FROM CHANCE TO CHOICE

Genetics and Justice

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INTRODUCTION

CHALLENGES OF THE GENETIC AGE

A powerful alliance of government, business, and science is propelling society into a new era in which human beings will possess a much greater understanding of the most basic functions of all forms of life. With this understanding will come unprecedented control over living things, including ourselves. Scientific knowledge of how genes work will empower human beings to cure and prevent diseases. It may also let us shape some of the most important biological characteristics of the human beings we choose to bring into existence.

No one knows the limits of our future powers to shape human lives – or when these limits will be reached. Some expect that at most we will be able to reduce the incidence of serious genetic diseases and perhaps ensure that more people are at the higher end of the distribution of normal traits. More people may have long and healthy lives, and perhaps some will have better memory and other intellectual powers. Others foresee not only greater numbers of people functioning at high levels, but the attainment of levels previously unheard of: lives measured in centuries, people of superhuman intelligence, humans endowed with new traits presently undreamt of. One thing, however, is certain: Whatever the limits of our technical abilities turn out to be, coping with these new powers will tax our wisdom to the utmost.

PREVIEWS OF PERPLEXITIES

Consider a few of the perplexities with which the genetic revolution is likely to confront us in the future.

Scenario 1: Genetic Communitarianism

A disaffected member of what the media refer to as a religious cult announces that the group is attempting to implement its vision of the good society by "mass producing" human embryos cloned from the group's leaders. He claims that the group has its own genetics lab and hopes to adapt for use on humans techniques for cloning embryos commonly employed in the commercial production of animals. Several members of Congress express outrage and urge that the government take action against the religious group. A spokesperson for the American Civil Liberties Union says that if we value reproductive freedom and freedom of religion, we must respect the right of religious communities to attempt to transmit their beliefs and way of life to future generations, whether by the traditional methods of teaching and indoctrination or by the application of genetic technology.

Scenario 2: Personal Choice or Public Health Concern?

A single, inexpensive blood test for prospective parents can detect high risk for virtually all serious genetic disorders as well as a broad range of genetic susceptibilities for illnesses. An initiative is afoot to provide mass genetic screening using this test. A government commission examining the feasibility of this proposal notes that the program's cost-effectiveness depends on whether a sufficient number of those tested "act on the knowledge of positive results – that is, whether they choose to avoid conception of affected fetuses." An advocate of the mass screening program says "this is a public health matter; people should not be free to inflict avoidable diseases on their children, especially if we are ever to have an affordable health care system that provides coverage for everyone." An opponent replies that "genetic services of any kind are strictly a matter of personal choice – respect for reproductive freedom requires this. People must be free to act on the test results as they see fit; any program that will result in pressures that limit reproductive freedom would be unacceptable."

Scenario 3: The Quest for the Perfect Baby

Excerpt from the introduction to a dissertation in a history of medicine written in 2040:

In the 1990s, as in the preceding three decades, parents mainly practiced negative eugenics, using tests for major chromosomal defects such as Down syndrome and aborting "defective" fetuses. By 2020 the standards for acceptable babies had been raised: prospective parents routinely aborted fetuses that were otherwise healthy but that had genes that gave them a significantly higher than average risk of breast cancer, colorectal cancer, Alzheimer's dementia, or coronary artery disease. By 2030, the trend was toward even higher standards: Fetuses with any of a range of "undesirable" or "less than optimal" combinations of genes were routinely aborted, including those predicted not to be in the highest quintile with respect to intelligence or even height. Widespread use of these techniques by parents who could afford them began to raise the average level of health, physical strength and stature, and intellectual ability in the population, a trend encouraged by nationalist politicians. But the insistence of many parents that their child be in the upper quintile created a spiral in which no amount of genetic boost ever seemed enough.

Scenario 4: Health Care in the Age of Genetic Intervention

At a congressional hearing, Dr. Philip Jones testifies that the standard benefit package that all insurance companies are federally mandated to offer should be expanded to include what are popularly called "mood enhancer" drugs for all persons who have the "mild depression gene," even though these individuals do not usually meet existing criteria for having bipolar affective disorder. According to Jones, "What is important is whether clinical science can help people live better lives; the fact that a person's mood swings don't qualify as bipolar disorder isn't really important." A spokesperson for the National Association of Health Insurers protests, "Health care coverage stops where treatment for disease ends; there's a right to health care, but there's no right to be happy." Jones, shaking his head with a somewhat patronizing air, replies, "What we now know about the way genes affect the brain and hence the personality renders the distinction between psychiatric disorders and undesirable psychological conditions unimportant."

