SEVEN

GENETIC INTERVENTION AND THE
MORALITY OF INCLUSION

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(Gen From Chance to Choice, Buchanan et al)

OBJECTIVES

The Morality of Inclusion

So far this volume has examined ethical issues concerning how, when, and by whom genetic intervention technologies should be employed. Until now, the tacit assumption has been that the project of using genetic science to improve human lives is not only ethically permissible but laudable. The present chapter articulates, analyzes, and evaluates an arresting critique of this basic assumption that has been advanced by some members of the disabilities rights movement. Addressing the radical disabilities rights challenge will reveal how the prospect of advances in genetic knowledge and genetic intervention pushes the limits of ethical theory by raising profound issues about what we referred to in Chapter 3 as the morality of inclusion.

These two objectives are intimately related. The critique by disabilities rights advocates is a profound challenge to the reassuring assumption that the new genetics avoids the exclusionary features of the eugenics movements that were noted in Chapter 1. The concept of the morality of inclusion provides the key to articulating the various dimensions of exclusion and understanding their moral significance.

At the deepest level, a theory of the morality of inclusion would articulate criteria for membership in what might be called the primary moral community, specifying the characteristics that individuals must have in order to qualify as worthy of equal consideration and respect. Such a theory would also delineate the scope and limits of our obligations to include other individuals or groups in various mutually beneficial cooperative arrangements and hence make them eligible not only

for the concrete benefits of participation in those arrangements but for the status of equality that is accorded to those who stand in relations of reciprocity with one another.

Here the concept of a cooperative framework, which we introduced and expanded upon in Chapter 3, is of critical importance. The term covers a wide range of structures within which cooperation can occur, from the internal organization of business firms to the most basic institutions of a society. In the United States and other “developed” societies, the most basic cooperative framework consists, to a large extent, of the competitive market system. The more fundamental and pervasive a cooperative framework is in a society, the more debilitating it is for an individual if he or she cannot participate effectively in it. In some cases, the gap between the capacities an individual possesses and the requirements for participation in the cooperative framework is so wide that it can be said, without much exaggeration, that the individual is excluded from participating. In most cases, however, exclusion is not total; instead, there are limitations of varying degrees of severity upon the effectiveness with which an individual can participate.

Individuals may be unable to participate effectively in a framework for cooperation in several different ways. Hence different strategies will be required for overcoming exclusion. If existing law excludes certain people, we can fulfill our obligations of inclusion by changing the law, allowing those who have the requisite capacities to participate in our cooperative endeavors to do so. But in other cases there is a mismatch between what the cooperative framework demands of participants and the capacities of some individuals. Even if they are not legally prohibited or otherwise actively barred, they cannot participate effectively. Some cooperative frameworks are more vital for a person’s prospects, interpersonal relationships, and self-esteem than others. When a mismatch between a person’s abilities and what may be called the dominant cooperative framework of society occurs, the results may be devastating.

When this happens, a theory of the morality of inclusion should be able to tell us whether and to what extent we are obligated to undertake efforts to enable those individuals to participate. This could occur either through changing the cooperative framework so that its demands do not exceed their capacities or through enhancing their capacities so that they can meet the demands of the cooperative framework.

An adequate theory of the morality of inclusion would answer at
least three questions: Which beings qualify as members of the primary moral community? Under what conditions are participants in a cooperative framework obligated to include individuals who can participate effectively? And to what extent is there an obligation to ensure that the nature of society's most fundamental framework for cooperation renders it more rather than less inclusive? (More generally, to what extent should our choice of frameworks for cooperation be guided by a commitment to making more individuals able to participate effectively in them?)

This question is of crucial significance not only because whether an individual can participate effectively in the dominant cooperative framework will have dramatic effects on his or her life prospects for tangible social goods such as income and access to rewarding occupations. In addition, and in some ways more important, those who are excluded from participation in the dominant cooperative framework are relegated to the inferior status of dependency. They are not regarded, and tend not to regard themselves, as fully equal to those whose relationships with one another are characterized by the reciprocity that binds together active participants in the dominant cooperative scheme. Instead of being regarded as fundamentally equal subjects of relations of justice, they may be regarded as objects of charity.

Neglect of the Morality of Inclusion in Ethical Theory

Traditional and contemporary ethical theories have frequently grappled with the question of who qualifies as members of the primary moral community, with different theories offering different criteria. (Kantian theories focus on the capacities required for rational agency; utilitarian theories require only sentience — the capacity for pain and pleasure.) The other two questions about the morality of inclusion have rarely been addressed, however, in a systematic manner, and in many theories are never explicitly raised at all.¹

Whether an individual is able to participate in the most basic coop-

¹ For an articulation of some of the issues that a theory of the morality of inclusion would address and a selective historical survey of the failure of mainstream ethical and political theories to do so, see Buchanan (1993). As an example of a contemporary theorist who discusses some issues of membership but does not consider whether there are obligations to modify cooperative arrangements to include those now unable to participate effectively in them, see Walzer (1983), especially Chapter 2, pp. 31–62. To that extent, the morality of inclusion is a neglected but important part of ethical theory.

erative framework of society usually determines the share of social wealth to which the person has access. Hence it would be assumed that theories of distributive justice would address issues of inclusion. But theorizing about distributive justice often proceeds on a simplifying assumption that obscures the third question: namely, that the basic framework of social cooperation is one in which all or most individuals who are members of the primary moral community are able to participate effectively (Rawls in Sen and Williams 1982; Rawls 1993). Given this assumption, the fundamental problem of justice is taken to be: How are the burdens and benefits of social cooperation to be distributed among the members of a society considered as participants in one basic cooperative framework?

Unfortunately, what most theorists of justice overlook is that proceeding in this familiar way slides over a prior question of great significance: How does the choice of a cooperative framework influence who will be able to participate effectively in that effort? Given their capacities, some individuals will be able to participate effectively in some frameworks but not in others. Choosing a framework for cooperation will amount to choosing who will be disabled — unless special efforts are made through genetic intervention or otherwise to achieve a match between the demands of a cooperative framework and the abilities of all individuals. As the new genetics increases our control over which abilities individuals will have, this third question of the morality of inclusion becomes more pressing.

The Allegation That the New Genetics Is Exclusionary

Some of the most passionate criticisms of the new genetics come from those who claim that efforts to use a knowledge of how genes work to cure or prevent disease and disability is exclusionary. For these critics, efforts to draw a clear line between the old eugenics and the new genetics obscure a sinister shared characteristic: Both promote exclusion rather than inclusion.

The old eugenics excluded "defective" individuals from the primary moral community, branding them as dangerous carriers of inferior germ plasm who threatened humanity with moral and physical ruin. The new genetics is seen by some members of the disabilities rights community as a tool for excluding individuals with "bad genes" not only from particular tangible benefits such as insurance and employment, from the most basic good of all — the equal respect and consid-
eration that are owed all members of the primary moral community—and even from life itself through selective abortion. In addition, some advocates for the rights of persons with disabilities charge that the effort to develop more sophisticated capacities for preventing genetically based disabilities is fundamentally misguided: Instead of changing individuals to fit society, we ought to change society to accommodate individuals.

All these complaints about the allegedly exclusionary character of the new genetics can be subsumed under the three questions that a theory of the morality of inclusion ought to address. The remainder of this chapter concentrates on the second and third concerns about exclusion: the complaint that the effort to use genetic science to eradicate diseases and disabilities denies those with "defective" genes their status as persons entitled to equal moral worth, and the charge that instead of attempting to eliminate disabilities by changing individuals, the goal should be to change society so that the genetic conditions some individuals have are not disabling.

The more obvious and tangible issue of exclusion—the risk of genetic discrimination in insurance and employment—will not be the focus of our inquiry. This topic has been exhaustively examined elsewhere (Capron 1997; Rothenberg 1997). Our emphasis will be on what we take to be more subtle yet more basic issues of exclusion that the new genetics raises and with its tendency to push the limits of ethical theory.

Before proceeding to what we take to be less obvious dangers of exclusion, however, it may be useful to emphasize one point that has not received sufficient attention in the public discussion of employment and insurance discrimination on genetic grounds.

That point is quite simple, but important: Unless something is done to eliminate the threat of widespread genetic discrimination in employment and insurance, the chief public justification for using tax monies to finance the Human Genome Project and related genetic research will be discredited. That justification was that public monies were to be used to benefit the public. If the knowledge that this infusion of public funds produces is systematically used to the disadvantage of citizens at higher genetic risk for certain diseases, then it cannot be said, without serious qualification, that these public funds are being used to benefit the public. Instead, at most we can say that they are being used to benefit some members of the public and to harm others.

Furthermore, if individuals are able to avoid insurance or employment discrimination only by not being tested for genetic conditions (which is now often the case), then they will not benefit from the knowledge that the public’s support helped to create (even if they are not harmed, as they would be if they were tested and then suffered discrimination as a result). For those who might benefit from genetic testing but are afraid to avail themselves of it lest they suffer discrimination, all the fine rhetoric about the need to support genetic research so that “we” can gain knowledge to better “our” lives will ring hollow.

THE PUBLIC PROMISE OF THE NEW GENETICS: BETTER LIVES FOR ALL THROUGH MEDICAL GENETICS

Nobel Prize–winning molecular biologist Walter Gilbert described the mapping and sequencing of the human genome as “the grail of molecular biology.” Those who know Gilbert and respect his sophistication would have no doubt hasten to point out that he does not in fact attribute supernatural powers to mastery of the sequence of base pairs that make up the total human genetic complement. They would plead that he ought to be forgiven for indulging in public relations rhetoric to garner support for the Human Genome Project.

Nevertheless, his choice of metaphors is revealing: The implication is that possessing a comprehensive knowledge of human genetics, like possessing the Holy Grail of legend, will give us miraculous powers. Hyperbole aside, such rhetoric seems to appeal to the best of the Western tradition’s zeal for progress—the idea of improving human lives through the practical application of scientific knowledge. The search for the grail is a noble quest—the pursuit for the greater good of humanity as a whole, not a self-interested endeavor or an effort to achieve a benefit merely for some.

