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Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability

Curiosity and pregnancy go naturally together in human experience; indeed, the former is no less primal and fundamental than the latter. And for as long as humankind has enjoyed even a rudimentary understanding of the biology of childbearing, the wonder of that process has been inseparable from the wondering that has accompanied the period of invisible gestation—wondering if the pregnancy will persist until birth, worrying about how mother and child will fare, guessing what the child will look like, trying to discern if it will be healthy, imagining how it will change the life of the family, and wondering about its destiny. With wondering comes watchful waiting and an attitude of expectation tinged with uncertainty. Ordinary language still registers this set of linked attitudes when we say colloquially that a pregnant woman is “expecting.”

These elements of the human experience of pregnancy and prenatal development cannot be merely fortuitous. Nor does it seem possible that they have no bearing on the reaction of adults—the mother, to be sure, but also the father and others who socially make up what will be the child’s primary care-giving community—to the baby once it is born. The cultural meaning of pregnancy and the experience of it by closely attentive adults is not a mere prelude to the child-rearing practices of a society, but is inextricably bound up with them.¹ Expectation binds in advance. And while the traditional speculations of the prenatal period can lead to disappointment at birth, it is nonetheless remarkable how quickly adults will focus on newborn traits that fulfill hopeful expectations and tend to ignore those that do not. Bright eyes quickly replace big ears as the topic of conversation among relatives and visitors to the nursery. Of course, some traits are too serious or consequential to overlook, and some disappointments persist. But for the most part, the social/psychological time of pregnancy makes the family ready to accept

the newcomer, who after all has been a presence in several adult lives (not only the mother’s) for some time.

A moment ago, I referred to “invisible gestation.” That notion requires qualification. The physically hidden aspect of pregnancy has certainly been a part of its human fascination and mystery. One can only speculate what course human culture and evolution would have taken if the female body were transparent and if fetal development had taken place in the public gaze. But from the earliest times people have found ways to make the invisible visible. Soothsaying and other arts of divination have been employed to make predictions about the future child. Looking for tell-tale signs by studying material thought to have some connection with the mother or the child, whether it be the entrails of spirit animals or the color or consistency of the woman’s excrement, is an age-old practice. Among women in virtually all cultures a folk wisdom has developed concerning how a pregnant woman could glean information about her baby from its movements and from her own emotions and bodily responses during pregnancy.

The science of modern obstetrics and gynecology may have become the predominant means we have of making the invisible visible and the unknown known today, but it has not completely displaced other modes of knowledge and folk wisdom. Nor is there any reason why it should. Nonscientific—perhaps I should say nonmaterialistic—modes of knowledge may not be reliable guides to therapy and medical decision making, but pregnancy is too intimate and too significant an event within the family and within the culture to have its meaning exhausted by science. The curiosity it generates will not be satisfied by materialistic formulations and representations alone. The folk wisdom, personal interpretations, and tacit knowledge that are inevitably spurred by pregnancy continue to have psychological and cultural value and meaning even in an era when those forms of knowledge have been discredited by science and modern medicine.²

Thus, the inner workings of human pregnancy and gestation have never been entirely invisible or impenetrable to the prevailing forms of knowledge. This is far too important a topic for curious humans to leave alone. Nonetheless, there is a sense in which the veil covering gestation has been lifted more radically in recent years than ever before in human history. Physical technologies that generate images from reflected sound, so-called sonograms, and biochemical technologies that generate information about the fetus’s genotype and chromosomal structures, prenatal genetic testing, are two scientific advances that have made

gestation visible in unprecedented ways. As the Human Genome Project has prompted new research on gene sequencing and mapping, new genetic markers for disease and disabling conditions have been discovered. At present there are tests for genetic markers associated with some four hundred conditions. The number of such tests increases almost daily, and technological developments now in the offing suggest that future testing will be both less costly and less risky or invasive.³ The pressure to use such testing even in the absence of other risk factors, such as family history or parental age, will surely mount. Making the invisible visible, and structuring our moral perception of pregnancy, childbearing, and disability in particular ways—these are the leitmotifs of prenatal genetic testing I explore in this chapter.

If we are attentive to these themes, we shall be reminded that sometimes the practice of ethical deliberation requires a strategy of indirection. One needs to defer a direct assault on specific moral and policy questions until we have taken stock of the tacit assumptions informing those questions and the way in which they are typically posed. How can society balance reproductive rights and procreative liberty against the equal recognition and respect due persons with disabilities? Should access to prenatal testing for certain conditions be curtailed or even prohibited altogether? Who should decide, and on what basis, which prenatal genetic tests will be made widely available and with what kind of counseling to accompany them?