Scenario 5: The Genetic Enhancement Certificate

Katherine and Bill are applying for the same management position in a large firm. Included in Katherine's dossier is a genetic enhancement

certificate from Opti-Gene, Inc. It certifies that the bearer has "benefited from cutting-edge genetic enhancement technology" and asserts that those who have had the package of services in question on average have fewer colds and other common respiratory infections, are less likely to suffer depression, and score higher on tests of memory skills. Bill, who cannot afford genetic enhancement, protests that "hiring on the basis of genetic enhancement is just as unfair as hiring on the basis of race or gender – it's a violation of equal opportunity and makes a travesty of the merit system." Katherine replies indignantly, "Merit means the position goes to the best candidate, and I am the best candidate, so what's the problem?"

THE NEED FOR SYSTEMATIC ETHICAL THINKING

Reflection on scenarios such as these prompts two sorts of self-doubt. We worry whether, like the sorcerer's apprentice, we will suffer the consequences of partial knowledge, overestimating our power to predict and control the causal chains we initiate through the application of our newfound knowledge. But we also worry about values. Even if we were more assured than we should be that our technical control will be complete, we would continue to wonder whether we will be able to distinguish between what we can do and what we ought to do. Do we have the ethical resources to use our genetic powers wisely and humanely? Or are we like hapless space-travelers embarking on an interstellar voyage equipped only with a pocket compass? Do existing ethical theories, concepts, and principles provide the materials for constructing more adequate instruments for moral navigation?

In the face of these doubts about whether our values will keep pace with our powers, there is an unfortunate tendency to rest content with inarticulate forebodings about the dangers of "playing God" when confronted with revelations of particular new genetic discoveries or technical breakthroughs. The admonition not to play God is useless, except as a general warning against hubris. It tells us nothing about how we should respond to any particular choice we may confront.

Something more is needed. A systematic vision of the moral character of the world we hope to be moving toward is required. The primary objective of this book, accordingly, is to make a contribution toward answering a single question: *What are the most basic moral principles that would guide public policy and individual choice concerning the use of genetic interventions in a just and humane society*

in which the powers of genetic intervention are much more developed than they are today?

Accomplishing this will require responding to many other questions, among the most important of which are: What are the most important ethical problems to which greatly increased powers of genetic intervention will give rise? Are these new problems? How adequate are the resources of existing ethical theory to cope with them? And what sorts of ethical principles and distinctions are needed to help a society equipped with formidable powers of genetic intervention avoid the mistakes and evils of the eugenics movements of the late nineteenth and early to mid-twentieth centuries?

GENOMIC RESEARCH AND GENETIC INTERVENTION

The Human Genome Project and Related Genetic Research

Our knowledge of how genes function is growing at an almost imponderable rate. The Human Genome Project is ahead of schedule in achieving its goal of determining the sequence of the three million or so base pairs of nucleotides that make up the complete genetic material of a human being. Presumably the coming years will also bring a great expansion of our knowledge of how particular genes function. Almost daily, newspaper headlines proclaim startling and sometimes disquieting discoveries and feats of technological virtuosity, from the identification of a "fat gene" to the cloning of a sheep from an adult sheep's mammary cell. Eventually these advances will bear practical fruit: the ability to use knowledge of how genes function to intervene in significant ways in human life. The Human Genome Project, in part because of the impetus it has given to the rapid, worldwide sharing of information and technique, does much to guarantee that the stream of genetic knowledge will continue to increase in volume and speed.

Although it is the most highly publicized locus of research, the Human Genome Project does not stand alone. Many other projects for human genetic research are funded by the National Institutes of Health in the United States and by government agencies in other industrial countries. And private, commercial research efforts are increasingly capitalizing on the knowledge base provided by the Human Genome Project and other government-funded research and on the expertise of researchers in academic institutions, many of which are publicly funded. Although the research for this book was funded by

the program for Ethical, Legal, and Social Implications of the Human Genome Project of the National Institutes of Health, our concern is broader. We will speak generally of "human genomic research" or even more broadly of "advances in genetic knowledge," recognizing that the study of nonhuman organisms has contributed and will continue to contribute to an understanding of how genes function in human beings.

Modes of Genetic Intervention

As a rough, initial categorization, modes of genetic intervention can first be divided into direct and indirect interventions. By "direct genetic interventions" we mean primarily two modes: gene therapy, in which normal or desirable genes are inserted into either somatic (body tissue) cells or germline cells (gametes – sperms or eggs – or embryos); and gene surgery, in which abnormal or undesirable genes are "switched off" – that is, deactivated so that they no longer produce their distinctive effects.

