

# Causing Disabled People to Exist and Causing People to Be Disabled\*

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## I. SELECTION FOR EXISTENCE

Attempts to determine or to select what kind of person or people to bring into existence are controversial. This is particularly true of “negative selection” or “selecting against” a certain type of person—that is, the attempt to prevent a person of a certain type, or people of that type, from existing. Virtually everyone agrees that some instances of negative selection are objectionable—for example, that selection against healthy people would be wrong, particularly if this were combined with positive selection of people with serious diseases. But some people believe that all negative selection is objectionable and therefore that all “selection for existence,” whether positive or negative, is objectionable. For if negative selection is objectionable, it seems to follow that positive selection is as well, since the attempt to bring a person of a certain type into existence is simultaneously an attempt not to bring into existence a person who is not of that type. In short, positive selection is implicitly negative as well.

Why would someone believe that, for example, the attempt to avoid having a child with Tay-Sachs disease is objectionable? The reasons given vary but usually appeal to the idea that to decide that certain people ought not to exist is to discriminate against people of a certain type on the basis of values that are contested or not universally valid. I will not discuss the view that all selection is wrong, which is in any case the view of only a small minority.<sup>1</sup> Most people believe that some forms of se-

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1. For objections that seem intended to apply to all forms of selection, see Leon R. Kass, “Implications of Prenatal Diagnosis for the Human Right to Life,” in *Intervention and Reflection: Basic Issues in Medical Ethics*, ed. Ronald Munson, 6th ed. (Belmont, CA: Wadsworth, 2000), 617–24. For cogent responses to many of the common objections to selection, see Dan W. Brock, “Is Selection of Children Wrong?” in *The Enhancement of Human Beings*, ed. Julian Savulescu (Oxford: Oxford University Press, 2006), forthcoming.

lection are benign and indeed desirable, while other forms are pernicious and perhaps impermissible. What makes the difference between selection that is acceptable and that which is objectionable?

I will approach this question by focusing on one particularly controversial form of negative selection: selection against the disabled. Many people do in fact seek to “select against” a disabled child—that is, they seek to avoid having a disabled child and to have a normal child instead.<sup>2</sup> But the practice draws considerable criticism, particularly from disabled people and their advocates. I will argue that the main objections are difficult to sustain because they also seem to imply the permissibility of causing disabilities in ways that are clearly impermissible.

## II. METHODS OF SELECTION

There are various ways of trying to prevent oneself from having a disabled child. The commonest ways involve screening technologies that can be deployed either before or after conception. Preconception genetic screening seeks to detect heritable genetic defects in the potential parents. Other forms of preconception screening look for nongenetic conditions that increase the probability of a person’s having a disabled child. If preconception screening detects a risk factor, there are several ways that this knowledge can be used to reduce the probability of a person’s having a disabled child. If nongenetic screening finds a risk factor for disability, it is sometimes possible to alter the conditions that have elevated the risk. This is significant because many congenital disabilities and most forms of mental retardation are not genetic but are caused by conditions during pregnancy.<sup>3</sup> If genetic screening finds an abnormality in one or both potential parents, they can attempt to avoid having a child at all by practicing contraception or sexual abstinence. Eventually it may become possible to repair defective genetic material in selected parental gametes prior to conception. But at present the most effective way to use genetic knowledge acquired through preconception screening to enable people to have a normal rather than a disabled child is to employ Preimplantation Genetic Diagnosis, or PGD.

2. It may seem objectionable to contrast “disabled” with “normal,” since the latter term has normative connotations that may suggest that those who are not normal are inferior. Rather than coining a term such as “the abled” or using the term “nondisabled” (which would be rather like calling a person of average height a “nontall, nonshort person”), I will simply stipulate that those I will refer to as “normal” are simply those whose abilities of certain types lie above a certain unspecified threshold and are characteristic of the great majority of human beings.

3. Eva Feder Kittay, with Leo Kittay, “On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with My Son,” in *Norms and Values: Essays on the Work of Virginia Held*, ed. Joram G. Haber and Mark S. Halfon (Lanham, MD: Rowman & Littlefield, 1998), 172–203, 180.

Preimplantation Genetic Diagnosis uses in vitro fertilization (IVF) to create multiple embryos, which are then individually tested for genetic defects. This enables the potential parents (or parent) to select for implantation in the woman's womb an embryo that does not have the defect that would cause disability. The remaining embryos, some or all of which may have the defect, are either frozen indefinitely or discarded—the same fates that befall supernumerary embryos created in vitro in fertility clinics.

Preimplantation Genetic Diagnosis is intermediate between pre-conception screening of the potential parents and prenatal screening, which tests the embryo or fetus for abnormalities after implantation in the uterus. If prenatal screening identifies a defect, genetic or otherwise, that will cause the fetus to be disabled, the main remedy at present is abortion. In some cases the abortion terminates the woman's efforts to have a child. There are various reasons why this might be so: her relation with the man with whom she conceived the aborted fetus may have ended, she may regard another pregnancy as too onerous to undertake, the abortion itself may have affected her ability to conceive, and so on. Alternatively, the abortion might be followed by the conception of a different, normal child. One way the potential parents could increase the probability of having a normal child following the abortion would be to use PGD prior to any subsequent pregnancy.