In other words, the rhetoric of the supporters of the Human Genome Project and of genetic research generally is explicitly inclusive, in part no doubt to distinguish the new genetics from the exclusionary old eugenics. Genetic science is now to serve human beings generally, rather than any particular people or nationality or “race.” Indeed, the very idea of the Human Genome Project appears to highlight what all human beings have in common rather than what differentiates them one from another: The human genome that is the object of an inter-
national network of mapping and sequencing projects is a composite, not the genome of any particular person or even a composite representing any one subgroup of humans.

Moreover, the official rhetoric has tended to equate the new genetics with medical genetics—the emphasis has been on the prevention and cure of diseases, rather than on the other uses to which genetic knowledge and technology might be put, including the enhancement of normal characteristics or the production of novel traits. One consequence of this emphasis on disease is to minimize the danger that the new genetics will be hijacked for the pursuit of those dubious ideals that were prominent in the racist eugenics of the past. In this sense, the official rhetoric of the new genetics is that of an inclusive, medical genetics.

Enthusiasts for the new genetics react defensively to any suggestion that current scientific endeavors harbor the taint of eugenics. After all, what could be controversial about the goal of improving human life through the application of a scientific knowledge of genes? Surely the difference between the old eugenics and the new genetics is unmistakable: The former was particularistic and exclusionary, condemning as defective all those who failed to meet supposed criteria of racial purity or human perfection; the latter is universalistic and inclusive, seeking to prevent suffering for all of humanity through the eradication of genetic disease. In addition, the exclusionary vision of the old eugenics was aided and abetted by faulty science, whereas the new genetics is truly scientific.

CHALLENGING THE RHETORIC: THE RADICAL DISABILITIES RIGHTS ADVOCATES’ COMPLAINTS

Where enthusiasts for the new genetics see inclusion and progress, some in the disabilities rights movement see exclusion and moral retrogression. The charge is that the very conception of progress that lies at the core of the ideology of the new genetics radically devalues individuals with disabilities, inflicting on them what may be the gravest injury of all—a denial of their equal moral worth and even their very right to exist.

The source of injury is said to be a fundamentally flawed conception of the value of human lives (International Association of Societies for Mental Disabilities 1995). Lives that include impairments are assumed to be without value if not a positive evil to be eradicated. Thus the disabilities rights advocates’ view stands the new geneticists’ claim to universalistic progress on its head. Not only is the alleged universalism indicted as exclusion, but also the very notion of progress is said to rest on a distorted view of the basic value that is supposed to guide the quests for progress. Scientific control over natural endowments will not mean improvements for all of humanity. Instead, it will result in harm to the fundamental interest of some human beings—those with disabilities.

The disabilities rights advocates’ critique of the new genetics appears to be nothing short of a rejection of the basic idea of striving “to make human lives better by selection based on genetic knowledge” (International 1995). “Selection” here includes not only choosing who will be born and who will not (through genetic testing and abortion to avoid the birth of individuals with certain conditions) but also choosing the characteristics of those who will be born by genetic interventions on gametes (sperm and egg cells) or embryos (fertilized eggs) to eliminate or counteract genetic influences that would cause disease.

Furthermore, the charge is not simply that the effort at improvement through selection in either of these ways is unwise or in some way morally questionable. The claim is that it is unjust—that it violates the most fundamental rights of people with disabilities and is nothing less than a degradation of the core of morality, the proper appreciation of the value of human lives. What is striking about the radical disabilities advocates’ critique, then, is that it is directed squarely against medical genetics—which proponents of the new genetics have taken to be the most laudable and uncontroversial application of genetic knowledge. Taken at face value, this critique condemns any effort to eliminate disabilities through medical interventions, genetic or otherwise (although it is true that the radical disabilities rights critique has focused primarily on genetic intervention). For if taken literally the slogan “change society, not individuals” does not merely insist that we try to make the social world more accessible to those whose impairments cannot be corrected; it would require accommodating those with impairments rather than using medical science to prevent or correct impairments.

Given the universalistic and progressive self-image of those who engage in or support the new genetics, this critique evokes incredulity and indignation. Indeed, it is tempting to dismiss the radical disabilities advocates’ objections as hysterical, paranoid, or extremist. This,
however, would be a mistake, as we shall see. For there is some truth in this critique. Humanity’s emerging powers of genetic intervention do raise important and in some ways novel issues of justice and exclusion – issues the rhetoric of universal progress obscures. On closer examination, however, it will turn out that neither the disabilities rights advocates nor the enthusiasts for the new genetics have grasped the fundamental implications of genetic intervention for our understanding of justice, of the moral significance of disabilities, or of the morality of inclusion.

SORTING OUT THE CONCERNS OF DISABILITIES RIGHTS ADVOCATES

Several distinct objections can be discerned in the disabilities rights advocates’ critique. Here we will concentrate on what we take to be the objections that strike at the heart of the legitimating rhetoric of the new genetics, those that challenge the claim that, at least so far as the application of genetic science is restricted to the prevention of disease, the new genetics is nonexclusionary and benign.

The Loss of Support Argument

Before proceeding to the most fundamental objections to the new genetics, however, we should note a different criticism of “improvement through selection” that is often voiced by those from the disabilities rights movement. This is the charge that as the application of genetic science reduces the number of persons suffering from disabilities, public support for those who have disabilities will dwindle. Although we discuss this “loss of support argument” mainly to distinguish it from what we take to be more fundamental objections, three points merit consideration.

First, the objection rests on a sweeping empirical generalization: that as the number of persons with a certain disability decreases, support for those who have that disability will decrease, and that this is true for disabilities generally. Without attempting to settle the empirical issue, we would only point out that it is not enough to state the generalization. Data to support it must be marshaled. To our knowledge, those who advance the “loss of support argument” have not borne this burden of evidence. Moreover, we do know of at least one instance in which a reduction in the incidence of a genetic disease

(achieved through voluntary carrier testing) resulted in more resources being used to support the decreasing number of those who had the disease. This was the case of the Thalassemia testing program in Greece (Kitcher 1995).

Second, whether or not support will diminish in a particular case will depend on a number of factors, not the least significant of which is whether the public is alerted in advance to the danger of reduced support. In fact, the prediction that support will decrease as science reduces the incidence of genetic diseases is much less plausible today than it would have been twenty years ago, precisely because the disabilities rights movement has succeeded in awakening the public and policy makers to the need for support.

Third, even if there should turn out to be some loss of support for certain genetically based diseases as their incidence declines, it would not follow that seeking to reduce their incidence is wrong, all things considered. The most fundamental problem with the loss of support argument is that it only considers the interests of those who will have disabilities in a world in which disabilities are less common. It entirely neglects the legitimate interests that people have in not having disabilities. (In addition, as we argue later, this argument also fails to recognize that those who are not disabled and who are not at significant risk of being disabled can have legitimate interests in reducing the incidence of disabilities.)

Consider first the interest a person has in not having disabilities. Surely this is a morally legitimate interest. It is true that in some cases this interest is not relevant, because the disability is avoided only by preventing the existence of the person who would have been born with it. Obviously, in this case, one cannot justify the intervention by citing the interest some person has in not having the disability.

But there are other interventions that do serve the interest that individuals have in not having disabilities. For example, it will very likely become possible to correct some genetic anomalies by intervening on the embryo. In this case, it will be correct to speak of preventing an identified individual from having a disability and to justify the intervention by appealing to that individual’s interest in not having a disability. Similarly, genetic science will be able to prevent disabling genetic conditions in other, perhaps less dramatic, ways, not by manipulating the genes of embryos but by administering drugs that mimic the products of normal genes or that counteract the deleterious effects of abnormal genes. In these cases, too, we may correctly say that the
application of genetic science makes identifiable individuals' lives better by preventing genetically based diseases, and that such individuals have a legitimate interest in avoiding the damage to them that would occur without the intervention.

Once it is recognized that the incidence of genetically based diseases may be reduced without preventing the birth of individuals who would have disabilities, it should be evident that the loss of support argument must be rejected. It fails to give any weight to the legitimate interests that individuals have in avoiding disabilities. This can be seen more clearly once we recognize that the general form of this argument has nothing peculiarly to do with genetic interventions. If the risk of loss of support is a reason for not undertaking genetic interventions, then it is also a reason for not undertaking conventional medical interventions as well. By this logic, it would be wrong to treat babies' eyes at birth to prevent blindness due to contact with gonococcus bacteria during vaginal delivery. But surely it is not only permissible but morally obligatory to prevent babies from being blinded, if this can be done safely and effectively, even if it could be shown that there is some significant risk of loss of support for the blind.

The risk of loss of support is familiar in the case of so-called orphan drugs. When the number of individuals suffering from a particular malady is small enough, it may not be profitable for pharmaceutical companies to produce drugs valuable to these individuals. In the United States, special legislation provides financial incentives for companies to produce such drugs by increasing the length of patents so that companies have more time to cover their costs.

The situation of orphan drugs illustrates an important point: There is a societal obligation to maintain support for those who are ill or disabled, but it does not follow that this generates a valid claim on the part of those individuals that society must ensure that their numbers do not diminish. So even if proponents of the loss of support argument could do what they have not done – supply strong empirical evidence for the generalization that loss of support would result – this would not suffice to show that any limitations on efforts to prevent disabilities are called for.

One last example will reinforce this point. Suppose that Jill is a young adult who faces life with paraplegia unless she undergoes a surgical procedure. If she has the surgery, she can look forward to a life with all the opportunities that go with normal mobility.

She chooses to have the surgery. As a result of her choice, the ranks of the disabled will diminish by one. Does her action harm people with disabilities? Presumably not – her cure is very unlikely to make much of a difference. Suppose that many people in her situation make the same choice, with the result that there is a significant reduction in the number of people with paraplegia. Have those who had the surgery harmed the people with paraplegia who cannot be cured or who for some reason chose not to be cured? If by harming someone is meant worsening their condition, then it may well be true that large numbers of surgical cures for paraplegia might harm those who remain paraplegic. It does not follow, however, that widespread use of the curative surgical intervention should be prohibited or that it would be morally wrong.

It is necessary here to distinguish between being harmed and being wrongly harmed. Even if the minority who remain uncured are harmed by widespread use of the surgical intervention it would not follow that they have been wrongly harmed, unless one is willing to make the implausible claim that those who elected to be cured had no right to make this choice. But whether they have a right to make such a choice will depend primarily upon whether they have a legitimate interest in avoiding being disabled and whether that legitimate interest is of such moral weight that it warrants the special protection implied in the notion of a right. Having a right to do something means having a sphere of discretion to do what might otherwise be wrong, including what may contribute to a worsening of the condition of others. For example, if you have a right to compete with me for a certain prize, then the fact that your entering the competition worsens my condition does not show that you wrong me by competing.