At present, gene therapy in human beings has been limited to somatic cells. For example, normal genes have been inserted into the bone marrow of patients who suffer from certain blood disorders due to the inability of their own genes to produce particular proteins. In the future, it is expected that gene therapy and gene surgery will be performed on human germline cells, with genes being inserted into or deactivated in gametes and embryos (fertilized eggs).

Gene therapy today involves the insertion of cloned normal genes – genes that occur naturally. Naturally occurring genes may come either from other human beings or from nonhuman animals. But it may eventually become possible to create new genes – that is, to synthesize new sequences of base pairs to produce effects that are not found in nature. Genes, after all, are just functionally significant sequences of base pairs.

From a technical standpoint, a fruitful combination of methods – at least for some conditions – would be to complement gene therapy on germline cells with gene surgery. The desirable gene would be introduced early enough in the gamete or embryo to replicate and keep reproducing throughout all the cells of the organism (rather than being inserted, decaying, and being reinserted into a particular tissue), and the undesirable gene would be "knocked out." Alternatively, recently isolated *totipotent* human embryo stem cells may eventually provide

the ideal platform from which to develop a range of gene therapies. (A totipotent cell is one that can develop into any kind of tissue or organ, given the proper biochemical stimulation.)

In contrast to direct intervention, *indirect genetic intervention* means primarily genetic pharmacology and embryo selection. By *genetic pharmacology* we mean the use of knowledge about genes to design drugs that will either substitute for the chemical products that would be produced by a normal gene in an individual who has an abnormal one, augment the chemical products of normal genes or counteract the effects of an undesirable or abnormal gene (e.g., by disrupting the protein it produced; Lewontin 1997). Furthermore, someday novel sequences of base pairs – new genes synthesized in the laboratory – may produce drugs that will either ameliorate or prevent diseases, give individuals new desirable traits, or enhance desirable traits they already have or would have when they become fully developed. Embryo selection involves three main steps: "harvesting" embryos, subjecting them to DNA analysis, and implanting an embryo that possesses the preferred characteristics.

There is a third category of intervention that may be called genetic, though perhaps with some stretching of the term. It involves the application of knowledge about genes but without the use of either modifying genes, genetic pharmacology, or embryo selection. There are two subcategories: when genetic information is used in regard to reproductive decisions and when it is used to prevent or ameliorate genetically based diseases in an already existing individual. For convenience, we call the first group "reproductive genetic testing interventions" and the second "therapeutic genetic testing interventions."

Reproductive genetic testing interventions are done in response to information revealed by genetic testing, where the testing is performed either on persons who intend to have children or, after conception has occurred, on the fetus. In one sense, the difference between these modes of genetic testing and embryo selection is not great: In the latter, testing is done on embryos rather than on prospective parents or fetuses.

If such a test reveals a risk of genetic disease or of some other undesirable condition, any of several steps may be taken to reduce or eliminate the risk. If it is determined that a woman is carrying a fetus with a genetic defect such as the chromosomal anomaly known as Down syndrome, she may elect to abort the fetus. If a couple undergoes carrier testing (by a blood test) and learns that they both carry a

gene for cystic fibrosis or Tay-Sachs disease, they may choose not to have children, to have children by sperm or by egg donation, or to adopt. At present we lack the capacity to use gene therapy, gene surgery, or genetic pharmacology in any of these cases. The only way to reduce the risk of having a child with an abnormal or undesired genetic condition is to avoid having that child.

The second subcategory, therapeutic genetic testing intervention, has been widely practiced in the United States in the case of the hereditary metabolic disorder phenylketonuria (PKU) for more than 30 years. A blood test is performed on infants at birth. If it is positive for PKU, a special diet is used to avoid the buildup of an enzyme that causes brain damage.

The gene for another potentially lethal genetic disorder, hereditary hemochromatosis, or inherited excessive iron storage disease, was identified by a private genetic technology company in 1996. A blood test for the two mutations that cause the disease has just become available. The treatment for hemochromatosis, like that for PKU, is remarkably "low-tech," consisting of regular phlebotomies (bloodlettings) to deplete stored iron. Because hereditary hemochromatosis is by far the most common serious genetic disease in the United States (approximately 4 persons per 1,000 of the Caucasian population are homozygous, i.e., have two copies of the mutation, and 1 in 10 is heterozygous, i.e., has one copy), and because treatment is inexpensive and effective, some argue that testing for hemochromatosis should become the next mass genetic screening program in this country.