It is, of course, increasingly common for surgery to be performed on fetuses, and it is likely to be possible eventually to correct disabling fetal conditions, genetic and nongenetic, through gene therapy, pharmaceutical intervention, or surgery. To cure a fetus of a condition that would otherwise cause that same individual to be disabled would not be an instance of "selection for existence." It would not prevent a disabled individual from existing but would enable one and the same individual to be normal rather than disabled. It would, one might say, involve selection against disability but not against the disabled. Similarly, a pregnant woman who uses prenatal screening only to enable herself to be better prepared if her child turns out to be disabled is not engaged in selection.<sup>4</sup>

It is important to note certain further distinctions among the different forms of selection. Sometimes people choose between allowing a disabled individual, near the beginning of its life, to continue to live and simply eliminating that individual by killing it. I will call such choices same-child choices. Suppose we begin to exist at conception so that all

4. When I presented a different paper on disability issues at Yale University in 2002, I was told by a member of the audience who worked in a prenatal screening clinic that he and others who practice prenatal screening do so only to enable parents to be better prepared for the arrival of a disabled child.

embryos and fetuses are the same individuals as—that is, numerically identical to—the persons they might later become. In that case all instances of abortion that are not followed by the conception of another child are same-child choices. Selection via killing is obviously a radical means of selection and is permissible, if at all, only in the case of fetuses and, perhaps, newborn infants.<sup>5</sup>

Suppose that, as many people believe, we do not begin to exist until some point after conception. Some people have held, for example, that we begin to exist at the point at which the primitive streak develops in the embryo and twinning ceases to be possible. Others have argued that we begin to exist with the onset of significant activity in the fetal brain (a point that is sometimes referred to as “brain life”). And still others have contended that we begin to exist only when the fetal brain develops the capacity to support consciousness, which occurs sometime between twenty-two and thirty weeks after conception.<sup>6</sup> If some view of this sort is correct, only abortions performed after one of us has begun to exist in association with the fetal organism would constitute same-child choices. An abortion performed before that point would not kill an existing individual of our sort (though it would, of course, kill a developing human organism) but would instead prevent one of us from coming into existence. If such an abortion would not be followed by the conception of a different child, it would be an instance of negative selection via what I call a child-or-no-child choice—that is, a choice that determines whether or not an individual will exist. Another example of a child-or-no-child choice is a choice following preconception screening of whether to conceive a child. If screening reveals a risk factor and the choice consequently goes against conception, this too is an instance of selection.

Continue to assume that we do not begin to exist until some point after conception. Suppose that a pregnant woman undergoes prenatal screening prior to that point, discovers that the fetus has a defect, and immediately aborts the pregnancy. She then conceives and brings to term another child who turns out to be normal. Suppose she had decided in advance of both pregnancies that she would have only one child, so that she would not have sought a second pregnancy had the first not been aborted. The abortion, by hypothesis, does not kill someone like you or me but merely prevents one of us from existing. The woman’s combined action therefore substitutes a possible normal child for a possible disabled child. It is an instance of selection via what I call

5. I discuss the morality of infanticide in Jeff McMahan, “Infanticide” (unpublished manuscript, Department of Philosophy, Rutgers University, 2002).

6. I have argued for the third of these views in Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life* (New York: Oxford University Press, 2002), chap. 1.

a different-child choice—that is, a choice that determines whether one individual or another will exist. In this case the woman’s choice is between having a disabled child and having a different, normal child.

Consider next a case in which preconception screening detects a risk factor in one or both of the potential parents. If the factor is genetic, they may use PGD in order to try to have a normal rather than a disabled child. Or, if the factor is not genetic, they may seek to correct the conditions that have elevated the risk and only then attempt to conceive a child. In both cases the delay in fertilization would ensure that their child would be produced from different genetic materials and would thus be a different child from the one they would have had in the absence of screening. This too is a different-child choice in which selection is accomplished through the substitution of a possible normal child for a possible disabled child.

There are other examples of the same sort. Again assume that we do not begin to exist until some point after conception. And suppose a woman who undergoes prenatal screening prior to that point discovers a defect in the fetus. In this case there is a treatment, but the treatment involves a radical genetic alteration of the embryo. Since this alteration would, by hypothesis, occur prior to the point at which an individual of our sort would begin to exist, and since it would involve radical genetic modification, we may suppose that it would be “identity determining” with respect to the individual who would develop from the embryo. Let us suppose, in other words, that if the embryo is subjected to genetic therapy, it will develop into a normal child but that this child will be a different individual from the disabled child who would have developed from the embryo in the absence of genetic therapy. This would be a case in which what seems to be a “cure” is in fact a form of selection via the substitution of a possible normal child for a possible disabled child. The therapy as described would prevent a disabled child from existing and cause a different, normal child to exist instead.<sup>7</sup>

Next consider a case in which a radical form of genetic therapy is administered after the point at which one of us has begun to exist in association with the fetal organism. (If we begin to exist at conception, all cases of genetic therapy administered to a fetus will be of this sort.) Suppose that the genetic modification is so significant that it is identity determining. It is controversial whether there could be such a case, but if there could it would not be a case involving cure. Curative therapies must be “identity preserving.” In this case, by contrast, what would ap-

7. For further discussion, see Jeff McMahan, “Wrongful Life: Paradoxes in the Morality of Causing People to Exist,” in *Rational Commitment and Social Justice: Essays for Gregory Kavka*, ed. Jules Coleman and Christopher Morris (Cambridge: Cambridge University Press, 1998), 208–47.

pear to be a cure would in fact be an instance of selection via replacement: an individual who would have been disabled would be replaced by a different individual who will be normal. This would seem to be no different morally from aborting a defective fetus after the point at which one of us has begun to exist and then conceiving a different, normal child. Both would involve eliminating an actual individual and creating a different individual in its place.

### III. THE OBJECTIONS TO SELECTION

Those who oppose the use of these methods to prevent the existence of individuals with serious diseases also, and a fortiori, oppose their use to prevent the existence of individuals with disabilities. But most people believe that a principled distinction can be drawn between these two forms of selection. People with serious diseases do not, it might be argued, constitute a distinct social category, nor are their afflictions the product of social discrimination. But the disabled, by contrast, do form a salient social category, and, it is often claimed, their problems are to a considerable extent, if not entirely, attributable to social discrimination. On this view, screening for serious congenital diseases and selecting against those who would have them is not invidious or discriminatory, while screening for disabilities and selecting against the disabled is. Efforts to prevent the existence of people with disabilities are relevantly like efforts to prevent the existence of persons of minority races in a racist society or efforts to prevent the existence of female or homosexual children in a society that discriminates against women and homosexuals.