As will become more evident later in this chapter, our critique of the loss of support argument reveals quite general features of other arguments advanced on behalf of persons with disabilities. First, whether their proponents recognize it or not, these arguments are not limited to interventions to prevent genetic diseases. They apply to all disabilities regardless of their etiology, and their general implications are highly implausible. Second, like the loss of support argument, the other arguments considered here are flawed because they consider only some of the legitimate interests at stake. They give no weight to the legitimate interests that persons have in not having disabilities. Thus, ironically, their arguments are exclusionary.
The Justice Trumps Beneficence Argument

We have just seen that the “loss of support argument” overlooks the legitimate interests that people have in avoiding disabilities. This interest is not merely legitimate – that is, not subject to any moral criticism as such. As we saw in Chapter 3, it is the basis of a claim of justice. There we argued that there are cases in which justice requires interventions to correct or prevent genetic defects. The chief basis for this conclusion is that an adequate account of justice includes a commitment to equal opportunity, and that genetically based disabilities, like other disabilities, impair opportunity.

The conclusion that genetic interventions can be required by justice has a direct and devastating implication for another argument advanced on behalf of persons with disabilities and against genetic intervention. This is the “justice trumps beneficence” argument. This argument asserts that while only beneficence, not justice, speaks in favor of genetic intervention to prevent disabilities, the widespread use of genetic interventions to prevent disabilities puts disabled persons at risk of suffering grave injustices (International Association of Societies for Mental Disabilities 1995). More explicitly, the argument is:

1. Genetic intervention to prevent disabilities is not required by justice but only by the value or principle of beneficence.
2. The widespread use of genetic intervention to prevent disabilities would create a serious risk of injustices to disabled people.
3. Justice trumps beneficence (when the pursuit of beneficence creates a risk of serious injustice, the avoidance of injustice should take precedence).
4. Therefore, widespread genetic intervention to prevent disabilities ought not to be undertaken.

In a nutshell, the “justice trumps beneficence” argument contends that it is wrong to act on the principle of beneficence to the detriment of the principle of justice.

Consider premise 2. Our critique of the loss of support argument has already shown that even if a reduction in the incidence of disabilities does put disabled persons at risk for loss of support, it does not follow that we should forgo the effort to prevent disabilities by genetic or other means. In the next section of this chapter we examine another interpretation of premise 2 of the “justice trumps beneficence” argument, one that focuses on a different risk to those with disabilities.

There we evaluate the allegation that genetic intervention to prevent disabilities expresses a radical devaluation of persons with disabilities, which violates their right to be recognized as persons of equal moral worth. But here we wish to attack the third premise, which is false for two reasons.

First, some benefits are not “mere benefits.” Achieving a great good or avoiding a great harm can in some cases be obligatory, not merely commendable or desirable. Indeed, there can be instances in which the obligation to achieve a great good or to prevent a great harm trumps obligations of justice, because those particular obligations of justice are less weighty.

To fail to consider this possibility is to make the mistake of assuming that obligations of justice are the weightiest obligations in all circumstances. What distinguishes these obligations from others, including obligations to provide benefits and to avoid harms, is not their relative strength, but their grounds – the kinds of considerations that are appealed to in justifying the assertion that there is an obligation (Buchanan 1987). So even if it were true that beneficence but not justice speaks in favor of genetic intervention to prevent disabilities, it would not follow that we ought never to intervene when intervention creates a risk of injustice.

Second, we have shown in detail in Chapter 3 that justice – and more specifically, equal opportunity as one component of justice – sometimes requires genetic intervention to prevent disabilities. And in Chapter 6 we saw that our obligations to prevent harm can also require genetic interventions, whether these obligations are understood to be obligations of justice or not. So it is a mistake to say that the prospect of genetic intervention to prevent disabilities puts mere beneficence against justice, even if it can be shown that such intervention would put people with disabilities at risk of being treated unjustly.

The justice trumps beneficence argument portrays an unequal contest between the need to protect people with disabilities against the most fundamental injustice, on the one hand, and the merely desirable goal of conferring benefits, on the other. But this is inaccurate. Instead, we have either a conflict between obligations of justice (or to prevent serious harms) and obligations to minimize the risk of injustice. Whether we should undertake genetic interventions to protect equal opportunity (or for the sake of preventing serious harm) or refrain from intervening in order to avoid the risk of injustice to people with disabilities will depend on the nature of the injustice for which people
with disabilities are put at risk and the likelihood that this injustice will occur.

But if this is so, then we can proceed to examine the claim that the widespread use of genetic intervention to prevent disabilities puts people with disabilities at risk for being treated unjustly and we can dispense with the justice trumps beneficence argument, which we have seen is unsound anyway because of its oversimplified conception of strength of obligations of justice relative to those of beneficence.

The Expressivist Objection

This objection, or rather this family of objections, focuses on what may be called the expressive character of decisions to use genetic interventions to prevent disabilities. The claim is that decisions to intervene – and indeed the whole enterprise of developing the knowledge and technology to make such interventions possible – express negative judgments about people with disabilities, and that these judgments themselves constitute a profound injustice to those people.

The negative judgments allegedly expressed in the enterprise of genetic intervention are said to betray a profound misunderstanding of the core concept of morality: the value of human life. The mistake is to assume that only "perfect" human lives are of sufficient value to be allowed to exist or to come into existence.

According to the expressivist objection, this error is not merely a mistake in ethical theory. To express these negative judgments about people with disabilities is itself an injury to them, a violation of their most fundamental right – the right to be regarded as persons of equal worth.

In addition, the social acceptance of the enterprise that expresses these negative judgments, the project of using genetic knowledge for improvement through selection, puts persons with disabilities at risk in more concrete ways. Those who are not regarded as members of the community of persons with equal worth, those whose fundamental value is denied, are likely to be neglected and abused, if not exterminated. The negative judgments allegedly expressed in the new genetics, then, are these:

1. The lives of individuals with disabilities are not worth living.
2. Only perfect individuals should be brought into the world. (Imperfect individuals have no right to exist.)

Disabilities rights advocates rightly reject both judgments. Those who advance the expressivist argument are quick to emphasize that the first judgment reveals an ignorance of the joys and fulfillments that even severely disabled individuals can experience. The second judgment is rejected on the grounds that it rests on a false assumption about what makes individuals worthy of equal respect and concern, and hence of life. It is not whether or not someone measures up to some supposed standard of perfection that matters so far as equal worth is concerned, but rather an individual's humanity (or, on some accounts, personhood).²

It is no doubt true that people who have not experienced serious disabilities themselves, or been close to people who are seriously disabled, sometimes – perhaps often – fail to appreciate the quality of life of people with disabilities. They may focus only on the suffering and limitations the disability entails, underestimating both the positive experiences people with disabilities can have and the remarkable capacity that human beings have to adapt their expectations and goals to changes in their abilities (Buchanan and Brock 1989).

Even if this is true, however, it does not follow that all or even most of those who are not disabled believe that disabilities as such, or even serious disabilities, make life not worth living. It may well be true that many people believe that there are some disabilities so severe that they make life not worth living. And it may be that some interventions to prevent disabilities are undertaken out of this belief. But from this it does not follow that whenever we intervene to prevent a disability our action betrays a belief that the lives of disabled persons are not worth living.

What, then, would lead some disabilities rights advocates to conclude that the enthusiasm for using genetic science to reduce the incidence of disabilities expresses the judgment that the lives of disabled people are not worth living or that such people ought not to exist? The answer, apparently, is that they believe that central to the new genetics is the decision to prevent disabilities by avoiding the birth of people with disabilities – and that this decision must rest on the

² A human being (in the biological sense) is simply a member of the species *homo sapiens*. To be a person in what might be called the moral sense is to be an individual who has the capacity for acting on reasons, and, according to some accounts, a sense of himself or herself as a being who persists over time. Given these definitions, not all human beings are persons (e.g., those who are permanently unconscious), and there may be some persons who are not human beings (extraterrestrial individuals).
judgment that life with disabilities is not worth living or that less-than-perfect individuals ought not to exist or have no right to exist (Asch 1995).

As a general form of argument, the expressivist objection is invalid. An example that has nothing to do with genetic intervention will show why this is so. Suppose that a woman can either conceive a child when she has German measles (rubella), knowing that if she does there is a significant risk that the child she bears will suffer a serious impairment, or she can delay conception until her illness passes. Surely the woman’s decision to postpone conceiving a child need not be an expression of the belief either that if the child were born with an impairment its life would not be worth living or that were it born with an impairment it would have no right to live or be unworthy of equal respect and concern.

To reveal more conclusively the weakness of the expressivist argument, we must clarify what it means to say that a decision expresses (or presupposes) a particular judgment. This happens if and only if either, as a matter of psychological fact, one could only be motivated to make this judgment if the person ascribed to the judgment (i.e., that one could not psychologically make the decision if he or she did not believe to be true what the judgment affirms), or one cannot rationally make the decision without believing what the judgment affirms. So the expressivist objection is that decisions to use genetic intervention to prevent disabilities rationally or motivationally presuppose either the judgment that the lives of disabled individuals are not worth living, or the judgment that less-than-perfect individuals ought not to exist, or both.

**Preventing Disabilities without Terminating the Lives of Individuals with Disabilities** It should be clear that the expressivist objection only applies to those genetic interventions that prevent disabilities by preventing the existence of individuals who would have the disabilities in question. If the disability is prevented in other ways, there is no reason whatsoever to believe that the decision expresses a judgment: that life with those disabilities would not be worth living or that the individual who had those disabilities ought not to exist.

This is a significant point because some modes of genetic intervention do not prevent disability by preventing the existence of individuals who would have the disability. To see that this is so, it is useful to distinguish the following four types of intervention:

- Preventing a genetic condition that would be disabling by “switching off” the gene that produces the disabling condition or by inserting normal genes either into embryos or gametes or into individuals after they are born.
- Avoiding conceiving a fetus with a genetic condition that would produce a disability by using contraceptives when genetic testing reveals a significant risk of the condition.
- Avoiding conceiving a fetus with a genetic condition that would produce a disability by using artificial insemination or embryo transplant.
- Preventing the birth of an individual determined to have a genetic condition that would produce a disability or to be at high risk of having that condition by aborting the fetus.