Who among us has the wisdom to answer such far-reaching questions? They go to the heart of human choice, parental responsibility, and the exercise of conflicting freedoms in our society. Rather than attempting an answer to them, my purpose here is to circle around and behind them, while making the familiar seem strange. I do this because I am persuaded that there is something fundamentally amiss in the very way we have fashioned ethical and policy questions regarding the use of prenatal genetic testing technology. The problem is not so much that these questions are hard to answer (although they are), as it is that they are often framed in a peculiarly naïve way, a characteristically American individualistic way, if I may say so. The trouble with the ethics of prenatal genetic testing is that the more we talk about “ethics,” the more our moral sensibilities and moral insights are attenuated, and the more our moral deliberations are blind to the background influence of the reality-constituting power of the technology itself. I believe that one task of a bioethical analysis should be to call that particular framing of the problem into question.⁴ It is important to work toward the

development of a different interpretative framework, a different angle of vision, that brings technological power more squarely and directly into ethical deliberations, both those conducted by expectant couples and their physicians and other counselors, and those conducted by the society as a whole at the policy-making level.

Before discussing prenatal genetic testing in more detail, I want to sharpen the distinction drawn above between two different types of ethical analysis. One approach, by far the most conventional and commonly found in the literature of the field of bioethics, takes the interpretative frame of individual freedom of choice for granted and proceeds from there. If the use of a particular technology is involved, the technology is assimilated into the universe of choices among which the individual agent can choose. The burden of discussion then falls into two parts. First, should any limitations or constraints be placed on the freedom of the individual agent in her choice making? Second, what should the agent choose, that is, what choice(s) should she make?

The Freedom of the Chooser

In consideration of the first question there are typically two outside agencies or forces pitted against the individual with his own internal values, desires, and conscience. The first of these forces is the coercive power of the state and the society with its laws, incentive systems, and rewards. The second of these forces is the influence of the surrounding culture and belief systems that affect the individual, including the norms of religion, custom, and tradition, and the pressures of conformity with the behavior of others.

These are classic questions of freedom in liberal political philosophy.⁵ And insofar as our contemporary habits of mind in bioethics still bear the stamp of the liberal philosophical tradition, the burden of proof will be on these “outside” forces of law or custom. What consideration is important enough to justify overriding the freedom of choice and freedom of conscience of the individual? The only unambiguous answer to that question in our public morality today is some variant of the classic answer John Stuart Mill gave over a century ago, namely, harm to others.

Another sometimes persuasive form of justifying a social limit to freedom is the notion of harm to self. Here the issue is usually not so much whether freedom can be overridden as whether a free choice is really being proposed in the first place. In order to justify constraining

the individual's preferred choice, it is necessary to show that the choice or action in question does not really express the values and identity of the agent himself, either because there is some deficiency in his information or understanding, because there is some background coercion at work, or because the agent's rational faculties are diminished and therefore the individual should be protected from doing harm to himself, even if there is no likely harm to others involved.

Thus, simply deferring to a person's assertion of freedom might not be the ethically justifiable thing to do in several types of situations. For instance, we might prevent someone from making a donation to a fraudulent charity. Or we might prevent a person from committing an action that we discover is being motivated by blackmail. Or we might prevent an intoxicated person from driving home after a party even though he insists on doing so.

What Should the Chooser Choose?

If no ethical justification can be found for outside forces to override the freedom of the individual to choose in light of his own values, interests, desires, and conscience, then the question that ethical deliberation must focus on is the justification of one choice rather than another. But by the time one gets to this point in the analysis, little remains to be done. By definition, the choice now in question is taken to be a socially harmless, authentic, rational, and self-regarding one.

It is not clear what remains in the interior of a person's moral conscience since social and cultural norms have been treated as external constraints and have been determined to play no morally decisive role. Ethical deliberation, and the role of the ethicist as counselor or advisor to the individual, becomes little more than a rational balancing of competing desires, interests, or radically private, idiosyncratic values. An outward, public moral life that is conceived as essentially a struggle for power and control goes hand in glove with an understanding of an inner moral life that is hollowed out and a conception of moral deliberation that has more in common with *techne* in Aristotle's sense (the efficient manipulation of technical information) than *phronesis* (mature reflection and deliberation contemplating a practical action in the world).⁶

In sum, when bioethics adopts the frame of individual choice on any given issue involving the use of technology, the default assumption will normally be that the technology, having been shown to work and

having been made available, is morally permissible; it is a *prima facie* moral option, so to speak. This individual choice frame assumes, in other words, that the technology will naturally and necessarily be in demand, that it is on balance better to have it than not to have it, and that individuals who have a reasonable interest in using the technology should be given access to it, subject to their sharing a fair burden of its cost and maintenance. The burden of proof will normally be on those who would justify limiting access to, or the use of, the technology for some reason. Bioethics will examine any and all arguments purporting to justify such limits on the technology, and bioethics will adduce the private moral reasons pro and con for an individual decision to use the technology in a given instance or life circumstance. From mechanical ventilators, kidney dialysis, and other life-extending technologies to experimental organ transplantation and genetic testing, across this spectrum of biomedical technologies bioethics has adopted this frame of individual freedom and rational choice and has deployed its armamentarium of concepts and categories drawn from various types of ethical theory and moral philosophy, mainly those growing out of the British analytic tradition.⁷

An alternative approach to ethical analysis would not focus on being altogether so "practical" or decision specific in the first instance, but would rather call attention to the very way in which the issue and the moral problem is being framed, both by those writing in the field of bioethics, and, more importantly, by the professional shapers of ideas in our society more broadly—voices from the medical and scientific professions, from government and private industry, and voices from special interest groups who adopt an adversarial interest in relation to the new technology or in relation to the underlying medical conditions the technology will affect.