In order to understand more clearly the objections that are specific to selection against the disabled, it is necessary to separate objections that focus on the ends of selection from those that focus on the means. The means sometimes involve killing, as in abortion, or suspension of animation, as when rejected embryos are frozen following PGD. The force of the objections to such means depends, obviously, on the moral status of the embryo or fetus. The objections will be strongest if the embryo or fetus has full moral status, the same status that you and I have. It would have that status if, for example, we begin to exist at conception and have the same status at all times at which we exist (except, perhaps, if we forfeit it through action for which we are responsible). Objections focused on the means will be weaker if the embryo or fetus has a lower but not negligible status. That might be true if, for example, we begin to exist at conception but acquire the properties that confer the highest moral status only gradually, or only at some later point in our development. Finally, there might be no objections to means such as killing and freezing if the embryo or fetus has no moral status, which might be true during the period before one of us begins to exist, assuming that we do not begin to exist at conception.

To understand what people find objectionable about selection against the disabled, we should, to the extent that this is possible, ignore objections that focus on the means and thus may apply equally to other acts that employ the same means but have nothing to do with disability. Suppose, for example, that someone objects to the selective abortion of fetuses that would be disabled. If this person has no objection to preconception screening for a certain disease but objects to the selective abortion of fetuses with that disease, it is reasonable to infer that this person's objection to abortion in the case of disabled fetuses is in part just an objection to the means of selection—that is, to the killing of fetuses. But our concern here is with objections that are specific to selection against the disabled. It may be difficult, however, to achieve a complete separation of questions of ends and questions of means.

What, then, are the objections that focus primarily on the ends rather than on the means? One is that selection against the disabled is itself a form of discrimination. It seeks to rid the world of people of a certain type, either by preventing these people from existing or by preemptively eliminating them before they acquire the moral status that would prohibit their elimination. Another is that selection expresses a malign, pernicious, or demeaning view of the disabled. Both of these objections typically focus on the ways in which the discriminatory or expressive effects of selection are harmful to existing disabled people. The effort to prevent disabled people from existing reinforces other forms of discrimination against existing disabled people by implicitly confirming or endorsing the status of the disabled as undesirable or burdensome. It also, if successful, reduces the number of disabled people, thereby making each disabled person more unusual and more isolated, while at the same time reducing the political visibility and power of disabled people generally. And the view of existing disabled people that is implicitly expressed by attempts to prevent others like them from existing can be deeply hurtful and wounding. Social acceptance of the routine practice of selection constitutes a form of public endorsement of this hurtful and humiliating view.

It is possible that both discrimination against the disabled and the expression of demeaning views of the disabled are objectionable independently of any harm they inflict on disabled people. They can both be understood as failures of due respect that may wrong disabled people even when they do not cause harm—for example, even in instances when disabled people are unaware that they have occurred.

There are also other objections to selection against the disabled. Some have argued, for example, that selection reduces human diversity, which may be bad not only impersonally but also in its effects on others. A gradual reduction in the number of disabled people in society would, among other things, deprive people without disabilities of the insights

into human nature and the nature of the good life that contact with disabled people may afford.

The idea that the disabled have much to offer others is undoubtedly true and often movingly expressed. Pearl Buck, who had a mentally impaired daughter, wrote that “without her I would not have had the means of learning how to accept the inevitable sorrow, and how to make that acceptance useful to others. . . . A retarded child, a handicapped person, brings its own gift to life, even to the life of normal human beings. That gift is comprehended in the lessons of patience, understanding, and mercy, lessons which we all need to receive and to practice with one another.”<sup>8</sup> Similarly, Eva Feder Kittay, also the mother of a mentally impaired daughter, observes that “the world would be a poorer place without persons with Down’s syndrome or other sources of retardation, without people like . . . Sesha [her daughter]. Our household has been immeasurably enriched by Sesha. People like . . . Sesha . . . force us to think much more profoundly about what it is to be human, what our obligations are to others, why we have these obligations, what the source of human joy and sorrow is. . . . We understand so much more about who we are and what moves us, when we see what moves Sesha.”<sup>9</sup> Leon Kass even suggests, with rather more dubious propriety, that “in a strong family, the experience with a suffering and dying child might help the healthy siblings learn to face and cope with adversity.”<sup>10</sup>

These and other similar reflections directly imply the desirability of having disabled and retarded individuals among us. They capture something that is both true and profound. But we must be careful in extracting their practical implications.

#### IV. THE EXPRESSIVE EFFECTS OF SELECTION

Does selection against disabled people really express any unambiguous message? Let us consider various forms that selection can take and seek to determine what each might express. For the sake of brevity, I will henceforth use the following terms to refer to the possible responses to a positive screening for disability. Acts that prevent the existence of a disabled child and cause the existence of a different normal child instead are acts of *substitution*. Acts that eliminate an individual that would have been disabled and cause the existence of a normal child instead are acts of *replacement*. And I will refer to abstention from procreation simply as *abstention*.

When people undergo preconception screening and decide, on

8. Cited in Kass, “Implications of Prenatal Diagnosis for the Human Right to Life,” 621.

9. Kittay, “On the Expressivity and Ethics of Selective Abortion for Disability,” 181.

10. Kass, “Implications of Prenatal Diagnosis for the Human Right to Life,” 622.

discovering that they are at risk of having a disabled child, to abstain from procreation, this is sometimes thought to express the view that disabled people ought not to exist or that it would be better if disabled people did not exist at all. Or, if the potential parents' reason for avoiding having a child is that they are averse to assuming the responsibility of caring for a disabled child, their action may be thought to express the view that it is a misfortune to have a disabled child or that disabled people are not worth the burdens they impose on others.

The potential parents may, however, believe only that *they* would find the rewards of having a disabled child insufficient to compensate for the burdens; they need not believe that this would be true of others. In that case there would be no more reason to think that their action expressed the general view that a disabled child is not worth the cost than there would be to suppose that another couple's use of contraception expresses the view that it is bad to have children.