In addition, knowledge of how genes work will lead to greater knowledge of how genes interact with different environments. Increasingly, we can expect to identify subgroups of the population who have genetic characteristics that may call for special environments if their physical or cognitive development is to be maximized. Here, unlike with PKU and hemochromatosis, tailoring an environment to the special developmental needs of a genotypic subgroup of the population may not be a matter of offering a therapy to treat a disease.

For example, we already know that some children benefit from special environments for learning to read or do mathematics. It may well turn out that there are genetic markers that will help pick out those with special learning needs or special needs for nutrition if their cognitive development is to be maximized. (It is already known that the Tohono O'Odham Indians of southern Arizona and Sonora, Mex-

ico, experience extraordinarily high rates of diabetes on a "normal" white American diet but not when they eat their traditional foods.) Intervening to tailor environments to the needs of genotypic groups may not be genetic intervention as ordinarily understood, yet it is intervention based on knowledge of how genes work in various environments.

Our choice of topics in this book deserves a word of explanation. Only in Chapter 5 are we concerned primarily with the role of genetic testing in reproductive choices. The remainder of the book concentrates mainly on direct genetic interventions and genetic pharmacology, with much of what we say having direct implications for embryo selection as well. The reason for this focus is twofold: First, some of the most fundamental ethical issues arise most clearly in the case of direct genetic interventions and genetic pharmacology. Second, there is already considerable literature on ethical issues in both genetic testing reproductive interventions and genetic testing therapeutic interventions (Cook-Deegan 1994; Andrews et al. 1994; Russo and Cove 1995).

Our reason for giving genetic pharmacology equal billing with direct genetic interventions perhaps warrants explanation. When ethical issues arising from the new genetics are discussed in the popular media – and even in the bioethics literature – the focus is often on "genetic engineering," a phrase that evokes images of scientists splicing genes together to create new kinds of organisms. Nonetheless, genetic pharmacology is likely to be one of the most potent applications of genetic science in the immediate future. (Venture capitalists, including some of the largest pharmaceutical companies, appear to agree with this prediction.) "Engineering" human embryos, if it occurs at all, will probably happen only in the relatively distant future. Dramatic advances in genetic pharmacology are a much nearer and surer prospect. Another alternative to the embryo engineering is embryo selection. Like genetic pharmacology, it seems to be more likely to see extensive use in the nearer future.

THE SHADOW OF EUGENICS

Even the brightest aspirations of the new genetics are from time to time dimmed by the shadow of eugenics. The very term has been in such bad odor since the era of Nazi "racial hygiene" (Proctor 1988) that few people today wish to be associated with eugenics. Indeed,

controversies over the new genetics often proceed as if the rival parties assume that if it can be shown that someone's views are "eugenic," they are thereby discredited. Much energy is then spent in trying to attach the label to an opponent or avoid being labeled a eugenicist.

Such exercises tend to be long on rhetoric and short on cognitive content. Attitudes toward eugenics are much like the common view of Marx's *Das Capital* – people know it is wrong though they know little about it – or, more charitably, like the attitude toward Freud's theory of the unconscious: "He was on to something, but he went too far."

At present, neither those who assert that the new genetics is infected by the evils of the old eugenics nor those who indignantly defend the new genetics' moral purity have made a convincing case. Two things are needed for the satisfactory resolution of this controversy: an ethical autopsy on the old eugenics and an examination of the ethical presuppositions and implications of the new genetics. The first task is taken up in Chapter 2; the remainder of the book is devoted to the second.

To evaluate the charge that the new genetics is infected by the evils of eugenics, it is necessary to unearth the ethical assumptions that provide the best justifications currently available for pursuing genetic knowledge and for attempting to use this knowledge to intervene in human lives. As with the attempt to articulate the underlying values of the eugenics movement, our task here requires considerable reconstruction, because those who endorse the expansion of our genetic knowledge and powers of intervention rarely make their ethical assumptions explicit, and they certainly offer nothing like a developed ethical theory.

In part, our attempt to articulate the ethical underpinnings of the new genetics is dialectical. We proceed by stating objections against or worries about the new genetics, and we see how defenders of the new genetics might best reply to them. Chapter 7 contains the most severe criticisms of the new genetics – those voiced by some members of the disabilities rights movement. Answering these criticisms requires making explicit some of the most fundamental moral assumptions that justify the development and use of technologies for genetic intervention to prevent disease and disability. Other chapters provide additional elements of an ethical framework that both justifies the general goal of developing our powers of genetic intervention and provides principles to guide the application of those powers.