This enterprise, as akin to social and cultural criticism as it is to ethics, will focus on the dynamics and implications of locating values questions about biomedical technology and its use in one conceptual frame rather than another.⁸ How comprehensive a conception of "technology" does a given frame presuppose? What kind of relationship is postulated between the technology and those who make use of it? How are the conditions of choice and moral agency to be understood, and what is taken to be integral to those conditions and what is taken to be merely incidental? What alternatives to the frame of individual freedom of choice exist for social critique? Can such a frame and such

a language of social critique be deployed without sacrificing important liberal and pluralistic values upon which a free and open society depends, and without unduly limiting the human right of all persons to improve the quality of their lives by availing themselves of the benefits of scientific and technological progress?

These are daunting questions. Hugging the shore with conventional liberal bioethics may seem an attractive option if it spares us the toil, indeed the danger, of exploring them. Yet the costs of forgoing this more ambitious exploration of the common sense behind the very questions we pose about biomedical technology, with the hypothesis that these questions are neither neutral nor innocent, are substantial. Chief among them, I think, is the illusion of freedom that is created when we underestimate the reality-shaping power of biomedical technology and its implications for the kind of parents, citizens, and human beings we are.

Assumptions Behind the Conventional Wisdom

I believe there would be widespread agreement in our society today with the following proposition:

Prenatal genetic testing is a technology that can assist prospective parents in exercising their freedom of informed choice in reproductive decision making. The main problem with prenatal testing today is that the information the available tests provide is subject to inaccuracy and misinterpretation. False negatives are possible because genetic impairments can often originate from more than one site; positive findings often will not be sufficient to predict the probability, timing, or severity of symptomatic disease during the child's lifetime. Thus, no one course of action by prospective parents logically or ethically follows from most test results. Reproductive decision making in the face of predicted genetic impairment is highly personal and intimate.

As the technology improves, the information it provides will become more accurate, specific, and reliable. And even though medical therapies to prevent or cure symptomatic disease may still be lacking, advance warning of the possibility or probability of genetically associated disease in the child's future is still valuable for prospective parents who may wish to factor it into their family planning, financial, and career decisions. Although painful, knowing about a prenatal genetic impairment is rationally preferable to not knowing.

This portrait of the moral situation posed by prenatal genetic testing amounts to the conventional wisdom in mainstream professional circles and even at the grassroots level among those who have some information

about genetic testing. It contains several implicit assumptions that should be singled out for our purposes here.

One assumption is that genetic testing technology is a morally neutral tool or instrument of individual decision making and choice. The technology carries with it no intrinsic value commitments, either positive or negative, concerning whether to terminate the pregnancy or allow the child to be born and to undergo the predicted disease or experience of disability. Technology is a tool and hence not an appropriate object of ethical evaluation in its own right. Test results are true or false, but not moral or immoral. And human choices and actions can be judged from a moral point of view, but not the technology (or technologically mediated information) that informs them.

Another assumption is that the main technical problem pertinent to an ethical assessment of prenatal genetic testing is the quality of the information the technology provides. Indeed, the only role of technology (genetic testing and background theories of the genetic contribution to disease) in this story is to provide information. To be sure, the quality of this information leaves much to be desired and creates a number of moral quandaries due to its uncertain and probabilistic character. But it is never considered to have any morally significant role other than as a source of information about the child's future health. And the limitations in the knowledge provided are assumed to be a function of the undeveloped state of the technology itself, which in principle is subject to progressive correction and improvement. In other words, the ethically problematic nature of genetic knowledge is assumed to be a purely contingent feature of the current and corrigible state of science and technology rather than something inherent in this form of knowing *per se*.

Finally, the reality of genetic testing and reproductive decision making is seen as a radically private, intimate one. Like Mary before them, prospective parents in the genetic testing era ponder in their own hearts the information they receive about their forthcoming child.⁹ On this account, it is easy to lose sight of the enormous public apparatus of scientific research and testing facilities, to say nothing of the enormous public (whether governmental or corporate) investment and expense that genetic testing technology represents. It is breathtakingly implausible, as a matter of fact, to characterize the use of genetic testing in obstetric practice in our society as a "private" act in any sense.

Even more telling is the assumption that each parent must somehow find her own meaning in the prospect of a predicted medical and social

future for her child. Through years of social conflict and controversy over the woman's legal and moral right to have an abortion, our society, for good or ill, has come to rest on the belief that the decision to continue a pregnancy is a radically private one, and we assume an incommensurability of moral meaning among women in our pluralistic society on this existential question. This resting point on abortion has come to spill over and to color all of our thinking about reproductive decision making. If there are no broader cultural resources for a woman (or a couple) to draw on when it comes to terminating a pregnancy, if the woman must fall back upon her own moral interiority in the face of *that* decision, why should we expect it to be otherwise when a woman (or couple) has to contemplate the reality of rearing and caring for a child with a severe chronic illness or disability?