Alternatively, the potential parents might recognize that, if they were to have a disabled child, they would probably be very glad they did, as most parents of disabled children are. In that case their refraining from procreation might express nothing more than the view that their having a disabled child would be worse for them only relative to what they contingently care about now. They could concede that if they were to have a disabled child their personal values would likely be different, though equally rational.<sup>11</sup>

Another possibility is for people to undergo preconception screening and then, if they are found to be at risk, to seek to have a normal rather than a disabled child by means of the alteration of nongenetic conditions, PGD, or, in the future, the alteration of their own genetic material. Each of these tactics would affect which genetic materials would be combined; therefore, the normal child who would be born if the tactic were successful would be a different individual from the disabled child who would have been born in the absence of screening. These are, in other words, different-child choices involving substitution. They might, therefore, be thought to express the view that it is worse if disabled people exist than if normal people do, or that the lives of disabled people are worse than those of normal people. Or, especially given the costs of screening and substitution, they might be thought to express the view that it is worse or more burdensome to have a disabled child than to have a normal child. Again, however, there is no reason to presume that those who practice preconception screening and sub-

11. For elaboration, see Jeff McMahan, "Preventing the Existence of People with Disabilities," in *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, ed. David Wasserman, Jerome Bickenbach, and Robert Wachbroit (New York: Cambridge University Press, 2005), 142–71.

stitution believe that their preferences are or ought to be shared by others.

Next consider prenatal screening that prompts people both to abort a fetus that would be disabled and to refrain from further efforts at procreation. Like preconception screening followed by abstention, this might be thought to express, though even more emphatically, the view that it is better if disabled people do not exist or the view that disabled people are not worth the costs they impose on others. (The expression might be taken to be more emphatic in this case because most people assume that the abortion would involve the killing of an individual who would later have been disabled. If, however, we do not begin to exist at conception and the abortion were performed before the point at which one of us would have begun to exist, this case would be relevantly like preconception screening followed by abstention.) Alternatively, the abortion might signal only that some people feel, from a prospective point of view, that having a disabled child would be worse for them, though not necessarily for others, than having no child at all.

Finally, consider prenatal screening that prompts people to abort a fetus that would be disabled and to have a different, normal child instead, perhaps through PGD. If we do not begin to exist at conception and the abortion is performed before one of us begins to exist, it involves only substitution. If it is performed after one of us has begun to exist, it involves replacement. Either way, aborting an impaired fetus and then conceiving a normal one in its stead might be thought to express the view that disabled people have less value than normal people, or that they have less good lives, or that they are less desirable or more burdensome to have as children.

What this brief survey shows is that there is no single, determinate, unambiguous message that these various forms of selection—involving abstention, substitution, and replacement—express. Even if we focus, for example, only on acts of substitution, there is no single view that they all express. What an act of selection expresses depends on the reasons for which it is done. And for each form or type of selection, people's reasons for engaging in it vary. Different acts express different views. Some people, for example, have reasons that are wholly personal, while others take their reasons to apply to everyone. As I noted earlier, some people concede that their reasons are grounded only in what they contingently care about at present; they accept that if they were to have a disabled child their patterns of concern would be different but could be equally rational. Their acts might then express different though equally defensible evaluations.<sup>12</sup>

Even if an instance of selection were unequivocally expressive of

12. *Ibid.*

a certain view or evaluation, there may be little reason to suppose that people generally would be informed, attentive, or clever enough to understand the message properly. Suppose that one woman undergoes preconception screening, discovers that any child she might conceive would be disabled, and decides on that basis to abstain from procreation. Suppose that a second woman undergoes prenatal screening, discovers that the embryo she is carrying would be disabled, and decides on that basis to abort the pregnancy and employ PGD to enable her to have a normal child. If we were to ask people which of these two instances of selection conveys the more sinister view of the disabled, I suspect that most people would say the second, as it involves the killing of a disabled individual. But they could easily be wrong. The second woman might, for example, believe that an early embryo has no higher moral status than a sperm cell and might be motivated solely by the thought that a normal child would be less demanding to care for than a disabled child, while the first woman might have a horror of disabled people and be profoundly averse to having a disabled person for a child. The first woman's act would express the more pernicious view of the disabled, but it would not be possible to infer that view from her action alone; one would need to know precisely why she acted as she did.

Here is another example. Suppose that a pregnant woman discovers through prenatal screening that the embryo she carries has a genetic defect that will cause it to be disabled. Her doctors offer her a form of genetic therapy for the embryo that would involve quite radical genetic alteration but would correct the defect. She believes, correctly, that the embryo would be numerically the same individual as the person into whom it would later develop in the absence of the therapy but that the therapy would cause a *different* person to develop from the embryo—that is, that the therapy would be identity determining. Suppose she believes that the embryo has significant moral status but feels that having a disabled child would be so awful that she decides to give her interests priority and consents to the therapy. In having the therapy, she believes that she has engaged in selection through replacement—that is, that she has sacrificed the life of a disabled individual for the sake of her own interests. Although her action is an instance of selection that in fact expresses her view that it is better to kill a disabled individual with significant moral status than to have a disabled child, people untutored in metaphysics who learn of her action will interpret it as an instance of curing a disabled individual in utero. They will assume that it expresses no more than the view that it is worse for an individual to be disabled than not.

## V. WHAT MIGHT THE PROHIBITION OF SELECTION ACCOMPLISH?

The foregoing examples show how very difficult it is to draw valid inferences about what people's reasons and motives are for engaging in the practice of selection and thus about what the practice might express. But suppose that people will tend to draw inferences from the practice whether those inferences are valid or not and that the inferences will be largely unfavorable to the disabled. If so, should we discourage or ban screening for disability in order to prevent the perceived forms of disrespect and the associated harms to the disabled? This depends, at least in part, on what the other effects of prohibiting or limiting access to the various methods of selection would be.

One effect would be that some people who believed themselves to be at risk of having a disabled child would choose to abstain from procreation. If they would have tried to have a child if some form of screening and selection had been possible but would otherwise be unwilling to try, they would in effect be being deprived of the opportunity to have a child. This would be harmful to them, given their desire for a normal child, and might also be worse impersonally if it would prevent the existence of a child whose life would have been worth living.

This consequence of banning screening, or making it harder to obtain, would not be without expressive significance itself. The action of those who would abstain in these circumstances could, in many cases, be reasonably interpreted as expressing the view that, for them at least, having a disabled child would be so bad that a high probability of having a normal child, which is something they desire, would not be worth even a very small risk of having a disabled child. This is scarcely an improvement on the messages that might be expressed by selection.