TWO MODELS FOR GENETIC INTERVENTION

The Public Health Model

Our "ethical autopsy" on eugenics, in Chapter 2, identifies two quite different perspectives from which genetic intervention may be viewed. The first is what we call the public health model; the second is the personal choice model.

The public health model stresses the production of benefits and the avoidance of harms for groups. It uncritically assumes that the appropriate mode of evaluating options is some form of cost-benefit (or cost-effectiveness) calculation. To the extent that the public health model even recognizes an ethical dimension to decisions about the application of scientific knowledge or technology, it tends to assume that sound ethical reasoning is exclusively consequentialist (or utilitarian) in nature. In other words, it assumes that whether a policy or an action is deemed to be right is thought to depend solely on whether it produces the greatest balance of good over bad outcomes.

More important, consequentialist ethical reasoning – like cost-benefit and cost-effectiveness calculations – assumes that it is not only possible but permissible and even mandatory to aggregate goods and bads (costs and benefits) across individuals. Harms to some can be offset by gains to others; what matters is the sum. Critics of such simple and unqualified consequentialist reasoning, including ourselves, are quick to point out its fundamental flaws: Such reasoning is distributionally insensitive because it fails to take seriously the separateness and inviolability of persons.

In other words, as simple and unqualified consequentialist reasoning looks only to the aggregate balance of good over bad, it does not recognize fairness in the distribution of burdens and benefits to be a fundamental value. As a result, it not only allows but in some circumstances requires that the most fundamental interests of individuals be sacrificed in order to produce the best overall outcome.

Consequentialist ethical theory is not unique in allowing or even requiring that the interests of individuals sometimes yield to the good of all. Any reasonable ethical theory must acknowledge this. But it is unique in maintaining that in principle such sacrifice is justified whenever it would produce any aggregate gain, no matter how small. Because simple and unqualified consequentialism has this implication,

some conclude that it fails to appreciate sufficiently that each individual is an irreducibly distinct subject of moral concern.

The public health model, with its affinity for consequentialist ethical reasoning, took a particularly troubling form among some prominent eugenicists. Individuals who were thought to harbor "defective germ plasm" (what would now be called "bad genes") were likened to carriers of infectious disease. While persons infected with cholera were a menace to those with whom they came into contact, individuals with defective germ plasm were an even greater threat to society: They transmitted harm to an unlimited line of persons across many generations.

The only difference between the "horizontally transmitted" infectious diseases and "vertically transmitted" genetic diseases, according to this view, was that the potential harm caused by the latter was even greater. So if measures such as quarantine and restrictions on travel into disease areas that infringed individual freedom were appropriate responses to the former, then they were even more readily justified to avert the greater potential harm of the latter. This variant of the public health model may be called the *vertical epidemic model.* Once this point of view is adopted and combined with a simple and unqualified consequentialism, the risks of infringing liberty and of exclusion and discrimination increase dramatically.

The Personal Service Model

Today eugenics is almost universally condemned. Partly in reaction to the tendency of the most extreme eugenicists to discount individual freedom and welfare for the supposed good of society, medical geneticists and genetic counselors since World War II have adopted an almost absolute commitment to "nondirectiveness" in their relations with those seeking genetic services. Recoiling from the public health model that dominated the eugenics movement, and especially from the vertical disease metaphor, they publicly endorse the view that genetic tests and interventions are simply services offered to individuals – goods for private consumption – to be accepted or refused as individuals see fit.

This way of conceiving of genetic interventions takes them out of the public domain, relegating them to the sphere of private choice. Advocates of the personal service model proclaim that the fundamental value on which it rests is individual autonomy. Whether a couple

at risk for conceiving a child with a genetic disease takes a genetic test and how they use the knowledge thus obtained is their business, not society's, even if the decision to vaccinate a child for common childhood infectious diseases is a matter of public health and as such justifies restricting parental choice.

The personal service model serves as a formidable bulwark against the excesses of the crude consequentialist ethical reasoning that tainted the application of the public health model in the era of eugenics. But it does so at a prohibitive price: It ignores the obligation to prevent harm as well as some of the most basic requirements of justice. By elevating autonomy to the exclusion of all other values, the personal service model offers a myopic view of the moral landscape.

In fact, it is misleading to say that the personal service model expresses a commitment to autonomy. Instead, it honors only the autonomy of those who are in a position to exercise choice concerning genetic interventions, not all of those who may be affected by such choices. As we show in Chapter 5, this approach wrongly subordinates the autonomy of children to that of their parents.