Given this framing of the issue, it must be the case that decisions about the continuation of pregnancy in light of prenatal genetic tests do not admit of questions of public morality at all. For there are no permissible paradigms of parental virtue or responsibility available in the public moral life of a secular, pluralistic society upon which parents can draw. Even most religious traditions are hesitant to insist on mandatory, prescriptive teachings in so emotionally fraught and theologically turbulent an area, allowing believers to fall back upon prayer and their own consciences as they struggle to decide how great a burden of caregiving they are able to shoulder and how much suffering they can permit their child to be subjected to.

In a culture where questions as fundamental as these are thought not to admit of public interpretation or social guidance, the pressure is enormous to turn to technologically mediated "facts" to push us in the direction of one decision or another. And the more this happens, the less plausible it becomes to maintain that the technology that generates these "facts" is merely a morally neutral tool that plays but an instrumental role in the decision-making process. The more secularized reproductive decision making becomes, the more technology ceases to be a side show and the more it becomes the main event.

Earlier I identified three assumptions implicit in the conventional wisdom concerning prenatal genetic testing. These were (1) the value neutrality of the technology; (2) the problem of unreliable knowledge; and (3) the radical privacy of contemplating genetic impairment in the unborn child. I propose to discuss the first two points now and then return to the third point at the end.

Technology as Tool, Technology as Power

Why has the understanding of technology as a value-neutral tool been so persistent in American thinking and the reality-shaping effects of technology so tenaciously overlooked? One important reason lies in the narrow, one-dimensional way the concept of "technology" is defined in most discussions and in the popular consciousness. Technology is equated with one aspect of its physical manifestation, namely, it is defined as machinery or gadgets. This leaves out a much more fundamental conception of technology as a system of knowledge, a system of institutional social organization, and a system of power.¹⁰

For example, the factory system of mass production manufacture is a "technology" in the proper sense of the term. It is an integration of various bodies of knowledge, from physics and chemistry to industrial psychology and time-motion studies, with various forms of hierarchical social organization (radically different from the organization work in preindustrial workshops or agriculture) and various types of machinery. This technology is held together by a form of authority and power that demonstrates its enormous capacity to structure human lives as well as to fashion natural raw materials into market commodities.¹¹ To equate the "technology" of the industrial era with devices such as the steam engine, the drill press, or the conveyor belt is far too narrow a perspective to be of much use for social or historical analysis. Even so, the "machine" can be a powerful symbol—technically a synecdoche (a rhetorical figure in which the part stands for the whole)—of the factory system as a technology or a system of power. In this regard, one thinks of the remarkable portrayal of the struggle between the worker and the giant cog wheels of the machine in Charlie Chaplin's "Modern Times."

To analyze technology and its effects in terms of a system of power and a specific pattern of socially institutionalized interaction among several persons is to depart from the perspective that puts discrete individuals (or dyads like the so-called "doctor-patient relationship") and separate decisions or choices at the center of attention. If Heidegger's work on technology arguably went too far in eliminating individual human agency altogether in favor of a superindividual force at work in history, contemporary American thought surely errs at the opposite extreme in its affection for market models and rational choice theories in which any notion of technology as system has no place.¹²

Prenatal genetic testing is not best understood as a value-neutral instrument of individual choice. It constrains choice in the subtle ways, and it helps to define the very situation as one that calls for choice making rather than some other mode of mental orientation and response (e.g., meditation or prayer and watchful waiting; or seeking out conditions of solace and mutual support with others). It calls forth the executive functions of our culture, in sometimes exaggerated degree: when the presence of technology presides over the scene, someone must take charge of the situation, no drift or indecision is to be allowed, logical order must be restored to behavior under stress and at risk of dissolution. Technology demands a response; it does not necessarily force any particular choice, but it does force choice in general. It is a commonplace to observe with virtually any technology that once it is available, then, like a genie out of its bottle, it cannot be undone or put out of the sphere of social reality. So the very existence of prenatal genetic testing for a given condition to some extent changes the moral status and cultural valance of that condition if it later appears.

Suppose a couple is offered a test for Tay-Sachs and decides to forgo it. If the child eventually becomes symptomatic with the disease, that cannot be considered a tragic surprise or shock to the parents, but rather stands as an example of willful and deliberate ignorance. No matter how understandable and justifiable the decision not to be tested may be, since the available cultural interpretation of what the onset of the disease means in the parents' life is not the same, the range of available cultural reactions to it cannot be the same either. There is a subtle cultural difference between, on the one hand, the kind of sympathy we give when someone receives sudden bad news that could not have been known in advance, and, on the other, the kind of sympathy we give when someone finds out something awful that could have been known before and could have been altered, albeit at a psychological and moral cost.

I am not suggesting that sympathy is unavailable to us as an appropriate response in the second case, only that its quality, to paraphrase Shakespeare, will be strained. So, to some extent the very existence of a prenatal test places a moral onus on those who choose not to use it because they cannot say later that they had "done all they could" to alleviate or avoid the trouble.¹³ Of course, if they say at the time of refusing the test that they are prepared to accept either an impaired or an unimpaired outcome with their baby, then sympathy is probably the wrong cultural response to the outcome anyway. But even then their

equanimity in embracing the baby regardless of its health status is not the same as the apparently identical response of surprised parents before the test was available. There is a reflective, calculated quality to the former case that is lacking from the more spontaneous temperament of the latter.