Opting for the first form of intervention in no way presupposes – either motivationally or rationally – a judgment that only perfect individuals should exist or that people with disabilities ought not to exist, any more than performing conventional surgery to restore a blind person’s sight does. In either case the motive may be, and often is, simply the desire to remove serious limitations on the individual’s opportunities and to avoid needless suffering. One can be motivated by this desire and can rationally decide to act on it without believing either that the individual’s life with the limitation is not worth living or that only perfect individuals should exist. If Jill decides to undergo the surgical procedure to cure her paraplegia, she need not believe that her life or anyone else’s life as a paraplegic is not worth living, nor need she consciously or unconsciously believe that only perfect individuals should exist.

Similarly, the second and third modes of intervening to prevent disabilities need not express either of the negative judgments the expressivist argument attributes to those who advocate genetic interventions. To be willing to undertake either of these options, all that is necessary is the desire not to bring into the world an individual whose opportunities will be severely limited and who may also experience considerable suffering.

A number of beliefs may account for this desire, any of which would make the decision fully rational. First, someone may simply wish to be spared avoidable and serious strains on his or her marriage or family. Or he or she may wish to avoid putting additional pressure on limited social resources needed for the achievement of distributive
justice in health care and in other areas, including the support of existing individuals who have disabilities.

In the second and third interventions, using contraception, artificial insemination, or embryo transplant, acting on these desires does not violate anyone’s rights because there is no existing individual who has rights that might be violated. It is the coming to be of an individual that is avoided. No existing individual’s life is terminated. So even if one believes that fetuses are persons with all the rights that persons have, including the right not to be killed, avoiding disabilities by avoiding conception of individuals who would be disabled neither violates anyone’s rights nor necessarily expresses any negative judgments about the lives of people with disabilities. Furthermore, to judge that it is morally permissible to avoid bringing a disabled person into the world, a person need not judge that disabled persons ought not to be born any more than judging that it is not wrong to refrain from getting a Ph.D. commits someone to the judgment that no one ought to get a Ph.D.

Only the fourth mode of intervention has any prospect of being vulnerable to the expressivist objection, because it is only in that case that there is a decision to terminate a life that will involve a disability. This point is extremely important because it shows that even in principle the expressivist objection cannot provide a reason for abandoning or restricting genetic interventions per se, but at most only one mode of intervention.

**Genetic Intervention and the Status of Fetuses**

Notice, however, that even in the fourth type of intervention the decision to intervene — to abort a fetus with a disabling genetic condition — need not express either of the two negative judgments about people with disabilities. Someone who decides to terminate a pregnancy after learning that the fetus she is carrying has Down syndrome may simply be motivated by the very same desire that motivates the decision to undertake any of the other three modes of intervention: the desire not to bring into the world an individual with seriously limited opportunities. Nor is there anything illogical or irrational about acting on this desire while firmly rejecting the judgment that the lives of disabled people are not worth living or that people with disabilities have no right to exist.

In the case of the fourth mode of intervention, as with the other three modes, the desire to avoid the birth of an individual with disabilities may be based on any of several quite morally unexceptionable considerations. A person may wish to avoid serious strains on a marriage or the ability to fulfill responsibilities to existing children, or to avoid diverting scarce resources needed for the achievement of distributive justice — and yet the individual may consistently believe that the lives of many or even of all individuals with Down syndrome are worth living and that every child and adult with this genetic condition has the same right to life and to recognition of equal worth as any other person. Nor need the person believe that only perfect individuals ought to exist. An individual can rationally decide to abort a fetus with a genetic defect while nevertheless believing that persons with disabilities are of equal worth if he believes that fetuses (or at least fetuses up to and including the stage at which the abortion is performed) are not persons and hence do not have the rights and equal moral status of persons.

To believe that it is permissible to avoid a serious disability by selective abortion one need not believe that individuals with that disability ought not to be born. All that is necessary is the belief that the fetus has no right to be born. Furthermore, one can — and many people apparently do — consistently believe both that fetuses, whether they will have disabilities or not, have no right to be born (because they are not persons) while believing that all persons, including those with disabilities, have a right to exist, and hence a right not to be killed, because they are persons.

Similarly, there is nothing inconsistent or motivationally incoherent about believing that one ought not bring a disabled child into the world and believing that it is not the case that individuals with disabilities ought not to be born. (Someone can believe that she ought not to marry without believing that marriages ought not to occur.)

Perhaps those who advance the expressivist argument will still not be convinced of our rebuttal. The appeal of the argument is its simplicity. Thus a person who herself has a disability, impatient with the subtleties and hair-splitting of the preceding arguments, might reply:

No analysis of the possible motives or of the coherence of the possible reasons for preventing disabilities can erase one simple fact: When you endorse the use of genetic science to prevent disabilities, you are saying that people like me ought not to exist. And when you say that people like me ought not to exist, you devalue me in the most fundamental and threatening way imaginable. Your conception of the value of human life denies that my life, imperfect as it is in your eyes, has value.

Recall, however, that to say that it is permissible to avoid disabilities by genetic interventions is not to say that we ought to reduce the
incidence of disabilities, much less that disabled persons ought not to exist. In Chapters 3 and 6 we argued that there can be obligations of justice, as well as obligations to prevent harm, that require genetic interventions. From this perspective, we are committed to the judgment that in the future the world should not include so many disabilities and hence so many individuals with disabilities. But it is not the people with the disabilities that we devalue; it is the disabilities themselves. We do not wish to reduce the number of people with disabilities by taking the life of any individual who has a disability.

Devaluing Disabilities, Not People with Disabilities  We devalue disabilities because we value the opportunities and welfare of the people who have them. And it is because we value people, all people, that we care about limitations on their welfare and opportunities. We also know that disabilities as such diminish opportunities and welfare, even when they are not so severe that the lives of those who have them are not worth living, and even if those individuals do not literally suffer as a result of their disabilities. Thus there is nothing irrational, motivationally incoherent, or disingenuous in saying that we devalue the disabilities and wish to reduce their incidence while valuing existing persons with disabilities, and that we value them the same as those who do not have disabilities.

Another example may help to dispel the charge that when we seek to reduce the frequency of disabilities we thereby devalue people who have them. Suppose that a parent encourages her child to work hard in school by pointing out that if he does not, his career opportunities will be limited to "menial" jobs in which there is little potential for development of new skills and little prospect of advancement. Must we say that such a parent devalues persons who do "menial" jobs? No such attitude is implied in the reasons the parent gives to the child for working hard in school or in her motives for doing so.

Of course, it may be true that some parents who have always engaged in "white-collar" work tend to underestimate the opportunities for development of skills and for satisfactions that some of the less skilled "blue-collar" jobs sometimes offer. Nevertheless, the advice the parent gives may be sound. She may be correct both in her judgment that this individual would be happier and more fulfilled with a different kind of job and in her prediction that doing well in school is a prerequisite for getting such a job. She may only be expressing concern for the well-being of her child in the light of a realistic estimate of the educational and economic facts of life, without in any way denigrating persons who perform menial labor.

None of this is to deny that some white-collar workers look down on blue-collar workers, nor that some "abled" persons devalue the "disabled." Nor is it to deny that some blue-collar workers have more job satisfaction than some white-collar workers or that some people with disabilities have more fulfilling lives than some people who do not have disabilities.

One last hypothetical will clarify our observation that devaluing disabilities need not imply devaluing individuals with disabilities. Suppose God tells a couple: "I'll make you a child. You can have a child that has limited opportunities due to a physical or cognitive defect or one who does not. Which do you choose?" Suppose that the couple answers as follows: "Lord, we choose the child without the defect; but if you should decide to give us the child who has disabilities we will love it as much as we would the other." There is surely nothing illogical or motivationally incoherent in this admirable response.

The proponent of the expressivist objection might concede this point but offer one additional argument:

Even if the decision to use genetic interventions to prevent disabilities does not necessarily express negative attitudes, such attitudes are all too common in our society. In fact, negative attitudes are so widespread and pronounced that many individuals with disabilities experience greater limitations on their opportunities as a result of stigma than from their physical or cognitive impairments. Undoubtedly, these negative attitudes are part of the motivation for the willingness to develop and use genetic interventions. We should not encourage these attitudes by using social resources to create vehicles for their expression and perpetuation.

This argument might be telling if there were nothing of moral significance to be lost by following its advice. There is something to be lost, however: the chance to avoid or correct serious limitations on individuals' opportunities and to reduce human suffering. Accordingly, the wiser course of action is to continue the laudable fight to change negative attitudes toward people with disabilities while developing genetic intervention technologies to accomplish the same goal that has inspired the greatest triumphs of the disabilities rights movements in overcoming physical barriers in the social environment. For it is crucial to remember that the strongest argument in favor of removing physical barriers is that this is necessary to achieve equal opportunity, and that all individuals have a right to equal opportunity.
Summary of Response to Expressivist Objection  It may be useful a: this point to summarize the main points of our complex discussion of the expressivist argument against genetic intervention. To be sound, the argument either must show that it is motivationally impossible or irrational both to devalue and seek to avoid disabilities while at the same time valuing equally individuals who have disabilities or it must defend the view that fetuses are persons, with all the rights that persons have, and that avoiding disabilities by aborting fetuses with disabilities is the moral equivalent of reducing the incidence of disabilities by exterminating disabled children and adults.

The first alternative is unconvincing. There are many instances in which we devalue (and seek to avoid) certain characteristics that some individuals have without devaluing individuals who have them. The second alternative comes at a steep price: Not only must the disabilities rights advocate articulate and defend an account of personhood that shows that fetuses are persons, he must also acknowledge that the fundamental error of those who advocate selective abortion to avoid disabilities is not that they devalue individuals with disabilities but that they fail to recognize that fetuses, whether disabled or not, are persons. The argument, then, would have nothing to do with disabilities as such.