One might counter this suggestion by noting that, although this message would be wounding, its expression would be muted because it would be conveyed through omission, or abstention, rather than action. It would be rather like an unuttered thought. That seems true. But a similar message is likely to be broadcast, indeed trumpeted, by the very action that would limit or prohibit screening for disability. For in order to achieve the goal of limiting or prohibiting the means of selection, the opponents of selection would have to present their reasons publicly. And one salient reason would be to prevent people from acting in ways that would express attitudes that are wounding to the disabled. So the message that the limitation or prohibition of screening and selection would convey to the disabled is this: "We want to protect you from learning what other people really think about you, or people like you."

This is hardly less wounding than the expressions that would be suppressed.<sup>13</sup>

If screening for disability were limited or proscribed, many of those at risk of having a disabled child would, as Hamlet says, defy augury and engage in procreation. This would lead to the birth of considerably more disabled children than would have been born had selection been possible, or more readily available. The existence of a greater number of disabled people would probably benefit preexisting disabled people by reinforcing their sense of collective identity and increasing or at least sustaining their political visibility and influence. And, as I noted, it is sometimes argued that the presence of disabled people in the lives of others offers valuable insights to those others and serves to extend their sympathies and understanding.

Yet most of the people who would have a disabled child when they could have had a normal child with the aid of screening would initially be understandably bitter. If they were vocal and aired their grievances publicly, this could be significantly more hurtful to the disabled, and more divisive, than the relatively unobtrusive practice of screening and selection. Most of these people—certainly most who would not offer their child for adoption—would love their disabled child, and many would soon become glad that they had had their actual disabled child rather than a different, normal child. This would not, however, necessarily indicate that their lives had gone better than they would have if they had had a normal child instead. Because of their personal attachment to their actual child, they can rationally be glad, from their present point of view, to have had that child even if their lives have gone worse than they would have if they had had a different, normal child instead.<sup>14</sup>

Taking these various considerations into account, it is difficult to conclude that restricting or prohibiting the practice of screening for disability would achieve desirable results on balance. The results I have suggested might follow are not obviously ones that opponents of selection would or should want to impose on others. But let us assume, for the sake of argument, that the practice of selection does express an objectionable and hurtful view of the disabled and that restricting or prohibiting the practice would have desirable effects. If nothing else, it

13. Here I agree with Dan Brock, in “Is Selection of Children Wrong?” that what is principally hurtful is the fact that people entertain attitudes and evaluations that are insulting or demeaning to the disabled. We need to challenge unwarranted and prejudicial attitudes and evaluations directly rather than merely attempting to suppress their alleged expression through the practice of selection. The latter would accomplish comparatively little if the attitudes and evaluations are left in place.

14. See McMahan, “Preventing the Existence of People with Disabilities,” which is indebted to Robert M. Adams, “Existence, Self-Interest, and the Problem of Evil,” *Nous* 13 (1979): 53–65.

would publicly express our repudiation as a society of any pernicious view or views about the disabled expressed by the practice of selection.

#### VI. CAUSING DISABLED RATHER THAN NORMAL PEOPLE TO EXIST

*The Aphrodisiac:* Suppose there is a drug that has a complex set of effects. It is an aphrodisiac that enhances a woman's pleasure during sexual intercourse. But it also increases fertility by inducing ovulation. If ovulation has recently occurred naturally, this drug causes the destruction of the egg that is present in one of the fallopian tubes but also causes a new and different egg to be released from the ovaries. In addition, however, it has a very high probability of damaging the new egg in a way that will cause any child conceived through the fertilization of that egg to be disabled. The disability caused by the drug is not so bad as to make life not worth living, but it is a disability that many potential parents seek to avoid through screening. Suppose that a woman takes this drug primarily to increase her pleasure—if it were not for this, she would not take it—but also with the thought that it may increase the probability of conception; for she wants to have a child. She is aware that the drug is likely to cause her to have a disabled child, but she is eager for pleasure and reflects that, while there would be disadvantages to having a disabled child, these might be compensated for by the special bonds that might be forged by the child's greater dependency. She has in fact just ovulated naturally, so the drug destroys and replaces the egg that was already present but also damages the new egg, thereby causing the child she conceives to be disabled.

Note that this is a different-child choice. Because the drug causes the woman's ovaries to release a new egg, the disabled child she conceives is a different individual from the child she would have had if she had not taken the drug. But even though her action is thus not worse for her actual child, most of us think that this woman's action is morally wrong. It is wrong to cause the existence of a disabled child rather than a normal child in order to enhance one's own sexual pleasure.

But those who, for the reasons I have cited, object to selection and seek to restrict or prohibit screening for disability cannot object to this woman's action without inconsistency. Here is why. Suppose that the commonsense view of the case of the Aphrodisiac is right—that is, that it is indeed wrong for the woman to take the drug. If that is so, it must be because there is a moral objection to causing oneself, by otherwise permissible means, to have a disabled child when one could have a normal child instead. But if there is such an objection, and it is strong

enough to make it impermissible to cause oneself to have a disabled rather than a normal child, it should also be strong enough to make it permissible to try, by morally acceptable means, to avoid having a disabled child and to have a normal child instead.

Those who object to screening and selection but are also inclined to believe that it is wrong for the woman to take the aphrodisiac might reply that to take the aphrodisiac is to cause oneself to have a high probability of having a disabled child rather than a normal child, whereas to refuse to engage in screening and selection is merely to allow oneself to have a higher probability than one would otherwise have of having a disabled child rather than a normal child. They could then appeal to the moral significance of the distinction between doing and allowing to argue that causing oneself to have a disabled rather than a normal child is objectionable in a way that allowing oneself to have a disabled child is not.

It is, however, not that opponents of screening and selection believe merely that it is *permissible* to refuse to engage in these practices; rather, they believe that one is morally *required* not to do so and that it is permissible for third parties to prevent others from engaging in them (for example, through imposing legal restrictions). But if it is morally *mandatory* to *allow* oneself to have a disabled child rather than to try, through screening, to have a normal child, it should be at least *permissible* to *cause* oneself to have a disabled rather than a normal child.