With testing, everything must be deliberate and everything is a decision. Nothing about the pregnancy seems just to happen by itself, to just be a given that we have no choice but to accept and deal with. Prenatal genetic testing technology shapes choice by in effect making everything into a choice. An ethical analysis that looks only at the dynamics of the interaction between the decision-making individual and others who seek to advise or shape those decisions is a fish that can't imagine water.

Knowledge and the Genetic Imaginary

A particular backward glance at a concern characteristic of the individual freedom of choice frame may be helpful at this point. Nothing I have said thus far relies on the violation of the principle of nondirective counseling that is a cardinal tenet in the genetic counseling field. I am talking about the influence of the background presence of testing technology on the space within which nondirective counseling is supposed to take place. I understand nondirective counseling to be a form of discourse and dialogue in which the professional counselor refrains from injecting his or her own personal biases or value judgments into the counseling dynamic. Nondirective counseling is also a norm of discourse according to which the professional does not exploit his or her professional authority in order to steer the client toward a decision that the counselor favors. So understood, I have no reason here to take issue with that professional ideal.

However, in a broader sense genetic counseling cannot be completely neutral or nondirective because the basic grounding of its professional discourse already derives from the genetic science and technology. The counselor (and the physician, who often takes on the role of counselor, *faute de mieux*) mediates between the client and the technology.¹⁴ And this mediation is largely a one-way street. The genetic counselor's task is to adapt the attention and focus of the prospective parents to the information that the technology provides and to the way it structures that information. The counselor is in no position to make the genetic testing industry accommodate itself more fully to the educational and emotional needs of couples faced with the prospect of rearing a chroni-

cally ill or disabled child. Genetic test results do not come with psychosocial information or folk knowledge gained from experienced parents about how best to nurture and develop a child with a particular kind of disability.

All systems of knowledge focus and exclude, and genetics is no exception. It is the rare genetic counselor who supplements the order of this technology and this knowledge with technologies and bodies of knowledge from other realms of human experience. Of course, they are not trained to do this, there is not enough time in the clinical encounter as it is now structured in most programs, and like all specialists prenatal genetic counselors can make appropriate referrals. My purpose is not to fault genetic counselors, but these factors and limitations of their practice confirm my basic point. The counseling may be neutral as regards the personal beliefs of the counselor, but it cannot be neutral as regards the very context of genetic technology itself. Far from being neutral in that regard, genetic counseling is constituted by that technology. Indeed, prenatal genetic testing is itself an aspect of the broader medicalization of pregnancy that surrounds pregnancy with the discourse of disease, danger, risk, and defensive measures against misfortune.¹⁵

This being the case, when both the testing and the discourse of genetic testing and counseling enter the domain of the existential experience of pregnancy, important consequences follow. The technology and discourse of genetic testing create a new social and discursive reality, which then becomes the touchstone and the reference point for all the information the parents receive and all the decisions they make from that point forward. And it is a strong-willed parent who can resist having this powerful reality-shaping force become the *only* reality of the pregnancy. Those who can do so are those who have a previously affected child perhaps, or those who have a strong, principled commitment not to discriminate against or to undervalue the lives of those with disabilities, or those with a deep religious conviction against abortion. And those parents, a cultural and ideological minority in America today, may successfully resist the reality-shaping force of prenatal genetic testing technology because, having refused the testing a priori, they avoid exposure to this information and this discourse during their pregnancy.

For a majority of women and couples, however, prenatal testing, when indicated, will continue to be the rule. Many discussions of the ethics of genetic testing see nothing worrisome in this state of affairs that could not be cured by more complete genetic information and a

better cognitive comprehension of that information. The underlying intuition is simple: good decision making depends upon accurate and reliable information. Improving the quality of information and enhancing the quantity of the information prenatal genetic testing can provide can do nothing other than lead to improved—that is, more rational and morally responsible—decision making by prospective parents. In the frame of individual freedom of choice, more information is always better than less.

Now, it is not easy to argue with this proposition without appearing to defend ignorance and irrationality. Making the case for these is not a promising task. Nonetheless, if we frame the meaning of genetic testing outside the perspective of individual freedom of choice and in a more communally oriented way, it is possible to argue that more information is not always better than less if the increase has the effect of narrowing our range of moral vision and attention to the point where some of the broader goals and interests of others or of the community as a whole are lost sight of.

Again, just as technology is not a mere instrument or tool for use by an agent, but is, in fact, an active force shaping that very agency itself, so, too, is information. Genetic tests do not provide simply “information” as some passive tool or raw material of decision making that individuals (either professionals or laypersons) are in complete control of during the decision-making process. Genetic tests provide a highly charged and theory-laden form of knowledge that structures our perception of our physical bodies, our social selves, and our temporal futures in selective and distinctive ways. And this form of knowledge also structures the perception of the bodies, selves, and futures of our unborn children.