Moreover, even if it were assumed that fetuses are persons and that hence killing them to reduce the incidence of disabilities is morally indistinguishable from exterminating disabled children and adults, this would have no negative implications for the other three modes of genetic intervention to avoid disabilities. None of these involves killing a fetus, so none can be described as killing a person, even if we assume that fetuses are persons. Therefore endorsing these modes of reducing disabilities need not express and does not presuppose the judgment that existing individuals with disabilities have no right to live.

To repeat: Advocating the fourth mode of intervention (selective abortion) is tantamount to saying that people like you (who have disabilities) have no right to exist on the highly controversial assumption that fetuses are persons. Opting for the first, second, and third modes of intervention has no implications at all for the worthiness or unworthiness of “disabled lives,” regardless of which view of the moral status of fetuses is correct. What appeared to be a distinctive objection to a new technology turns out to be a familiar objection to the age-old practice of abortion.

None of this is to deny that some members of the disabilities com-

munity are genuinely offended by what they take to be the misplaced zeal to harness the powers of science to prevent disabilities. Granted the shameful history of discrimination against and insensitivity toward persons with disabilities, their taking offense is perfectly understandable. However, it is one thing to say that certain behavior is offensive to a particular group, and quite another to say that the fact that the group is offended constitutes a violation of anyone’s rights.

In general, a liberal society cannot count the occurrence of offense, as distinct from rights violations, as a sufficient ground for curtailing liberty, whether it is the liberty of a person to choose a surgical procedure that will cure her own paraplegia or that of her child, or the liberty of a researcher to try to develop a technique for preventing a genetically based impairment (Feinberg 1984).

The Deaf Culture Argument

As a supplement to our critique of the expressivist argument, we must consider one final, striking argument that has recently been advanced by some members the deaf community. This argument has been advanced in response to a surgical intervention to alleviate deafness, but it is of broader interest, encompassing genetic interventions as well. What is fascinating about this anti-interventionist argument is that it directly challenges a basic assumption of our rebuttal of the expressivist argument—namely, that because disabilities limit opportunity, they ought to be prevented.

Some individuals who are deaf have argued that even though being deaf limits some opportunities, the deaf community has developed a rich culture that provides unique and valuable opportunities and benefits to its members. In particular, it is said that the “deaf culture” provides exceptional solidarity as well as a sign language that is uniquely expressive. The claim is that the goods conferred by membership in the community of persons who are deaf outweighs or at least counterbalances the limitations on opportunity that deafness entails.

The first thing to notice about this argument is that it is not easily generalizable as an argument against interventions to prevent disabling impairments generally. It is not so plausible to argue that there is a paraplegic culture or a Down syndrome culture, much less a Lesch-Nyhan or Tay-Sachs culture. Nevertheless, proponents of this argument have done an inestimable service by calling to our attention the fact that there is such a thing as the deaf community, that it possesses
at least some of the important features of a culture, and that belonging to this community brings important benefits.

What the argument overlooks, however, is that there is an asymmetry between the limitations on opportunity that deafness brings and the goods of membership in the deaf community. Without an enormous expenditure of social resources, the limitations imposed by being without hearing in a world in which most people hear are quite severe. Not being able to hear excludes a person from effectively pursuing many options, some of which are generally very important for most people.

But the benefits provided by membership in the "deaf community," while important and impressive, may not in fact be available only to those who are deaf. Solidarity is certainly available to members in other communities — religious groups, political groups, and any number of other forms of community and can do provide solidarity for many people. Nor is it at all obvious that an appreciation of the uniquely expressive character of sign language is unavailable to those who are not deaf. (It is no doubt true, of course, that a person who is not deaf will have less incentive to learn sign language and hence will be less likely to reap its unique benefits.)

But even if it could be shown that the distinctive benefits of sign language are only available to the deaf, it is one thing to say that those who are deaf gain a great good from this mode of communication. It is much less plausible to say that a reasonable person confronted with a choice between suffering the limitations of deafness while gaining the benefit of this mode of expression and avoiding the limitations of deafness but not being able fully to appreciate the unique expressive power of sign language would choose the latter. Yet it seems that the appropriate standpoint from which to decide whether to intervene to prevent children from being born deaf or continuing to be deaf is that of a reasonable person confronted with a choice ex ante.

Notice that this response to the deaf culture argument does not commit us to the view that a competent deaf individual ought to be subjected to hearing-restoring surgical intervention against his or her will. Our claim is only that the appropriate perspective for estimating whether to prevent or restore loss of hearing in an individual who is not competent to decide for himself or herself (a fetus or a child) is that of a reasonable person confronted with the choice of whether to be deaf or not. Nothing we have said about the commitment to removing barriers to opportunity warrants overriding the purely self-

regarding choices of competent individuals. The point, rather, is that the fact that being deaf can bring special benefits is not a sufficient reason for one person (a parent) to choose that another, nonconsenting person (a child) should suffer this impairment.

It may be possible to imagine a world in which a reasonable person, confronted with such a choice, would choose deafness, but this is not our world. To make such a choice reasonable for most people would require an enormous reallocation of social resources, indeed a radical restructuring of our modes of production and social institutions, in order to make it true that for most people who are deaf, the benefits of membership in the deaf community outweigh the limitations on opportunity that deafness brings.

The next sections of this chapter take up the issue of the scope and limits of the obligation to change society in order to reduce the opportunity-limiting effects of disabilities. There we argue that although such an obligation exists, it is a limited obligation. It is limited by the legitimate interest that persons without disabilities have in being able to participate in cooperative schemes that are suitable to their own capacities.

A proponent of the deaf culture argument might not be convinced, however. He might respond as follows:

Everything you say about being deaf is equally true of being black or being gay. In our society, being black or gay imposes significant, often severe, limitations on a person's opportunities. But surely this is no reason to prevent the birth of blacks or gays. Indeed, there is something grossly immoral about the very idea of striving to have a world in which there are no gays or blacks on the grounds that we ought to avoid bringing people into the world who suffer the limits on opportunity that people from these two groups often suffer. (Suppose there turned out to be a "gay gene" or complex of genes that significantly increased the probability, across a wide range of prevalent social environments, that an individual would be gay. Suppose also that the presence of this gene or complex of genes could be accurately detected in fetuses.)

There is, however, a fundamental difference between the limitations on opportunity that result from being deaf and those that result from being gay or African-American. The limitations a gay or black person suffers are injustices in a quite uncontroversial sense: They are forms of discrimination. While deaf people and others with disabilities certainly do continue to experience discrimination, they would continue
to suffer limited opportunities even if there were no discrimination against them. This difference is significant, because it has an important implication for how we ought to regard the costs of eliminating limitations on opportunity that result from being deaf as opposed to those that result from being gay or black.

The fact that it is costly to remove barriers of discrimination against blacks or gays has no moral weight because no one can have a morally legitimate interest in preserving unjust arrangements. (Achieving a fair distribution of the costs of reform is another matter, of course.) However, as we will argue in detail in the next section, the costs of changing society so that having a major impairment such as deafness imposes no limitations on individuals' opportunities are not so easily dismissed. Those costs count from a moral point of view, because there is a morally legitimate interest in avoiding them. Understanding what this interest is and how it can conflict with the interest that persons with disabilities have in being able to interact socially without limitations on their opportunities takes us to the heart of the theory of the morality of inclusion.

THE SOCIAL CONSTRUCTION OF DISABILITY AND THE MORALITY OF INCLUSION

Thus far we have examined and evaluated the allegation that the new genetics, even when restricted to the apparently benign enterprise of preventing or curing genetically based diseases, is nonetheless exclusionary, like the old eugenics. One complaint frequently raised by some members of the disabilities rights movement remains to be considered. As we noted earlier, it takes the form of an arresting slogan: We should direct our energies to "changing society, not people." Addressing the view behind the slogan forces us to face squarely the last of the three questions that a theory of the morality of inclusion should answer: To what extent is there an obligation to ensure that the nature of society's most fundamental framework for cooperation renders it more rather than less inclusive?

The slogan that we ought to "change society, not people" is an exhortation to modify our cooperative schemes to enable those who are now disabled to function effectively in them, rather than using genetic or other medical interventions to prevent or remove the characteristics of persons that make them unable to function effectively in cooperative schemes as they are now structured. Initially, at least, proponents of this slogan have focused on modifications of the physical features of the social world — installing curb breaks to make streets navigable for those in wheelchairs, ramps so that these individuals can enter public buildings, braille signs in elevators, and so forth.

But in principle the slogan has much more radical implications. Some people we now regard as disabled are barred from effective participation in various activities not because they lack physical access to them, but because a mastery of the complex rules, procedures, and symbolic manipulations required for these activities is beyond their cognitive or perceptual capacities.

Taken literally, then, the disabilities rights slogan urges us to simplify our cooperative schemes, if necessary, to make them more inclusive. Furthermore, the implication is that modifying our cooperative schemes is always or at least generally morally preferable to modifying people so that their capacities better match the demands of our cooperative schemes.

Distinguishing Disabilities from Impairments

The force of the disabilities rights slogan stems from a recognition of the fact that disabilities are at least in part socially constructed. To clarify what this means and why it is relevant to the morality of genetic interventions to prevent disabilities, it is first necessary to distinguish a disability from a physical or mental impairment. Building on this analysis, we will argue that in some cases it is not only permissible but morally preferable to modify individuals rather than the social environment.

By a physical or mental impairment we mean an impairment of some aspect of normal functioning for our species. For example, a lesion on the optic nerve that results in abnormally poor vision, whether caused by a gene, an infection, or trauma, is an impairment of (visual) functioning. Although we will sometimes simply speak of an impairment, an impairment of normal species functioning is what we will mean.

Impairments often result in disabilities, but they need not. A disability is inherently relational: Being disabled is being unable to do

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1 What we refer to here as an impairment may also be called a defect; however, some find the term offensive, given the unfortunate tendency of some to slide from talking about "a person who has a defective gene" to "a defective person."
something. More specifically, to have a disability is to be unable to perform some significant range of tasks or functions that individuals in someone’s reference group (e.g., adults) are ordinarily able to do, at least under favorable conditions, where the inability is not due to simple and easily corrigeable ignorance or to a lack of the tools or means ordinarily available for performing such tasks or functions. Each of these elements of the analysis of a disability warrants further explication.

First, someone may be unable to perform a certain range of tasks or functions but able to perform many others. Accordingly, in ordinary parlance we distinguish, somewhat misleadingly, being partially and totally disabled – even though many if not most of those who are labeled totally disabled are in fact able to perform a wide range of tasks and functions.