The crucial premise here is that if it is *impermissible* to try to *prevent* a certain type of outcome, such as having a disabled rather than a normal child, and if the prevention of that type of outcome is so objectionable that it is even permissible to deprive people of the means of preventing it, then it ought to be *permissible* to *cause* that outcome, provided one does so by otherwise permissible means. In short, if the outcome *must* be *allowed* to occur, how could it be *impermissible* to *cause* it to occur?

Consider again the opponents of screening and selection who also accept the commonsense view that it is wrong for the woman to take the aphrodisiac. The inconsistency of which they are guilty is this: they condemn the woman for causing herself to have a disabled child rather than a normal child, yet they also condemn those who try to cause themselves *not* to have a disabled child rather than a normal child. If they accept that there is a moral objection to causing oneself to have disabled rather than a normal child that is strong enough to make it wrong for the woman to take the aphrodisiac, they ought also to accept that it is permissible for people to try, by morally permissible means, to avoid having a disabled rather than a normal child and impermissible, other things being equal, for others to prevent people from being able to make this attempt.

The objections I have cited to screening and selection in fact imply

not only that it would be permissible for the woman to take the aphrodisiac but also that it would be wrong to try to prevent her from taking it and even wrong to criticize her action openly. If we were to attempt to prevent her from taking the drug—for example, by making the drug illegal on the ground that it causes birth defects—this could reduce the number of disabled people relative to the number there would otherwise have been, thereby threatening the political power of the disabled as well as their sense of collective identity. And if we were publicly to state the objections to the woman's taking the drug—that the disabled child's life would be likely to contain less good than the life of a normal child, that provision for the disabled child's needs would involve greater social costs, and so on—the implied claims about existing disabled people might be considered disrespectful and could be deeply hurtful.

If we turn to the objections to screening and selection that are concerned with the effects on people other than the disabled themselves, we find that their implication in the case of the Aphrodisiac is that it is positively desirable for the woman to take the drug. For the woman's causing herself to have a disabled rather than a normal child would have the effect of increasing rather than diminishing human diversity and would provide others with more occasions to gain important insights from their contacts with disabled people. I do not know of anyone who has argued that it would be desirable for at least some people to cause themselves to have disabled rather than normal children on the ground that this would ensure a healthy degree of diversity and enable more people to benefit from enlightening contacts with the disabled. For that would seem exploitative; it would treat the disabled as a means of benefiting others.

Again, opponents of screening and selection might appeal to the distinction between doing and allowing. They might argue that while it would, of course, be objectionable to cause disabled people to exist in order to benefit others, merely allowing them to exist with that aim in mind is a different matter. But even if the distinction between doing and allowing makes a difference in this area, it is not enough to make it acceptable even to allow disabled people to exist *for this reason*. This is why Kass's suggestion, mentioned earlier, makes some of us uncomfortable. Obviously he would not suggest that helping "siblings learn to face and cope with adversity" could be a reason to cause someone to exist who would suffer and die as a child. Nor would he suggest that we might refrain from seeking cures to certain childhood diseases in order to allow some children to suffer and die in order to strengthen their siblings' characters. Admittedly, it may seem *less* objectionable to cite this possible effect on siblings as an incidental benefit of prohibiting screening and selection, a benefit that could help to justify the prohibition by offsetting or counterbalancing the bad effects of having a

disabled child who would suffer and die young. If, however, such an effect is cited as contributing even in this indirect way to the justification for such a prohibition, that seems unacceptable.<sup>15</sup>

Kass's article on these issues provides a good example of the inconsistency I have sought to expose. In that article, he offers various criticisms of the practice of aborting abnormal fetuses, among which is the claim that a child with a congenital disease or disability "born at a time when most of his (potential) fellow sufferers were destroyed prenatally is liable to be looked upon by the community as one unfit to be alive, as a second-class (or even lower) human type. He may be seen as a person who need not have been, and would not have been, if only someone had gotten to him in time."<sup>16</sup> Yet later in the same piece Kass claims that "if we in the industrialized West wish to be really serious about the genetic future of the species, we would concentrate our attack on mutagenesis, and especially on our large contribution to the pool of environmental mutagens."<sup>17</sup> This latter comment implies approval of an attack on mutagenesis, but if such an attack were successful and we were able to diminish the pool of environmental mutagens, what effect might that have on those born with defects and disabilities resulting from mutagenesis? Should not Kass worry that they would be seen as people "who need not have been, and would not have been," if only we had been more effective in reducing our production of environmental mutagens? And if that would happen, would that not provide a moral reason, other things being equal, to sustain or even increase our contribution to the pool of environmental mutagens? Kass's concern about the expressive effects of selection, in short, suggests that it should be permissible to cause the existence of disabled people through the production of environmental mutagens.

In the case of the Aphrodisiac, the act that causes the woman to have a disabled child is identity determining—that is, it causes one child to exist rather than another. It is, in other words, a different-child choice rather than a same-child choice: it does not cause a child to be disabled who would otherwise have been normal. Perhaps surprisingly, this may also be true of certain cases in which disability is caused through prenatal injury. Suppose that we begin to exist not at conception but at some later point in pregnancy. And suppose that because significant alterations to an embryo or fetus prior to that point would alter the conditions of an individual's origin, these alterations could affect the identity of

15. It is worth recalling that Christian theodicy has on occasion descended to the suggestion that God causes or allows suffering in order to afford others the opportunity to exercise the virtue of compassion.

16. Kass, "Implications of Prenatal Diagnosis for the Human Right to Life," 618.

17. *Ibid.*, 621.

the individual who would later come into existence in association with the fetal organism. For example, a radical alteration of the structures of the developing embryonic brain might cause a different child to exist from the one who would have existed in the absence of the alteration. Given these assumptions, consider an instance of prenatal injury that causes disability but occurs prior to the point at which one of us begins to exist and causes sufficient damage to be identity determining. The injury in such a case would not cause a child to be disabled who would otherwise have been normal; rather, it would prevent the existence of a child who would have been normal and substitute in its place a disabled child who would otherwise never have existed. This substitution of one possible person for another is relevantly like the substitution that occurs in the case of the Aphrodisiac.