Such knowledge is not only a benefit, although a benefit it may be. It is also a danger and a burden. As it shapes our intellectual and moral perception in one way, we need a counterpoise to shape that perception in another way, an internal gyroscope to keep our moral balance. For the practice of parenting begins during pregnancy, not at childbirth, and as a moral practice it requires a balance, a breadth, and a multifacetedness of perception. Parenting requires white light, not light of a single color on the spectrum bent by the prism of a particular science and technology.

The kind of active, shaping knowledge that genetic testing provides creates a world within the human mind, a world validated by the leading intellects, scientists, and professionals of our time. Because it is an

intellectually constructed world does not mean that it is not real. And because I stress the sense in which genetics constructs rather than reflects some underlying natural reality about human biology, this does not mean that genetics is somehow not true, real, or scientific. The notion that reality is theory laden does not mean that there is no reality, only illusion. On the contrary, the illusion is the positivistic one that believes science can offer something better, more pure, than this.¹⁶

The world that is constructed from the information provided by prenatal genetic tests is a "genetic imaginary" of the future child. Looking at it in this way will help us to better appreciate the morally two-edged character of this knowledge and give us a purchase on why more information of the same kind might not necessarily be better. Moreover, it suggests that the key ethical problem with prenatal genetic testing is not really incompleteness or unreliability of the information parents are offered, but the humanly one-sided and morally corrupting effects of this knowledge relative to the entire range of realities and possibilities that the moral imaginations of prospective parents should be exploring.

The genetic imaginary is not a picture of the child or even a fragmented image of what the child will be. It is not open to exactly the same epistemological critique that Susan Sontag leveled at realistic theories of photography and that can be applied in a rather straightforward way to show the fallacy of taking a sonogram to somehow be a picture or a direct representation of the unborn child.¹⁷ (It also provides a way of critiquing the claims made by right-to-life groups several years ago on behalf of the sonogram-based video "Silent Scream.") Instead, the genetic imaginary is the basis for the possibility of conceiving the reality of the future child at all.¹⁸ In this sense it has more in common with the art of caricature than it does with portraiture. It is a selective focus on certain traits to capture the essence of the self.

Another way to grasp what I have in mind by the genetic imaginary is to relate it to the homunculi produced by *Scientific American* in 1948 based on the work of Wilder Penfield, a Canadian neurosurgeon who pioneered the use of electrical stimulation to map functions on the human cerebral cortex. Using brain maps of both sensory and motor functions, images of the body were constructed with body mass roughly proportional to the area of the brain devoted to these functions. Both the sensory homunculus and the motor homunculus are wildly misshapen creatures. The sensory figure has enormous lips, enormous hands and feet, and an especially outsized thumb. The motor figure likewise has

an enormous face and large hands with huge thumbs. In both cases the torso and lower body parts are withered and tiny.¹⁹

This is what the genetic imaginary based on the information given by prenatal genetic testing does. It offers to the mind's eye of the parent a homunculus shaped by the exclusive emphasis on some particular DNA sequence(s) and some particular biochemical processes associated with that sequence. If we look at our bodies only from the point of view of how much of our brain is devoted to motor coordination we will find that evolution has paid great attention to our facial muscles and to the musculature of our hands with dexterous fingers and an opposable thumb. These are surely excellent traits to have in a bipedal, social animal who fabricates and uses tools with its hands. But we would be very surprised when we met our first human being if this is all the information we had about her in advance.

The genetic imaginary does little mischief when the test results are normal, for in truth it evaporates from the parents' minds rather quickly as they turn to other sources of imagination in contemplating their future child. But in cases of abnormality and high likelihood of significant impairment and disability, the homunculus offered by the genetic imaginary can easily dominate the parents' vision. And this, as I indicated before, can have a morally corrupting effect.

Why? Not because the genetic information is invalid or is being misinterpreted. But because the imagined reality of the future child with a disability is being wrongly deformed and distorted. We are a society that gives women the right and the freedom to terminate a pregnancy, including those second trimester pregnancies that indicate the presence of severe genetic or congenital impairment. I support this right and believe this freedom on balance is a good thing. But one can support it more confidently in a context in which women are exercising a balanced and well-rounded moral imagination in their decision making concerning their pregnancies.

The reality and the experience of life lived with even severe disability is not simple or one-dimensional. It is certainly a far cry from the homunculus drawn by the genetic imaginary. Prospective parents contemplating abortion after an abnormal prenatal test must have the resources—through their own life experiences, the resources of their family and kinship network, their civic community, the assistance of health care professionals, or perhaps simply their own depth of character and empathy—to supplement the genetic imaginary with a fuller and

more expansive moral imagination. Only out of that imagination can good judgment, sound practical reasoning (*phronesis*), and ultimately just prenatal decisions and choices flow. Only out of that imagination can we strengthen the fabric of solidarity, care, and respect that binds those with disabilities into full membership in our moral community.