Second, disabilities are relative to a reference group. Where no members of a certain group are able to perform certain tasks and where the group is identified by reference to features other than this inability, we usually do not speak of any one of them being disabled. For example, because no infants are able to drive cars, we do not say that any infant is disabled in this regard.

Third, disabilities are inabilities that cannot be fixed by simply providing information or by supplying tools or means ordinarily available. If someone is unable to perform some task only because he or she has not been given the instructions for doing so (and most people, or most people who, like this individual, are competent adults, would not be able to perform that task without being supplied instructions), the person is not disabled relative to that task (e.g., a man who is unable to tie special knots but could readily tie them if told how to do so does not have a knot-tying disability). If someone is unable to do something only because he or she lacks the tools ordinarily required for doing it, the person is not disabled (e.g., a woman who is unable to hammer a nail only because she lacks a hammer is not disabled in this regard). On the other hand, if someone is blind and as a consequence of that blindness is unable to perform some tasks that others who are otherwise like the individual can perform and that the person could perform but for the blindness, then that individual has a (visual) disability.

Disabilities thus understood are not the same as physical or mental impairments, although impairments, if not compensated for, corrected, or prevented, can result in disabilities. Whether an impairment of the functioning that is normal for our species results in a disability depends on the social environment of the individual.

A simple illustration will bring home the significance of this crucial point. Suppose that someone has a hearing impairment due to sustained exposure to very loud noises. Damage to the auditory nerve makes the person unable to hear sounds in a certain range of frequencies, sounds that members of the human species with normal hearing can detect. However, the range of frequencies the individual cannot hear results in no disability because, given that person’s social environment, nothing he or she is likely to be required to do or would benefit from doing requires the ability to distinguish sounds in that range.

To summarize: Although every impairment of normal functioning constitutes an inability (to perform a normal function), not all impairments result in disabilities. Impairments become disabilities in one sort of social environment but not others.

Once the social nature of disabilities (as distinct from impairments) is understood, we can fully appreciate the force of the slogan that we should change the social environment, not people. The point is that if we are willing and able to change the social environment in appropriate ways, we can prevent an impairment from being a disability. If the social environment does not demand that individuals have a particular ability, then their lack of that ability due to an impairment of normal species functioning is not a disability.

Earlier we argued that justice may require genetic interventions to prevent disabilities because equality of opportunity is a component of justice and disabilities limit peoples’ opportunities. The point of the disabilities rights movement slogan is that it is a mistake to assume that the only way or the preferable way to prevent disabilities – and hence to achieve equal opportunity – is by preventing the physical or mental impairments that result in disabilities. Instead, we can break the connection between having an impairment and being disabled – if we are willing to make sufficient changes in our social environment.

It is quite correct to emphasize that there are two ways, not one, to prevent disabilities. One is by preventing impairments; the other is by modifying social arrangements so that impairments do not result in disabilities. But we still need an account of why we should, as the slogan says, prevent disabilities by modifying social arrangements rather than by modifying people.
Options for Eliminating Disabilities

According to the foregoing analysis, a disability is a mismatch between an individual’s abilities and the demands of a range of tasks. Given that this is so, there are four basic ways in which a better match could be achieved.

- Changing the individual through education, training, or some other nonmedical means.
- Changing the individual by medical means, including interventions to change her genome or to modify or counteract the effects of genes through genetic pharmacology.
- Changing relevant features of the physical infrastructure of social interaction.
- Changing the nonphysical – that is, the institutional – infrastructure of social interaction.

This last option is less familiar than others, but is in principle far-reaching in its implications. A small-scale, greatly simplified example will illustrate. Suppose that we wish to play a card game in which everyone in a mixed group of individuals ranging in age from 5 to 50 years can successfully participate. The “institutional infrastructure of social interaction” here is (mainly) the rules of the game. Choosing an institutional infrastructure means choosing which game, defined by which set of rules, will be played. If the game chosen is contract bridge, then some individuals in the group – namely, the 5 year olds – will not be able to participate effectively. There is another option, however: A simpler game (a less demanding infrastructure for social interaction) can be chosen so that everyone will be able to participate successfully. We can play “go fish.”

The question before us then is this: Why should we systematically favor modes of preventing disabilities that involve changing the physical or institutional infrastructure for interaction rather than changing the individual?

CHOOSING A DOMINANT COOPERATIVE FRAMEWORK

The Concept of a Dominant Cooperative Framework

Suppose that instead of looking for a card game to occupy us for a few hours, we are choosing what might be called the dominant cooper-

ative scheme for our entire society for the indefinite future. Doing this means we are choosing who will be disabled and who will not. The same individual may be disabled relative to one cooperative scheme, but “abled” relative to another (Wikler 1983; Buchanan 1993, 1995, 1996).

The dominant cooperative scheme in the United States and other industrial economies is highly complex. Among its more important elements are these: an institutional structure that includes a private and a public sector, each with its own distinctive norms of conduct; the dominance of competitive markets in the private sector; a complex division of labor; a legal system that defines “competent” individuals and confers on them an extensive range of civil and political rights, including the right to engage in exchange relationships under the law of property and contracts; and a thoroughgoing reliance on written language and symbols. This sort of cooperative scheme, which for convenience we can call “the industrial-symbolic economy,” requires individuals to have a complex array of literacy and numeracy skills if they are to participate effectively in it. These skills may not be needed to thrive in other, “developing” societies, where the division of labor is not so elaborate, where contractual relations and interactions over large distances and across long stretches of time are not so common, and where communication is exclusively oral. Accordingly, some individuals may be disabled in our sort of society, but not in others.

There are other prerequisites of successful participation in the industrial economy that may be less obvious. This sort of cooperative framework operates on the assumption that, for the most part, individuals (as opposed to families or clans) are to gain the materials of life through their own labor, which is to be sold in the market. The paid labor activities that are available to individuals in this economy in turn require certain minimal levels of physical strength, mental alertness, and stamina, and these in turn cannot be sustained without a certain minimum caloric intake, as well as rudimentary shelter and clothing.

Economists who specialize in economic development have begun to emphasize that in many parts of the world there are thousands of individuals who lack the basic resources for participation in the industrial-symbolic economy. They are unable to sell their labor or at least are unable to work long enough hours at a high enough wage to be able to purchase the food and shelter needed to live reasonably long lives, much less to thrive in the new cooperative framework that is rapidly replacing traditional modes of production. In the most extreme
cases, malnutrition during childhood and the enervating effects of lifelong parasites produce generations of individuals who are cognitively impaired and so physically weak that they are unemployable, except perhaps at very low rates for brief periods during childhood. Developmental economics, then, gives concrete examples of what it means to be excluded from effective participation in a dominant cooperative framework — and of how devastating the consequences of exclusion can be.

There are other, more subtle ways in which individuals can be excluded from effective participation in the dominant cooperative framework than by lacking sufficient material resources to be mentally or physically capable of meeting its demands. In our society, many individuals are excluded because they are deemed to be “incompetent.” Typically, rough and ready classifications of abilities along with equally crude legal conceptions of the level of these abilities an individual must possess to qualify as “competent” serve to qualify some and disqualify others from entering into contracts, marrying, disposing of property, and so forth. It is tempting to assume that these “gatekeeping” standards are, at least in principle, grounded on purely paternalistic considerations — that is, that minors or the seriously retarded are to be excluded from entering into contracts, for example, solely in order to protect them.

On reflection it becomes apparent, however, that those who are able to participate effectively in such complex interactions have an interest in excluding from participation those who are not. As the example of the very young children attempting to play contract bridge shows, participation by “disabled” individuals can cause “discoordination” and reduce the benefits that the “abled” might otherwise reap from complex forms of cooperation. The abled — those whose capacities can meet the demands of the more complex scheme of cooperation — have an interest in having that scheme chosen. Let us call this interest the “maximizing interest,” to distinguish it from the “interest in inclusion,” the interest that individuals have in being included in the dominant cooperative framework of their society.

It is important to note that dominant cooperative frameworks for entire societies have never been chosen, strictly speaking. Instead, they have emerged not according to any overall conception or plan or as the result of collective deliberation concerning alternatives, but rather from the cumulative and largely unanticipated effects of many individuals' actions over many generations.

At certain critical junctures in a society’s history, however, it may be possible to exercise some degree of control over some important elements of the dominant cooperative scheme, including those that will have a significant impact on who will be disabled. On the threshold of the genetic revolution, we find ourselves at such a juncture.

The opportunity to choose key elements of a dominant cooperative framework arises if three conditions are satisfied. First, it is recognized that new technologies are emerging that will have a significant impact on the dominant cooperative framework. Second, there are political institutions that enable some or all citizens to have an effective voice in consciously determining whether or how the emerging technology will be deployed. And third, a sufficient number of politically influential citizens or government officials are motivated to try to exert some control over the character of the framework. If these conditions are satisfied, important features of the dominant cooperative scheme may become objects of social choice, just as certain features of the physical infrastructure for interaction already have become, as the result of the campaign for physical access to public spaces for the disabled. Whether the third condition is satisfied may depend in part on whether there is an awareness that society has obligations of inclusion. For this reason, getting clearer about the morality of inclusion may be of some practical importance.

Why the Choice Is a Matter of Justice

The choice of a dominant cooperative scheme is a matter of justice because it determines who is disabled and who is not and because whether a person is disabled has profound consequences for his or her status in society, opportunities, and overall life prospects. Because of the economic and social advantages of being able to participate effectively in the dominant cooperative scheme, individuals have a fundamental interest in not being disabled, that is, in the dominant cooperative scheme being one whose demands are matched by their abilities. This is the interest in inclusion. That this is a morally legitimate interest seems clear enough, because inclusion is in general a necessary condition for protecting a person’s most basic interests — in well-being, in having a wide range of opportunities, and in self-esteem.

There is another reason, however, why the choice of a dominant cooperative scheme is a matter of justice. There is an opposing interest that a just social order will accord some weight: the maximizing inter-
est. Each individual has an important and morally legitimate interest in having access to a cooperative scheme that is the most productive and rewarding form of interaction in which he or she can participate effectively. Just as those whose abilities do not satisfy the demands of the dominant cooperative scheme are at a disadvantage, so do those who could participate in a more productive and rewarding scheme but are barred from doing so by restrictions designed to make the scheme more inclusive lose something of value. The problem with the slogan that we should “change society, not people” is that if taken literally, it ignores the legitimacy of this second interest.