If, therefore, the claim that preconception screening and substitution are impermissible implies that it is permissible to cause the preconception substitution of a disabled child for a normal child, as in the case of the Aphrodisiac, it seems that it also implies that it can be permissible, other things being equal, to inflict prenatal injury that leads to the birth of a disabled child, provided that the injury is caused before one of us begins to exist and is serious enough to be identity determining. And this is very hard to accept.

#### VII. CAUSING PEOPLE TO BE DISABLED RATHER THAN NORMAL

Many of those who oppose screening for disabilities and the selection of normal rather than disabled children might be willing to accept that it can be permissible to cause a disabled rather than a normal child to exist through action taken prior to conception, for this action may not be worse for any particular individual. If the disabled child's life would be worth living, its existence would not be worse, or bad, for it, and if, as in the case of the Aphrodisiac, the child's parent or parents would be just as content to have a disabled child as to have a normal child, their causing the disabled child to exist need not be worse for anyone. It might be worse impersonally, if the disabled child would have a less good life than a normal child would have had, but many people reject that consideration as a reason for preferring a normal child.

It is, however, more difficult to accept the permissibility of inflicting prenatal injury that causes disability. But most opponents of screening and selection believe that they can consistently reject the permissibility of causing prenatal injury. They can point out that the most common view of when we begin to exist is that we begin to exist at conception. And, if that is right, all prenatal injury occurs after we have begun to exist and is therefore very unlikely to be identity determining. Indeed, most will say that it *cannot* be identity determining. They will claim that

an injury that does not kill the fetal organism cannot cause an individual to cease to exist and be replaced by a different individual. This will be true, for example, if we are human organisms. If, however, prenatal injury is not identity determining, it harms and is therefore worse for the victim. It may make that individual's entire life worse than it would have been in the absence of the injury. Opponents of screening and selection can therefore argue that the prohibition of prenatal injury expresses only the view that it is worse for a person to be disabled than not to be (and many would suggest, further, that the main reasons why it is worse are the lack of social accommodation and the persistence of discrimination).

The problem is that many disabled people and their advocates deny this view. For example, Harriet McBryde Johnson, a disabled lawyer, rejects the view that she attributes to Peter Singer—namely, the “unexamined assumption that disabled people are inherently ‘worse off,’ that we ‘suffer,’ that we have lesser ‘prospects of a happy life.’”<sup>18</sup>

It might be thought that the view that the lives of the disabled are in general or on average no worse than those of normal people would be difficult to reconcile both with the universal aversion to becoming disabled and with the universal view that it is morally objectionable to cause another person to become disabled. But those who hold the view can seek to explain the common aversion to becoming disabled in terms of what might be called the “transition costs.” When a person who has not been disabled suddenly or even gradually becomes disabled, the process is often accompanied by pain and virtually always requires a period of adjustment and adaptation to the loss of certain abilities. When the abilities that are lost were essential to the person's ability to engage in activities that were central to her life, the adaptation requires the abandonment of goals and ambitions that may have been the main sources of meaning, personal value, and narrative structure in her life. The unity of the life may be shattered and years of invested effort rendered futile. Very few people will deny that this kind of loss is a serious misfortune (unless, perhaps, the person's goals or projects were themselves unworthy or evil). But those who contend that the lives of the disabled are no worse than the lives of others can still claim that it is only *becoming* disabled and not *being* disabled that is bad. (Some, as I noted, concede that being disabled can be bad but claim that this is only because of discrimination and the refusal of society to make adequate adjustments to accommodate the disabled.)

Similarly, those who contend that the disabled are on average no worse off than others can argue that there are several reasons why caus-

18. Harriet McBryde Johnson, “Unspeakable Conversations,” *New York Times Magazine*, February 16, 2003, 50–55, 74, and 78–79.

ing a person to become disabled is normally wrong even if it is not bad to be disabled. One is that causing a person to become disabled inflicts the transition costs I have just described. Another is that, even if there were no such costs, the action would still involve an objectionable interference in the person's life and thus a violation of his or her autonomy. Finally, causing a person to be disabled usually or perhaps always involves a violation not only of autonomy but also of bodily integrity.

Is it true that disabilities are, as some say, "neutral traits," and that our aversion to becoming disabled and our belief that causing a person to be disabled is wrong can be fully explained without assuming that disabilities are bad for those who have them? I think not. A single disability may seem neutral because it can be compensated for by other abilities that develop to fulfill its functions. Blindness, for example, may be compensated for by the enhancement of other senses, particularly hearing. But if disabilities were individually entirely neutral, they ought also to be neutral in combination; but they are not. If, to take the most extreme case, we consider all the abilities whose absence is regarded as a disability and imagine a human individual who lacks them all, it would be impossible to believe that that individual's life would not be worse than the lives of most others—or that it might be worse but only because of social discrimination and lack of adequate social accommodation.

It is true that things sometimes have effects in combination that they do not have in isolation. But this is not the way disabilities work. If we consider why a number of different disabilities would in combination make a life worse, the explanation will appeal primarily to effects that each would have on its own but that cannot be adequately compensated for because of the presence of the other disabilities. For example, the bad effects of blindness could not be adequately compensated for in the case of a person who was also deaf and wholly paralyzed. In short, the bad effects of disabilities are largely additive.

Moreover, even if the abilities whose absence is constitutive of disability are good only instrumentally, their absence is not always or necessarily compensated for by an unusually robust development of other abilities. The lack of an ability that is instrumentally valuable to those who have it is, in general, an obstacle to the achievement of the full range of goods characteristic of human life. Although the obstacle is frequently overcome, and sometimes heroically so, it remains an obstacle. I believe, moreover, that the value of certain abilities—particularly certain psychological capacities—is only partly instrumental. The possession and exercise of certain psychological capacities is intrinsically good for those who possess them. I cannot, however, attempt to defend this claim here.