The ethical use of prenatal genetic testing technology presupposes the existence of that community and that fulsome moral imagination. If these preconditions are lacking, we allow the wholesale introduction of prenatal genetic testing only at our own peril. In recent years we have made some progress at combating prejudice and discrimination against persons with disabilities, to be sure. Still, at present our society has few positive images of disability lives to bolster and nurture a well-rounded moral imagination. (It is something, by the way, that all temporarily able-bodied citizens, and not just prospective parents, need.) I am not certain that expanded prenatal genetic testing in our actually existing social and cultural environment in the United States will promote it, and there is a danger that increasing the power of this technology could hinder it.

Very few pregnancies go forward in a cultural silence, but medical and genetic discourse is not the only meaning-making language with which a pregnancy can be surrounded. Many parents and families still surround themselves with other types of discourse—religious, ethnic, genealogical, or kinship based—that carry very different interpretations of the pregnancy and that place it in the context of quite different narratives than those offered by medicine and genetics.

Here I confess to being torn. On the one hand, I recognize that inadequate access to excellent, state-of-the-art prenatal care is a major problem in our health care system today, and that universal access to such care is a moral imperative and a compelling public policy goal. At the same time, the plurality of narratives and discourses that surround pregnancy and make it meaningful to women, couples, and families is also a precious—and precarious—state of affairs. Greater homogenization of the prenatal care experience, greater univocality around the discourses of medicine and genetics, and greater exposure to an increasingly sophisticated and far-reaching array of prenatal tests as the technology advances—these are not prospects that we should embrace without significant moral reservation.

Clearly, work must be done to keep prenatal genetic testing limited to proper bounds within the standard of practice of universal prenatal care. Prenatal genetic testing as a technology (in the sense of a system

of power) and corporate economic interest must be challenged and brought under reasonable regulatory control. The lack of systematic national regulation, the virtual frontier state, of this industry and this technology in the United States today is a scandal.²⁰ However, this is not the place to pursue a discussion of regulation and policy reform, and so let me return to the perspective of a broader critique.

Radical Privacy?

No matter how prenatal genetic testing is regulated and deployed in the years ahead, there are several dangers that we must be on guard against. One, already mentioned, is the growing exposure of the experience of pregnancy to a univocal discourse of genetics at the expense of other ways of conveying cultural meaning to human procreation and childbearing, motherhood, and parenthood.

A second related concern is the gradual attenuation of these other narratives of pregnancy and other languages to give it cultural significance and meaning. We must not underestimate the power of science and technology to colonize and dominate the contemporary imagination. As genetic therapy and prenatal, intrauterine surgery develop, and as the spectrum of genetic markers and genetic tests expands, what Abby Lippman has called the “geneticization” of pregnancy will spread and tighten its grip on our tacit knowledge and common sense assumptions.²¹ The implications of this, particularly for those experiencing postnatal disability and chronic disease, will be profound. Indeed, what Lippman calls geneticization is the logical culmination of what I referred to above as the genetic imaginary. Her notion reminds us that many of the problems addressed in this chapter are not limited to imagining the body, the self, and the future of our children, but spread throughout the entire contours of our lives. A genetic understanding of a condition tends to “biologize” and localize what should be understood primarily in social and environmental terms. The Americans with Disabilities Act, for example, is based largely on a social-disability perspective that predates the current wave of geneticization in the popular media and culture. The rights and gains it secures for those with disabilities could be jeopardized if the opinion makers were to conclude that this public policy approach rests on false foundations. Indeed, the ADA is relatively vague when it comes to issues of genetic-related disability and genetic testing. It remains to be seen what future courts and legislatures will do in these areas.

A third concern is that the moral experience and sensibility that women (and their partners and families) bring to the experience of pregnancy will grow thin as a result of the breakdown of civic culture in the broader society and as a consequence of the generalized narcissism of our times.²² In this case, the only life narrative a woman or a couple will have within which to place their pregnancy will be the narrative of self-interest and career. As this cultural narrative and form of moral imagination (if it can be called that) places a premium on the notion of molding or engineering one's adult life as a monument to the self, it will have a natural affinity with geneticization or the notion that we can exercise control, through genetic technology, over the very biochemical architecture of our bodies, or those of our children. This is not an interpretative frame that is likely to offer a place of intrinsic value and unconditional love for an imagined future child with a serious disability. But, at least to me, an essential question remains: Does the problem lie with the child's genetic make-up, or even with the later manifestation of disability, or does it lie with this interpretative frame itself?

It is natural for human beings to be cultural. It is everywhere and inevitably the case that people need to assimilate their experience into systems of ordered meaning and to surround the most biologically and socially important occasions with multiple layers of significance. Pregnancy is such an occasion par excellence. I am not prepared to say to what extent individuals' and couples' freedom to use prenatal genetic testing should be limited; but I do believe that such testing is neither socially nor morally neutral and must be socially regulated rather than treated as a medical market commodity.

Some may read these reflections as a call for constraining curiosity, information, and human knowledge. There are some things that people simply should not know, because the knowledge will lead them into moral pitfalls. In fact, I have little sympathy for that argument, and I do not intend that these reflections oppose the spirit of Prometheus. I simply remember the terrible burden inherent in his gift of foresight. Rather than curtailing the acts of curiosity, knowing, and projecting meaning during the prenatal period, I am concerned that they will become too univocal and one-dimensional. The new genetic discourse, linked as it is to science in a culture that is in love with science, is and will increasingly be a powerful voice in the making of prenatal meaning. It has the power to colonize and to permeate all our thoughts and feelings as we make decisions that will affect the futures of our families.