The fact that there are two legitimate interests, not one, at stake in the choice of cooperative schemes is tacitly recognized in the most significant legislation addressing the needs of people with disabilities to date, the Americans with Disabilities Act (ADA). This federal legislation recognizes as legitimate the interest in inclusion by requiring private and public employers to undertake accommodations to the special needs of those with disabilities.

We have argued that a commitment to equality of opportunity requires efforts to prevent disabling impairments. At present, however, biomedicine’s powers of prevention are very limited. The requirement that workplaces be modified to accommodate persons with disabilities is a reasonable response to the inadequacy of the preventive strategy. In that sense, the same moral considerations that lead us to try to prevent disabling impairments also support the requirement of accommodation (Daniels 1997).

It is important to emphasize that the ADA adds the qualifier that all that is required in the name of equal opportunity is “reasonable” accommodations. The addition of this qualifier signals a recognition that the interests of employers, of workers who do not have disabilities, and of consumers of the goods and services that public and private organizations produce are also legitimate and should be accorded some weight.

The choice of a dominant cooperative scheme is a matter of justice because justice is concerned, among other things, with achieving a proper balance of conflicting legitimate interests. A closer look at our earlier example of a card game will make it clearer that the two interests in question are really in opposition, and that they are both legitimate.

The youngest persons in our imagined example have an interest in the chosen game being one in which they can participate effectively, and this means a simpler game. The older persons have an interest in the chosen game being one that is more challenging and complex, since this will be more enjoyable for them. This is not to say that the opposition of interests between the two groups need be total. It may be that some of the older people have an interest in being in a game that includes everyone (perhaps they are the grandparents of the youngest children). However, when the choice of a dominant cooperative framework is at stake, and extremely large numbers of unrelated people are involved, we cannot count on such an interest in inclusion being universal or dispositive.

There is another feature of the choice of a card game that is absent in the choice of a dominant cooperative framework for society that makes it more plausible to say that the latter choice is a matter of justice. In the card game, it may be feasible to resolve the conflict of interests simply by forming two different games, suited to the respective capacities of the two groups. Generally speaking, this is not an option in the case of the choice of dominant cooperative frameworks under modern conditions. The global economy is increasingly homogenizing the dominant cooperative schemes of all societies, forging a single world society defined by a single dominant cooperative scheme—that of the industrial-symbolic economy. Most people will have no choice but to try to participate in this emerging globally dominant cooperative framework. The conflict between the interest in inclusion and the maximizing interest cannot be avoided by sorting the parties out into different, noncompeting cooperative frameworks.

Overlooking a Basic Problem of Justice It is not simply the advocates of the slogan that we should “change society, not people” who have failed to see that the choice of cooperative framework is a problem of justice. Theorists of justice have not only failed to supply a principled account of how these conflicting interests ought to be balanced; they have almost without exception failed to identify the problem as one of justice. Instead, they have framed the first problem of justice as that of how to determine the fair distribution of the burdens and benefits of social cooperation, proceeding on the assumption that the basic character of the cooperative scheme is given, and that most or all individuals to whom distributive justice is owed are participants in that cooperative scheme. There is a prior problem of justice, however, as we have just seen: that of choosing the cooperative framework itself.

We have emphasized that because both of the opposing interests are
morally legitimate, the prior problem of justice cannot be resolved by ignoring one of the interests. Instead, there must be a balancing of interests. Presumably a proper balancing will give greater weight to the interest in inclusion, at least where the pursuit of greater inclusiveness does not result in a cooperative framework that is unable to deliver a reasonable degree of prosperity and a reasonable range of challenges and fulfillments for those who could have effectively participated in a more complex and demanding framework. Under these conditions, it is plausible to conclude that being excluded from effective participation is worse than simply not being able to participate in the most rewarding and fulfilling cooperative framework among those that a person can participate effectively in.

However, to say that the interest in inclusion is generally speaking weightier than the maximizing interest is not to say that the latter interest should be given no weight at all in the choice of cooperative framework. In some instances, a proper balancing of the interest in inclusion and the maximizing interest— or, more positively, an effort to achieve a better fit between individuals’ abilities and the demands of the dominant cooperative framework— may require changing individuals. Moreover, as we have already argued, this way of achieving a better fit cannot be ruled out on the grounds that it necessarily expresses negative judgments about the worth of disabled individuals or denies their right to exist. In a just society in which the powers of genetic intervention are highly developed, both society and individuals will be changed in order to reduce the incidence of disabilities, both for the sake of those who would have been disabled and for the sake of others.

**Justice as Self-Interested Reciprocity versus Subject-Centered Justice**

We have just seen that the debate over the use of genetic interventions to prevent disabilities raises a fundamental issue for the morality of inclusion: to what extent, if any, does justice require that social resources be used to help achieve a better fit between persons and the dominant cooperative framework, so that more persons can be full participants or normal competitors? Here it is important to point out that how this question is answered depends on a root choice among types of theories of justice (and of ethical theories generally).

Two basic types, justice as self-interested reciprocity theories and subject-centered theories, yield radically different answers about obligations of inclusion generally, and hence about the scope of societal obligations to use genetic interventions to promote inclusion. While the prospect of increased powers of genetic intervention does not uniquely raise this watershed issue in ethical theory, the debate between the proponents of genetic intervention and those who regard it as inherently exclusionary makes the theoretical choice more vivid and pressing.

Theories of justice as self-interested reciprocity hold that whether an individual is a member of the community of subjects of justice— individuals who have rights— depends on whether that individual can make a net contribution to social cooperation. Examples of this type of theory are woven through the history of philosophy in the West; variants are found in Epicurus, Hobbes, Hume, and, with the greatest sophistication, in the work of David Gauthier (Buchanan 1990). The core idea is that obligations of justice are based ultimately on rational self-interest and that consequently we have no obligations to those who have nothing to contribute to our well-being. Chapter 2 noted that the tacit acceptance of some version of justice as reciprocity may explain the strident tone of moral indignation that some eugenicists leveled at those “inferior types” whom they regarded as “useless eaters,” nothing but a drain on social resources.

In contrast, theories of subject-centered justice do not make an individual’s membership in the community of beings with rights depend on the ability to make a net contribution to social cooperation. Different variants of subject-centered theories pick out different characteristics that confer membership in the community of subjects of justice: Kantian theories emphasize the capacity for practical rationality (the ability to be motivated by the thought of what one ought to do); utilitarian theories emphasize sentience (the capacity for pain and pleasure, or more broadly, for happiness and unhappiness).

Subject-centered theories, unlike justice as self-interested reciprocity theories, provide the basis for taking the morality of inclusion seriously. According to these, persons are entitled to basic moral respect regardless of whether they have the capacity to make a net contribution to social cooperation. Since exclusion from the dominant cooperative framework is damaging in many ways, such theories require that we manifest our equal respect for all by undertaking efforts to enable individuals to be full participants in the dominant cooperative scheme. Justice as self-interested reciprocity theories, in contrast, recognizes no such obligations of inclusion; efforts to include individuals in a cooperative scheme are only required (as a matter of prudence) if the
contribution they will be enabled to make exceeds the costs of including them.

It is not within the scope of this volume to mount a systematic argument to show why we believe subject-centered theories to be superior. Here we will indicate only how radical justice as self-interested reciprocity is and how discordant it is with the general framework of moral assumptions within which our inquiry has proceeded. Put most simply, subject-centered theories are consonant with some of our most confidently held general considered moral judgments, including the conviction that there are human rights and that the most severely disabled people are entitled to equal moral respect. Human rights, by definition, are those that individuals have simply by virtue of their humanity, and being a net contributor to social cooperation is not a necessary condition for being human. (For a systematic criticism of justice as self-interested reciprocity, see Buchanan 1990.)

For our present purposes, the key point is that if an endorsement of the use of genetic intervention to prevent disabilities is to avoid the charge of being exclusionary, it must be unambiguously grounded in a rejection of justice as self-interested reciprocity. The first step toward developing a theory of the morality of inclusion to guide personal choice and social policy in a society of greatly enhanced genetic powers, then, is a resolute commitment to subject-centered justice.

How Genetic Interventions Might Affect the Character of the Dominant Cooperative Scheme

To revert to one of the scenarios sketched in the Introduction, suppose that advances in immunology based on increased knowledge of genes make it possible to enhance resistance to common illnesses, including the common cold, flu, depression, and cardiovascular diseases. The mode of intervention might be gene therapy or, more likely, genetic pharmacology. Those who can afford health insurance that covers these interventions will be sick less often and their illnesses will be less severe.

Suppose also, as is now the case, that most people in this country have access to health insurance and hence to these beneficial interventions but, as is also the case, that a significant segment of the population—say 15 percent—lack insurance and cannot afford the interventions. Under these conditions, which are far from fanciful, standard employment contracts, as we saw in Chapter 3, might come to be

geared to the health needs of those who have benefited from these enhancements. The number of sick days allowed to employees without loss of wages might decrease significantly, reflecting the lower risk of illness that now characterizes the “enhanced” majority.

In these circumstances, those who lack access to the interventions in question would face severe limitations on employability because they would be unable to meet prevalent expectations for work performance. They would be disabled relative to their social environment in the way that people with chronic illnesses are in our present social environment. Unequal access to enhancement technology would function to exclude them from the dominant cooperative scheme. Their position would be analogous to that of individuals in developing countries who are unable to compete in the labor market because they lack the minimal caloric intake or are severely weakened due to malaria or other parasites.

A somewhat more speculative example is based on the fact that the dominant cooperative framework in developed countries is increasingly shaped by sophisticated information processing technology. Suppose that advances in our knowledge of how genes code for proteins that affect brain functions eventually make it possible to enhance certain significant aspects of cognitive and perceptual performance that are relevant to the ability to use information processing technologies, including ever more sophisticated computers.