But suppose we assume for the sake of argument that Johnson and others are right to think that disabilities are neutral traits. And suppose

we assume further that the explanations I have cited of our aversion to becoming disabled and of our belief that it is wrong to cause people to become disabled are fully adequate. The opponent of selection who claims that it is not a misfortune to be disabled still faces a problem in explaining what is objectionable about causing disability through the infliction of prenatal injury. For the explanations I gave of why it may be bad to become disabled and why it is morally objectionable to cause someone to become disabled do not apply to the infliction of prenatal injury that causes a fetus to become disabled—assuming, that is, that the disability will be present from birth rather than having a delayed onset. For if the disability is present from birth, there cannot, in the nature of the case, be transition costs. Adaptation to the disability begins at birth. The congenitally disabled do not, for example, form goals or embark on projects that are fundamentally incompatible with the limitations imposed by their disability. They may, of course, experience discrimination, just as those with acquired disabilities may, but whatever unhappiness this causes is attributable to the discrimination, not to the disability.

So the infliction of prenatal injury does not impose transition costs. Nor can it violate an autonomy that the fetus does not possess. It may seem, however, to violate the fetus's bodily integrity. But if the violation of a fetus's bodily integrity is, in itself, seriously objectionable, most of us will have to rethink our beliefs about the permissibility of abortion. I have argued at length elsewhere that even a late-term fetus is not the kind of entity that can have a right to bodily integrity.<sup>19</sup> Yet even if I am right about that, it seems that something done to a fetus can violate the right to bodily integrity of the person into whom the fetus will later develop—for persons do have this right. I in fact accept this; yet I do not think that something done to a fetus's body can violate the right to bodily integrity of the later person unless the action is harmful to the later person. There can, of course, be acts of bodily invasion, intrusion, or alteration that violate the right to bodily integrity even if they are not harmful. But these are acts that are done without the person's consent. In general, the right to bodily integrity is not violated if the agent acts with the consent of the person whose body is affected. Thus, sex that is freely consented to does not violate the right to bodily integrity, while sex that is not consented to does. The problem with fetuses is that they cannot consent. Yet that cannot mean that every act that affects a fetus's body will, if the fetus lives, violate the right to bodily integrity of the person into whom the fetus will develop. Surgery performed on a fetus that will benefit the person the fetus will become does not violate that person's right to bodily integrity. But some things

19. McMahan, *The Ethics of Killing*, esp. 269–80 and 308–16.

done to a fetus *will* violate the later person's right. How can we distinguish between those acts that will and those that will not violate the right to bodily integrity? It seems reasonable to say that only those things done to a fetus's body that the later person will have reason to object to—in particular those that are harmful—can violate the person's right to bodily integrity. So, if being disabled is not harmful to or bad for the disabled person, then causing a fetus to be disabled will violate neither the rights of the fetus (because it does not have any rights) nor the right to bodily integrity of the later person.

It seems, therefore, that opponents of screening and selection who also claim that it is not worse to be disabled have no basis for objecting to the infliction of prenatal injury that causes congenital disability. Moreover, to object to the infliction of disabling prenatal injury or to enact measures to prevent it would seem to express a negative view of disability and perhaps of the disabled themselves. And, if effective, efforts to prevent disabling prenatal injury would have other effects comparable to those of prohibiting or restricting screening for disability and selection, such as reducing the number of disabled people who would be born, thereby also threatening the sense of collective identity and solidarity among the disabled as well as diminishing their visibility and political power. So for those opponents of selection who also hold that it is not a harm or misfortune to be disabled, it seems that there are not only no reasons to object to the infliction of disabling prenatal injury but even positive reasons, if other things are equal, not to object to it or to try to prevent it. While these people can recognize the impermissibility of causing a *person* to be disabled, they cannot—unless they embrace the implausible view that a fetus is a person with a right to bodily integrity—reject the view that it is permissible to inflict prenatal injury that causes an individual to be congenitally disabled rather than normal. Unless they are willing to accept that a fetus is a person with the same right to bodily integrity that you and I have, they seem committed to the view that it would be permissible for a pregnant woman to take an aphrodisiac knowing that this will cause her child to be disabled rather than normal, and that it would be wrong for others even to voice objections to this woman's action.

This conclusion seems to me unacceptable, and it will seem so to many others as well. There may, however, be some people who will find it acceptable, or even plausible. Among the latter might be those who have argued that it is permissible for deaf people to try to have children who are deaf. Many who have argued this way believe that it would be permissible, if possible, for a deaf couple to alter their developing fetus's auditory organs in order to ensure that the child would be permanently deaf. It is important to realize, however, that almost without exception, these people do not regard deafness as a disability. They believe that

deaf people have perfectly acceptable means of communicating and that children born to parents who belong to the culture of the deaf would be disadvantaged by being able to hear rather than by being deaf.

I will not consider the merits of this position here. The important point for my purposes is that, if it is a premise of this position that deafness is not a disability, then the claim that it can be permissible to inflict prenatal damage that causes deafness is not a counterexample to my argument. And it is hard to imagine that those who have defended this position with regard to deafness would be willing to generalize it to cover the causation of other congenital disabilities such as severe mental retardation or the absence of limbs.

#### VIII. CONCLUSION

I have argued that the main arguments of those who oppose screening for disability and selection against the disabled commit these people to other conclusions that are highly implausible. All opponents of screening and selection who appeal to the arguments I have cited seem committed to accepting the permissibility of action taken prior to conception that will cause the birth of a disabled child rather than a different, normal child who would have existed otherwise. And if action that affects an embryo or early fetus can be identity determining, these people will also be committed to accepting that disabling prenatal injury can be permissible provided it is identity determining and therefore not worse for the disabled child. Worst of all, unless they accept an implausible view of the status of the fetus, opponents of screening and selection who also contend that it is not worse, even on average, to be disabled rather than normal seem committed to accepting that it can be permissible to inflict prenatal injury that will result in a person's being congenitally disabled when he or she would otherwise have been normal. If my argument for these entailments is correct, it constitutes a *reductio ad absurdum* of the main arguments against screening and selection in the case of disability.