway selection,” whereby the practice of ADHD screening endorses various other traits’ negative selection. These types of concerns are critical to the estimation of a line between genetic markers that should and should not be made available to proto-parents. Subtypes may inform this line in the ADHD case, but geneticists must take care not to release a subtype into the decision room just because it lacks positive qualities (if such a subtype exists), or just because it is more severe than a subtype widely agreed to warrant nondisclosure.

Like the etiology of ADHD, the permissibility of ADHD screening is wound up in both social and scientific factors. Many of these factors suggest that ADHD screening should be prevented in the coming reproductive revolution. First, the recent and unprecedented escalation of ADHD diagnoses results, at least in part, from the condition’s incompatibility with adaptable social constructs like the contemporary school system. The condition seems not to be inherently detrimental, calling into question the suitability of the “Disorder” presupposed by the name “ADHD”. Moreover, positive traits like creativity and mental flexibility are linked to the neurotransmission styles of ADHD-possessor’s brains. ADHD endophenotypes, as intermediate manifestations of ADHD-implicated gene variants, help illuminate the biology underlying various qualities observed in those with the condition. Endophenotypic research may also provide the IVF era with genetically identifiable

ADHD subtypes, making screening more plausibly permissible than it is under the blunter conception of ADHD held today. Indeed, if some ADHD subtypes carry intrinsic burdens that make life unnecessarily challenging for patients and their families, such subtypes' markers may be negative selection candidates that proto-parents have a right to know about in the decision room. Undoubtedly, deliberate moral thinking is required by physicians to decide which markers to disclose, and by proto-parents to decide which embryos to discard. Instrumental to this moral engagement will be a growing, collective understanding of ADHD genomics and of the ways in which ADHD, conceived as such, represents a societal figment.

Conclusion

My project concerns philosophy in the sense that there are no clear guidelines with which to answer the questions I raise. Indeed, considerations of the form, “what should be done about future bioethical concern x?” are not neatly resolvable for a number of reasons. First, future concerns specific enough to possibly permit concrete resolutions must also be proportionately speculative. For instance, the relatively less speculative concern that NGS technology could catalyze morally problematic changes in reproductive practice is too broad to address directly; whereas the relatively more specific concern that mild ADHD subtypes may be subject to negative selection is too speculative to be resolved intelligibly. Such is the nature of zeroing in on a hypothetical, albeit anticipated, near-future reproductive zeitgeist.

Another reason that the moral concerns herein are not easily addressed involves the diversity of morality itself. As we have seen in the introduction, many of the numerous reproductive bioethical outlooks are somewhat incompatible with one another. My ethical inquiries do not stem from one outlook in particular, but any concern I raise may be viewed with a different degree of urgency than I attribute to it. Moreover, other competent thinkers might disagree that a concern I raise is actually concerning; or, alternatively, they might believe a certain concern is notably and problematically absent from my project. In light of these obstacles between asking and answering questions about future reproductive bioethical issues, I focus on thoughtfully elaborating the questions: my project is not a policy memorandum that proposes which traits should and should not be screened, but rather a philosophical

discourse that explores to what we should be morally attuned as modern genomics and reproductive medicine converge.

Recall the basis for this convergence: whole-genome sequencing by NGS is projected to exponentially decline in cost and to facilitate the discovery of numerous genetic markers. In turn, utilizing IVF and embryo sequencing will allow proto-parents greater control over the children they beget. Just as prenatal testing is embraced today by the mainstream as an invaluable reproductive tool, so too will PGD become indispensable for many proto-parents. The tension between what PGD could and should provide for proto-parents is of primary interest here: likely, NGS will improve such that many more genetic correlations could be identified than should be used as criteria for selective implantation. Bioethicists are thus responsible for preemptively investigating the permissibility of geneticists' pursuit of and proto-parents' selection against certain genetic markers.

I discuss some of the ways bioethicists systematize such investigations in the latter portion of the introduction. Many bioethical frameworks incorporate the classical moral theories of utilitarianism and deontology, as well Aristotelian ethics and virtue theory. Beauchamp and Childress' principlism, which generates criticism today as a problematic foundation of modern medical ethics, emphasizes the interests of the patient. Bioethical pragmatism and feminist bioethics also prioritize the patient, but they are conceived as a response to the alleged inadequacy of principlism; their respective positive arguments have to do with how to more effectively incorporate moral theory into medical practice. While pragmatist and feminist bioethicists have not primarily concerned themselves with high-technological genetic

intervention in reproductive medicine, their perspectives are highly relevant to this issue and could prove instructive. Additionally, virtue bioethicists have explicitly articulated frameworks for ethical screening and proto-parenthood; whereas Confucian bioethicists and certain fundamental religious authorities wholly reject IVF and PGD for these procedures' incompatibility with established metaphysical conceptions. My own bioethical inquiries are partly shaped by this myriad of divergent and overlapping bioethical outlooks.