Those who are fortunate enough to be able to afford access to these interventions have faster rates of neural processing, can recognize and recall more accurately longer sequences of complex strings of symbols, and can perform more quickly the complex operations required for the optimal use of sophisticated information processing equipment. If a majority or a substantial portion of the population enjoyed such enhancements, their greater capacities might influence the direction of technological development—just as the increase in average height of recent generations has influenced architectural specifications, the length of beds, and the distance between the driver’s seat and the brake pedal in automobiles. Computer hardware and software might exploit these enhanced capacities, with the result that those who lacked them could not operate the new systems optimally or even with acceptable proficiency. In this case, genetic intervention that provided enhancements for some would result in exclusion for others.

This is not entirely a science fiction example. Persons with visual disabilities and deficits in motor skills involving the use of their hands
are already barred from access to most computing technologies simply because the operating mechanisms (keyboards, screens, the mouse, and so on) are designed for those who do not have these disabilities. If new information technology continues to evolve without any attempt to widen access to it, then the limits on opportunity that people with disabilities already face may be greatly exacerbated, as employability and educational advancement come to depend more and more on the ability to use this technology effectively.

There is at the time of this writing at least one large-scale grant project that addresses an important aspect of the general problem: access to the “information superhighway” and related computer technologies (Perry 1996). The aim of this project is to help ensure that equipment will be designed to minimize barriers to access to the Internet and its successor technologies. The rationale for the project rests on the same insight that our hypothetical example is meant to convey: If technology is designed with reference to “normal” abilities, then it may restrict rather than widen opportunities for some, and this is true regardless of whether those who do not have “normal” abilities suffer from genetic or other impairments or are simply too poor to afford the interventions that set a new level of “normality” with reference to which new technologies are designed.

The preceding examples reveal how the availability of genetic interventions according to ability to pay might result in some people being excluded from the dominant cooperative framework or at least from certain important parts of it. But it must be emphasized that genetic interventions can prevent disabilities as well, by preventing the impairments that, given the features of the existing cooperative scheme, result in disabilities that seriously limit peoples’ opportunities.

**KNOWLEDGE OF GENETIC DIFFERENCES AND THE MORALITY OF INCLUSION**

Advances in genetic knowledge will force us to confront the basic issues of the morality of inclusion even when there is no possibility of genetic intervention to create a better fit between the abilities of individuals and the demands of the dominant cooperative framework.

In many cases, the most valuable knowledge concerning genes will be information about the interactions of specific genes with specific environments. In particular, it is very likely that we will learn that individuals with particular genotypes require particular environments, both physical and social, if they are to flourish. And in some cases, the needed environment will not be the one that now exists.

In this sense, the great expansion of knowledge that is made possible by the Human Genome Project and related genetic research may make the nature/nurture debate moot rather than resolve it. Instead of asking Which is more important (for this problem, this characteristic), genes or environment? the question will increasingly be Which combinations of genes and environments will produce the desired outcome? Better knowledge of how genes function will be knowledge of how they function in various environments, and this will enable us to identify and to select or construct the most beneficial environments for achieving desired results, including the goal of having more individuals as effective participants in the dominant cooperative framework.

Again, examples will clarify. Greater knowledge of the functioning of genes that influence sensory and neural processes involved in learning to read may lead us to the conclusion that there is no one optimal environment for learning to read for all people. Instead, we may learn to group individuals by genotypes and then develop different environments that are tailored to the needs of different groups. Increased genetic knowledge may lead to more effective environmental intervention, rather than to genetic intervention.

Knowledge of how different genotypes react differently in different environments may therefore open up new options for eliminating barriers to equal opportunity. However, the existence of these options raises new and perplexing problems of justice. The environment that is beneficial for one genotypic subgroup may be suboptimal or even dangerous for others. But tailoring an optimal environment for each genotypic group will, in some cases, be either impossible or extremely costly. If the majority learns to read or learns mathematics quite readily in one type of environment, but we discover that there is a minority of individuals who will do poorly unless provided with a special and rather expensive environment, what cost is society obligated to bear to provide it?

This question is already being debated in discussions of educational policy for persons with learning disabilities. It has become evident that tailoring learning environments to the special needs of students can produce significant benefits but that doing so is costly, partly because of the loss of economies of scale and the need for special training for teachers. Not surprisingly, parents of children who do not need these special environments are sometimes concerned that the resources allo-
cated to construct them represent an unacceptable subtraction from what is available to their children. As increased genetic knowledge enables us to sort people into groups having conflicting interests in how public funds are to be allocated and how public institutions are to be designed, problems of justice of this sort will arise with increasing frequency and urgency.

Knowledge of how different genotypic groups can be benefited or harmed by the same environment may also enormously complicate the task of designing just and effective public health policies. We have tended to think of public health measures as universalistic – as quite general interventions that are in the interests of all members of society, and hence as a form of social action that reinforces solidarity rather than creates divisions of interest. Everyone benefits from cleaner water and purer food, the elimination of the major infectious diseases of childhood through mass immunizations, and so on.

New genetic knowledge, however, may in fact serve to divide us one from another. For example, advances in genetic knowledge might lead to the conclusion that the majority of the population could benefit by introducing a particular chemical into water supplies, but at the risk of increasing the incidence of cancer for a minority. Similarly, devising effective public education programs to encourage healthy lifestyles will be much more difficult if we learn that what is good for some is bad for others. It might turn out, for instance, that ingesting at least 60 grams of protein daily (which some nutritional experts now recommend) has beneficial results for many people but heightens the risk of colon cancer for others, or that vitamin C supplements reduce the risk of cancer for the majority but cause liver damage for a minority.

It has often been remarked that new knowledge of genotypic differences may result in stigmatization and perhaps reinforce racism and similar exclusionary and discriminatory attitudes. What has not been sufficiently appreciated is that increased knowledge of genetic differences will force us to confront the most basic issues of the morality of inclusion. Among the most important of these is the extent of the obligation to commit social resources to ensuring that genotypic minorities – whether they be people with what we now recognize as disabilities such as blindness, or individuals who simply need a different environment in which to learn to read – do not experience limitations on their opportunities because the social world they inhabit has been designed by others, for others.

The possibility that new knowledge of genetic differentiation will create or exacerbate problems of just allocation of resources illustrates the general structure of the problems that a developed theory of the morality of inclusion must address. On the one hand, there is the morally legitimate interest in inclusion, on the other, what we have called the “maximizing interest.” What a theory of the morality of inclusion ought to supply is a principled, defensible way of balancing these interests. No such theory is offered here. Something can be said, however, to indicate the kinds of choices that would have to be made in constructing such a theory.

How much weight the interest in inclusion should be given vis-à-vis the maximizing interest, or other morally legitimate interests, will presumably depend in part upon whether there is a risk of near total exclusion from the dominant cooperative scheme. In other words, if a minority of individuals will simply not be able to participate at all in the economic mainstream of society unless societal resources are allocated to provide them with the special interventions they require, they have an exceptionally strong claim on resources. (This would certainly be the case for a Rawlsian theory of distributive justice or any theory that gives priority to the worst off, since being excluded from the basic cooperative scheme is presumably one of the worst liabilities an individual can have.) If a disability does not bar certain individuals from participation in a wide range of cooperative frameworks, including the dominant one of their society, but merely limits the effectiveness of their participation above some fairly generous threshold, then presumably their claim for special resources is weaker. Different types of general moral theories will give greater or lesser weight to the claims of the worse off, and this will result in different responses to the problem of exclusion.

According to some moral theories, at least, the numbers may count as well: within limits, the larger the genotypic minority requiring special allocations for health care or for education, the stronger their claim on resources. And it is worth stressing here that a theory need not be utilitarian in any thoroughgoing sense to make room for some consideration of the numbers.

Nor is it a matter of either opting for an absolute priority on improving the condition of the worst off or simply doing what improves the condition of the largest numbers of persons. A developed theory of the morality of inclusion might well include a limited priority for the worst off (giving them an especially weighty claim on resources
needed to bring them up to some threshold of participation in the dominant cooperative scheme, to make them “normal competitors” in the language employed in Chapters 3 and 4), balanced by a principle that accords increasing weight to the conflicting interests of others as their numbers increase, once the worst off have reached the threshold of participation. Or, since the resources needed to bring the worst off of the worst off up to the threshold of participation may be virtually unlimited, a more appropriate balance might limit the commitment to bringing (all of) the worst off up to “normal competitor” status by a consideration of the opportunity-costs to the better off, if their numbers are sufficiently greater. These rough reflections are intended only to indicate the rich potential for working out a theory of the morality of inclusion.

CONCLUSION

In previous chapters we have argued that both justice and our obligations to prevent harm make genetic interventions to prevent disabilities not only permissible but also obligatory. We have also argued that the use of genetic interventions for enhancements, not just for the prevention or cure of disease, is also permissible if it occurs within the constraints of justice we have tried to specify.

This chapter has explored some of the most radical and disturbing challenges to the entire enterprise of genetic intervention – those forcefully raised by some members of the disabilities rights movement. The unifying theme of these challenges is that the new genetics, like the old eugenics, is exclusionary, despite its proponents' efforts to present it as an inclusive endeavor for human betterment through the conquest of disease. In the process of articulating and evaluating various arguments that purport to show the exclusionary nature of genetic intervention, we have seen how anticipated advances in genetic science raise in vivid and sometimes novel forms some of the most basic but neglected issues of ethical theory – problems we have grouped under the rubric of the morality of inclusion.

The new genetics does provide weapons for exclusion. This is undeniable, even though, as we have seen, there is nothing inherently exclusionary about the enterprise of improving human lives through the selection of characteristics by the application of genetic knowledge. Members of the disabilities rights movement have performed an invaluable service by alerting the public to the potential for exclusion which the new technology represents. Indeed, they have been pioneers in exploring the morality of inclusion, treading ground that most moral theorists have lamentably neglected. While the theorists have concentrated on the problem of how to distribute the burdens and benefits of social cooperation among those who have ready access to the cooperative framework, disabilities rights advocates have rightly emphasized that there is a more basic moral issue: How can our cooperative frameworks – and above all our attitudes toward those who have disabilities – be modified so as to achieve greater inclusion?

In spite of its potential for exclusion, the new genetics also creates hitherto unimaginable opportunities for including more people as effective participants in fulfilling forms of social interaction, through genetic intervention and the use of genetic knowledge to tailor environments to individual needs. An awareness of both the negative and the positive potential of the new genetics prompts a more systematic development of ethical theory – one that recognizes obligations of inclusion but that also acknowledges and articulates the limits of these obligations.