No fetus is merely a genetic homunculus; each contains many shapes of future possibility and many imaginable lives, with or without disability. Retaining among ordinary women and men in our culture the capacity to see that is the key. A fecund imagination and a rich moral life for all is the route to ethically sound prenatal decision making in a genetics age.

NOTES

1. For a penetrating discussion of the significance of what she calls human "natality," see Hannah Arendt, *The Human Condition* (Chicago: University of Chicago Press, 1959).
2. On the notion of tacit knowledge, see Michael Polanyi, *Personal Knowledge* (New York: Harper Torchbook, 1964).
3. Cynthia M. Powell, "The Current State of Prenatal Genetic Testing in the United States," in this volume.
4. On the concept of frame in social analysis, see Martin Rein, "Value-Critical Policy Analysis," in *Ethics, the Social Sciences, and Policy Analysis*, ed. Daniel Callahan and Bruce Jennings (New York: Plenum Press, 1983), pp. 83-112. See also Erving Goffman, *Frame Analysis* (New York: Harper and Row, 1974); and Robert N. Bellah, Richard Madsen, William M. Sullivan, Ann Swidler, and Steven M. Tipton, *The Good Society* (New York: Vintage, 1992).
5. See, for instance, Joel Feinberg, *The Moral Limits of the Criminal Law*, 4 vols. (Princeton, N.J.: Princeton University Press, 1984-88).
6. For a discussion of the Aristotelian distinction between *techné* and *phronesis*, see Richard J. Bernstein, *Beyond Relativism and Objectivism* (Philadelphia: University of Pennsylvania Press, 1983), pp. 109-70.
7. A more extended discussion of the account given in the preceding paragraphs can be found in Willard Gaylin and Bruce Jennings, *The Perversion of Autonomy* (New York: Free Press, 1996). In this work, however, insufficient attention is paid to the problem of technology and its impact on our understanding of freedom, autonomy, and coercion.
8. Michael Walzer, *Interpretation and Social Criticism* (Cambridge, Mass.: Harvard University Press, 1987) and *The Company of Critics* (New York: Basic Books, 1988).
9. Luke 2:1-20.
10. For an incisive discussion of various conceptions of technology and their use in social and political theory, see Langdon Winner, *Autonomous Technology* (Cambridge, Mass.: MIT Press, 1977). Classic works in this regard are Jacques Ellul, *The Technological Society* (New York: Knopf, 1964); and Lewis Mumford, *The Myth of the Machine*, 2 vols. (New York: Harcourt Brace Jovanovich, 1964-70).

11. E. P. Thompson, *The Making of the English Working Class* (New York: Vintage, 1963).
12. Martin Heidegger, "The Question Concerning Technology," in *Basic Writings*, ed. David F. Drell (New York: Harper and Row, 1977). See also Fred R. Dallmayr, *Polis and Praxis* (Cambridge, Mass.: MIT Press, 1984).
13. See Ruth Faden, "Reproductive Genetic Testing, Prevention, and the Ethics of Mothering," in *Women and Prenatal Testing*, ed. Karen H. Rothenberg and Elizabeth J. Thomson (Columbus: Ohio State University Press, 1994), pp. 88-97; and R. Alta Charo and Karen H. Rothenberg, "The Good Mother": The Limits of Reproductive Accountability and Genetic Choice," in *Women and Prenatal Testing*, ed. Karen H. Rothenberg and Elizabeth J. Thomson (Columbus: Ohio State University Press, 1994), pp. 105-30.
14. See Charles L. Bosk, *All God's Mistakes: Genetic Counseling in a Pediatric Hospital* (Chicago: University of Chicago Press, 1992).
15. Barbara Katz Rothman, *Recreating Motherhood: Ideology and Technology in a Patriarchal Society* (New York: W. W. Norton, 1989).
16. Richard Rorty, *Philosophy and the Mirror of Nature* (Princeton, N.J.: Princeton University Press, 1979).
17. Susan Sontag, *On Photography* (New York: Doubleday, 1990).
18. Cornelius Castoriadis, *The Imaginary Institution of Society* (Cambridge, Mass.: MIT Press, 1987).
19. These images are reproduced in Carl Sagan, *The Dragons of Eden* (New York: Ballantine, 1977), pp. 36-37.
20. Ellen Wright Clayton, "What the Law Says about Reproductive Genetic Testing and What It Doesn't," in *Women and Prenatal Testing*, ed. Karen H. Rothenberg and Elizabeth J. Thomson (Columbus: Ohio State University Press, 1994), pp. 131-78.
21. Abby Lippman, "The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?" in *Women and Prenatal Testing*, ed. Karen H. Rothenberg and Elizabeth J. Thomson (Columbus: Ohio State University Press, 1994), pp. 9-34.
22. Christopher Lasch, *The Culture of Narcissism* (New York: W. W. Norton, 1979).