Recall that Tay-Sachs and sex function as controls in this philosophical experiment: it is largely uncontroversial that selecting against the former and *not* selecting for the latter are ethically defensible practices. As the main case studies, spina bifida, T2D, and ADHD represent traits for which selection is relatively more controversial. Spina bifida is the only one of these traits screened for today. Chief concerns arising from systematic selection against spina bifida include the trait's typical absence of cognitive impairment, and the notion that much of what makes spina bifida disabling derives from our societal failure to accommodate it. A handful of genetic markers for T2D and ADHD have been identified, but screening for these traits is prohibited today. Concerns arising from the T2D case involve the trait's typical adult onset, its disproportionate genetic prevalence in blacks and Hispanics, and its substantial and reducible environmental risk factors. With regard to ADHD screening, primary concerns include the trait's associated positive qualities and the societal aggravation (and thus, theoretical reversibility) of its negative qualities. Selecting against spina bifida, T2D, and ADHD alike is morally problematic more broadly for reducing human diversity and further tainting the social perception of

people who possess these traits. Yet arguments *for* selecting against spina bifida, T2D, and—perhaps to a lesser extent—ADHD, must not be overlooked: such arguments have to do with the intrinsic disability conferred by these traits as well as the financial burden they bear on families and health care systems. In hashing out these concerns, I provide a model of the deliberation that will be required to construct a moral decision room in the IVF era.

Certain general strategies must be employed in deciding which genetic information should be researched or made accessible to proto-parents. First, we must appreciate the influence that reproductive bioethics and genetics have on one another. Just as genetic advancements can vitalize moral concerns, moral concerns can instigate new courses of genetic research. Consider the TCF7L2 gene variant linked to T2D: this correlation raises the concern that TCF7L2 might be used as grounds for negative selection before environmental risk factors linked to obesity are resolved, representing an intervention that is harmful in its misplacement. In turn, this concern might spur genetic research on the degree of metabolic disruption caused by the TCF7L2 variant: if people with the variant are extremely prone to excessive weight gain, the variant becomes a more justifiable negative selection candidate; whereas if the metabolic abnormality conferred by the variant can be mitigated by avoiding a sedentary lifestyle and a hypercaloric diet, the original concern holds—environmental risk factors must be addressed before we even consider incorporating the TCF7L2 variant into PGD tests.

The scenario above begins with a genetic correlation. For an example of the mutuality of ethics and genetics that begins with a moral concern, consider the notion

that ADHD markers might also underlie valuable personality traits like creativeness, thereby fortifying arguments against ADHD screening. Such a concern regarding positive ADHD-related traits might then prompt research on the relevant endophenotypes. Suppose an endophenotype representing a neurotransmission style that confers inattention and creativeness is *also* found to implicate propensity for comorbid depression: the original concern about protecting the creativeness gene is thus complicated by the prospect that this gene increases its possessor's chance of suffering feelings of worthlessness. To be sure, that this gene is linked to depression does not necessarily make it permissible to select against; yet the force with which "creativeness" initially bolstered the argument (that this gene should not be a negative selection candidate) may be neutralized by the effect of "depression". Evidently, reproductive bioethicists and genetic researchers must be closely attuned to each other's work. To be most effective, bioethics cannot simply regulate genetic science; it must also actively respond to genetic advancements by proposing subsequent research that could help clarify a moral concern.

The construction of a moral decision room is also contingent upon reproductive bioethical efforts to spare proto-parents from the "prisoner's dilemma" that I mention in the previous chapter. Social pressure to select against certain genetic markers must be absolutely minimal if proto-parents are to make decisions that represent their own interests, and that will help maintain human diversity in the long run. Conversely, if proto-parents believe that neglecting to select against a certain genetic marker will place their prospective child at a disadvantage (because other proto-parents are selecting against this genetic marker), then they too will be

inclined to select against it. This scenario instantiates the prisoner's dilemma in that many proto-parents would prefer to live in a world with this genetic marker and its associated trait, and yet the absence of a platform for cooperation results in competitive decision making and a less desirable outcome for all (i.e., the greatly diminished occurrence of this trait). A task of reproductive bioethics, then, is to facilitate proto-parental cooperation. This may be achieved by regulating genetic information such that no proto-parent has access to genetic markers that 1) are prone to peer-pressured negative selection, and 2) underlie traits whose systematic reduction would constitute a real loss in human diversity. Whether a genetic marker meets these two conditions is not an exact science, but reproductive bioethicists may avoid harmful misjudgments by erring on the side of deeming a questionable genetic marker unfit for incorporation into PGD tests. The marker linked to a mild ADHD subtype, for example, seems to meet the above conditions and therefore might be best kept quiet (if researched at all). As we approach an IVF era, avoiding the prisoner's dilemma is one useful way to conceptualize the candidacy of a genetic marker for admission into the decision room, and for potential negative selection.

As a medic in the Vietnam War, Human Genome Project architect Craig Venter swam more than a mile out to sea with the intention of drowning; he ultimately changed his mind and swam back (Adams 2010). Without Venter, how much longer might it have taken to sequence the human genome in its entirety? The Project was only completed 13 years ago: if Venter's competitors were delayed enough by technology or finances, the buzz around the genomic revolution might

have come too late to provide the impetus for my own project; this page might have been lined with words of a different topic.

Through Venter's near death, we see how irreversible decisions bear permanence by instigating timeless casual chains of events, or the butterfly effect. The proto-parental decision room epitomizes such irreversible decision making: potential human life and all it entails begins or ends with the words "implant" or "discard". It is with this weight that we must ensure genomic insight and reproductive medicine are fused in a morally sound way; in the bioethical realm of pre-birth intervention, moral blunders are never correctible and always amplified. And ethically attuned decisions regarding pre-birth intervention are amplified just as much.

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