In addition, if genetic services are treated as goods for private consumption, the cumulative effects of many individual choices in the "genetic marketplace" may limit the autonomy of many people, and perhaps of all people. Economic pressures, including requirements for insurability and employment, as well as social stigma directed toward those who produce children with "defects" that could have been avoided, may narrow rather than expand meaningful choice. Finally, treating genetic interventions as personal services may exacerbate inequalities in opportunities if the prevention of genetic diseases or genetic enhancements are available only to the rich. It would be more accurate to say, then, that the personal service model gives free reign to some dimensions of the autonomy of some people, often at the expense of others.

A Third Approach

Much current thinking about the ethics of genetic intervention assumes that the personal service model is not an adequate moral guide. However, the common response to its deficiencies is not to resurrect the public health model associated with eugenics. Instead, there is a tendency to assume the appropriateness of the personal service model in general and then to erect ad hoc – and less than convincing – "moral

firebreaks" to constrain the free choices of individuals in certain areas. For example, some ethicists have urged that the cloning of human beings be strictly prohibited, that there be a moratorium or permanent ban on human germline interventions, or that genetic enhancements (as opposed to treatments of diseases) be outlawed. In each case the proposed moral firebreak shows a distrust of the unalloyed personal service model but at the same time betrays the lack of a systematic, principled account of why and how the choices of individuals should be limited.

The chapters that follow aim to avoid both the lack of attention to the moral equality, separateness, and inviolability of persons that afflicted the eugenics movement's public health model of genetic intervention and the narrow concern with autonomous individual choice that characterizes the personal service model. We argue that although respect for individual autonomy requires an extensive sphere of protected reproductive freedoms and hence a broad range of personal discretion in decisions to use genetic interventions, both the need to prevent harm to offspring and the demands of justice, especially those regarding equal opportunity, place systematic limits on individuals' freedom to use or not use genetic interventions.

We try to develop a systematic, defensible moral framework for choices about the use of genetic intervention technologies. Our view steers a course between a public health model in which individuals count only so far as what they do or what is done to them affects the genetic health of "society" and a personal service model in which the choice to use genetic interventions is morally equivalent to the decision to buy goods for private consumption in an ordinary market. Because our account locates the ethics of genetic intervention within the larger enterprise of ethical theorizing, it avoids the arbitrariness and lack of system of the moral firebreaks approach.

ETHICAL ANALYSIS AND ETHICAL THEORY

Although we discuss ethical principles for individuals, our focus more often than not is primarily on ethical principles for institutions. In most cases we try to refine, and sometimes reinterpret or modify, institutional ethical principles that are quite familiar. Prominent examples include the principle that the basic institutions in a society should ensure equal opportunity and the principle of individual self-determination (or autonomy). We also evaluate certain distinctions, such as that between positive and negative genetic interventions or

between treatments and enhancements, that some have tried to elevate to the status of institutional ethical principles.

Principles for Institutions

One of the main results of our analysis is that a proper respect for individual self-determination in the realm of reproductive choices must recognize an asymmetry between institutional ethical principles and those for private individuals who are prospective parents: In general, parents should have considerably more latitude to use genetic interventions to shape their children than governments should have to shape their citizens. So even though our emphasis is on institutional ethical principles, determining their proper scope and limits requires an exploration of principles for individuals.

A comprehensive ethical theory – which we do not pretend to provide here – would include an account of virtues as well as principles. Our concern is not to attempt to provide a theory of the connection between ethical virtues and choices concerning the uses of genetic interventions. Nevertheless, some of what we say has direct and important implications for the sorts of virtues persons will need to have, both in their capacities as private individuals and as citizens concerned with public policy, in a society of heightened genetic powers. In particular, we have a good deal to say about the attitudes toward genetically based disabilities and the commitments to "the morality of inclusion" that members of such a society must exhibit if our new powers are to be used justly and humanely.

By way of partial preview, this much can be said about the institutional ethical principles we believe are most essential for a just and humane society equipped with robust capabilities for genetic intervention. As a first approximation, we can say that among the most important principles are those of justice and the prevention of harm. This is hardly surprising or controversial. Things become more complex and interesting as we explore different concepts of what justice requires and different understandings of what constitutes harm, and as we attempt to ascertain the scope and limits of the obligation to prevent harm.

Justice

Following Rawls (1971, p. 3), we focus in Chapter 3 on the justice of basic social institutions and only by implication on the justice of

particular policies or actions. We identify two main headings under which considerations of justice arise in a society of developed powers of genetic intervention: equal opportunity and the morality of inclusion (the latter concept is introduced at the end of this section).

One important conception of equal opportunity requires protection against limitations on individuals' opportunities imposed by racial, ethnic, religious, or gender discrimination. This principle, we argue, is important but incomplete. We opt for a somewhat more inclusive concept of equal opportunity – a version of what John Roemer has called a level playing field conception, of which Rawls's notion of fair equality of opportunity is the most prominent exemplar. Level playing field conceptions require efforts to eliminate or ameliorate the influence of some or all other social factors that limit opportunity over and above discrimination.

The most direct and compelling implication of this conception of the principle of equal opportunity lies in the domain of just health care. Here we adopt the main lines of Norman Daniels's theory of just health care, as developed in several books and a number of articles over the past 15 years. The core idea is that a just health care system should strive to remove barriers to opportunity that are due to disease. ("Disease" here is understood as any "adverse departures from normal species functioning.")

Regardless of how the term "genetic disease" is defined, the etiologies of many diseases include a genetic component. If just health care puts a premium on eliminating barriers to opportunity posed by disease, the question is not whether or in what sense a disease is genetic, but whether there is an intervention (genetic or otherwise) that can cure or prevent it. Thus the level playing field conception has direct implications for genetic intervention: In general, genetic intervention will be an important means of achieving equal opportunity, at least through its use to cure or prevent disease.

We also argue that equal opportunity, as an important principle of justice, has another bearing on genetic intervention. This principle can impose conditions on access to genetic interventions that go beyond the prevention or cure of disease. If, for example, it should ever become possible to enhance some normal desirable characteristics, a consistent commitment to equal opportunity might rule out an unrestricted market for the dissemination of the relevant technology, for if valuable enhancements were available only to the better-off, existing inequalities in opportunity might be exacerbated. Under such condi-

tions, equal opportunity might require either making the enhancements available to all, even those who cannot pay for them or preventing anyone from having them. How we respond to the fifth scenario sketched earlier – The Genetic Enhancement Certificate – will depend on whether justice requires constraints on unequal access to enhancement technologies.

A deeper and more perplexing question is whether equal opportunity may require or permit genetic interventions for the sake of preventing natural inequalities that do not constitute diseases. On the account we endorse, health care does not include everything of benefit that biomedical science can deliver. Health care, so far as it is a concern of justice, has to do only with the treatment and prevention of disease. However, we argue that some versions of the level playing field conception extend the requirements of equal opportunity, at least in principle, to interventions to counteract natural inequalities that do not constitute diseases.

The rationale for such an extension is straightforward: If one of the key intuitions underpinning a level playing field conception of equal opportunity is the conviction that peoples' opportunities should not be significantly limited due to factors that are wholly beyond their control, then it appears that equal opportunity may require the interventions to counteract the more serious opportunity-limiting effects of bad luck in the "natural lottery," regardless of whether the disadvantage conferred by a person's genes is a disease, strictly speaking, as in our fourth scenario (Health Care in the Age of Genetic Intervention).

Examples such as that of the person with the "mild depression gene" may pull one toward the conclusion that equal opportunity requires genetic interventions in such cases, even if the intervention is not treatment for a disease, for the same reason that equal opportunity requires efforts to counteract the effects of being born into a family of lower educational attainment. In both cases, it seems wrong that a person's opportunities should be limited by wholly undeserved and unchosen factors.

We will also see, however, that there are other interpretations of the level playing field conception that stop short of the conclusion that equal opportunity generally requires interventions to prevent natural disadvantages beyond the realm of disease. One such interpretation, which we believe to be Rawls's, does not hold that all undeserved disadvantages as such, including less desirable genetic endowments, require redress as a matter of justice. Instead, this understanding of

equal opportunity only asserts that it is unjust to structure social institutions so as to base persons' entitlements to goods on their possession of natural advantages. According to this view, equal opportunity would not require intervention to prevent any and all instances in which an individual would have less desirable genetic endowments. Natural inequalities as such would not be problematic from the standpoint of justice. These alternative understandings of the level playing field conception of equal opportunity appear to have radically different implications for action: One seems to require what might be called genetic equality, the other does not. Thus, a satisfactory response to cases like our fourth scenario inevitably requires a sortie into the realm of ethical theorizing about the proper understanding and role of equality of opportunity in a theory of justice.

This divergence between different versions of the level playing field conception of equal opportunity provides the first illustration of one of the major aims of this book: to explore how the prospects of genetic interventions with human beings challenge existing ethical theory. The challenge takes two distinct forms. First, the prospect of vastly increased powers of genetic intervention brings with it the inevitability of new choices, the contemplation of which stimulates us to articulate existing ethical theories in greater detail (in this case distinguishing different variants of level playing field theories of equal opportunity, which appear to have different practical implications). Second, by placing within human control features of our condition that we have heretofore regarded as given and unalterable (the fate assigned to us by the natural lottery), the prospect of genetic interventions forces us to rethink the boundary we have traditionally drawn between misfortune and injustice, and indeed between the natural and the social.

Preventing Harm

In Chapter 6, we argue that the most straightforward and compelling case for developing and using genetic interventions is to fulfill one of the most basic moral obligations human beings have: the obligation to prevent harm. People have especially demanding obligations to prevent harm to their offspring, but through the agency of their political institutions, they also have obligations to prevent harm to others.

Taking seriously the potential of genetic interventions to prevent harm pushes the limits of ethical theory in two ways: first, by forcing us to ascertain more precisely the scope and limits of the obligation to

prevent harm; and second, by putting pressure on our very understanding of how harm is to be understood in ethical theory. Meeting the first challenge requires us to determine how the sometimes conflicting values of reproductive freedom and the obligation to prevent harm limit each other. Meeting the second requires us to take a stand on a fundamental question of ethical theory: whether behavior is subject to ethical evaluation only if it worsens or betters the condition of particular, individual persons. Some genetic interventions – those that prevent a genetic impairment by preventing an individual who would have the impairment from coming into existence – cannot be described as preventing harm, if a harm is a worsening of the condition of a particular individual. If the individual does not exist, then the intervention cannot worsen his condition.

In addition, our exploration of the obligation to prevent harm through genetic interventions calls into question common dogmas concerning "nondirective" genetic counseling and the right to refuse medical treatment in cases of "maternal/fetal" conflict – where a woman who intends to carry a fetus to term refuses treatment that would prevent a disability in the future child. Thus, whether it is morally permissible to require or at least encourage individuals to avoid a high risk of transmitting a genetic disease (Scenario 2: Personal Choice or Public Health Concern?) will depend in part on how the obligation to prevent harm is understood.

Limits on the Pursuit of "Genetic Perfection"

Parents, of course, are typically not just concerned with preventing harm to their children; they want what is best for them. As the capability for genetic intervention increases, however, ethical issues arise concerning the proper expression of this benevolent parental impulse. In Chapter 5, we distinguish between permissible and obligatory genetic enhancements, examine the social implications of some of the enhancements that parents might consider undertaking for their children, and argue that what Joel Feinberg has called the child's right to an open future places significant limitations on what it is permissible for parents to do in this regard.

We also distinguish between the ethical implications of the pursuit of improvements by individual parents and those that might be pursued by collectivities in the name of some communitarian vision of human perfection. In that chapter and in our exploration of the mo-

rality of inclusion in Chapter 7, we provide some of the distinctions and principles needed for a sound ethical response to the issues raised in the Genetic Communitarianism and The Quest for a Perfect Baby scenarios.

The Morality of Inclusion

The dawning of the age of genetic intervention also pushes the limits of theories of justice in another way – by calling into question the manner in which the fundamental problem of justice is characteristically framed.

Theories of justice generally begin with the assumption that the most fundamental problem is how to distribute fairly the burdens and benefits of a society – understood as a single, cooperative framework in which all members are active and effective participants. This way of formulating the issue of justice overlooks two vital points: first, that increasingly human beings can exert some control over the character of the basic cooperative framework within which the most fundamental questions of fair distribution arise; and second, that the character of the most basic cooperative framework in a society will determine who is and who is not "disabled." In other words, what the most basic institutions for production and exchange are like will determine the capacities an individual must have in order to be an effective participant in social cooperation (Wikler 1983; Buchanan 1993, 1996).

But if the choice of a framework of cooperation has profound implications for whether some people will be able to participate effectively, there is a prior question of justice: What is required for fairness in the choice of a society's most basic and comprehensive cooperative scheme? Attempting to answer this question stimulates us to gain a deeper understanding of the very nature of disability.

In Chapter 7, we distinguish genetic impairments from disabilities that have a genetic component, noting that whether or to what extent a genetic impairment results in disability depends on the character of the dominant cooperative framework and the kinds of abilities required for effective participation in it. We then argue that there is an important but often ignored obligation to choose a dominant cooperative framework that is inclusive – that minimizes exclusion from participation on account of genetic impairments. If obligations of inclusion are to be taken seriously, they too impose significant restric-