Genetics and Reproductive Risk: Can Having Children Be Immoral?
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Is it morally permissible for me to have children? A decision to procreate is surely one of the most significant decisions a person can make. So it would seem that it ought not to be made without some moral soul-searching.

There are many reasons why one might hesitate to bring children into this world if one is concerned about their welfare. Some are rather general, like the deteriorating environment or the prospect of poverty. Others have a narrower focus, like continuing civil war in Ireland, or the lack of essential social support for childrearing persons in the United States. Still others may be relevant only to individuals at risk of passing harmful diseases to their offspring.

There are many causes of misery in this world, and most of them are unrelated to genetic disease. In the general scheme of things, human misery is most efficiently reduced by concentrating on noxious social and political arrangements. Nonetheless, we shouldn’t ignore preventable harm just because it is confined to a relatively small corner of life. So the question arises: can it be wrong to have a child because of genetic risk factors?

Unsurprisingly, most of the debate about this issue has focused on prenatal screening and abortion: much useful information about a given fetus can be made available by recourse to prenatal testing. This fact has meant that moral questions about reproduction have become entwined with abortion politics, to the detriment of both. The abortion connection has made it especially difficult to think about whether it is wrong to prevent a child from coming into being since doing so might involve what many people see as wrongful killing; yet there is no necessary link between the two.

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Clearly, the existence of genetically compromised children can be prevented not only by aborting already existing fetuses but also by preventing conception in the first place. Worse yet, many discussions simply assume a particular view of abortion, without any recognition of other possible positions and the difference they make in how people understand the issues. For example, those who object to aborting fetuses with genetic problems often argue that doing so would undermine our conviction that all humans are in some important sense equal. However, this position rests on the assumption that conception marks the point at which humans are endowed with a right to life. So aborting fetuses with genetic problems looks morally the same as killing “imperfect” people without their consent.

This position raises two separate issues. One pertains to the legitimacy of different views on abortion. Despite the conviction of many abortion activists to the contrary, I believe that ethically respectable views can be found on different sides of the debate, including one that sees fetuses as developing humans without any serious moral claim on continued life. There is no space here to address the details, and doing so would be once again to fall into the trap of letting the abortion question swallow up all others. Fortunately, this issue need not be resolved here. However, opponents of abortion need to face the fact that many thoughtful individuals do not see fetuses as moral persons. It follows that their reasoning process and hence the implications of their decisions are radically different from those envisioned by opponents of prenatal screening and abortion. So where the latter see genetic abortion as murdering people who just don’t measure up, the former see it as a way to prevent the development of persons who are more likely to live miserable lives. This is consistent with a world view that values persons equally and holds that each deserves high quality life. Some of those who object to genetic abortion appear to be oblivious to these psychological and logical facts. It follows that the nightmare scenarios they paint for us are beside the point: many people simply do not share the assumptions that make them plausible.

How are these points relevant to my discussion? My primary concern here is to argue that
conception can sometimes be morally wrong on grounds of genetic risk, although this judgment will not apply to those who accept the moral legitimacy of abortion and are willing to employ prenatal screening and selective abortion. If my case is solid, then those who oppose abortion must be especially careful not to conceive in certain cases, as they are, of course, free to follow their conscience about abortion. Those like myself who do not see abortion as murder have more ways to prevent birth.

**Huntington’s Disease**

There is always some possibility that reproduction will result in a child with a serious disease or handicap. Genetic counselors can help individuals determine whether they are at unusual risk and, as the Human Genome Project rolls on, their knowledge will increase by quantum leaps. As this knowledge becomes available, I believe we ought to use it to determine whether possible children are at risk before they are conceived.

I want in this paper to defend the thesis that it is morally wrong to reproduce when we know there is a high risk of transmitting a serious disease or defect. This thesis holds that some reproductive acts are wrong, and my argument puts the burden of proof on those who disagree with it to show why its conclusions can be overridden. Hence it denies that people should be free to reproduce mindless of the consequences. However, as moral argument, it should be taken as a proposal for further debate and discussion. It is not, by itself, an argument in favor of legal prohibitions of reproduction.

There is a huge range of genetic diseases. Some are quickly lethal; others kill more slowly, if at all. Some are mainly physical, some mainly mental; others impair both kinds of function. Some interfere tremendously with normal functioning, others less. Some are painful, some are not. There seems to be considerable agreement that rapidly lethal diseases, especially those, like Tay-Sachs, accompanied by painful deterioration, should be prevented even at the cost of abortion. Conversely, there seems to be substantial agreement that relatively trivial problems, especially cosmetic ones, would not be legitimate grounds for abortion. In short, there are cases ranging from low risk of mild disease or disability to high risk of serious disease or disability. Although it is difficult to decide where the duty to refrain from procreation becomes compelling, I believe that there are some clear cases. I have chosen to focus on Huntington’s disease to illustrate the kinds of concrete issues such decisions entail. However, the arguments presented here are also relevant to many other genetic diseases.

The symptoms of Huntington’s disease usually begin between the ages of thirty and fifty. It happens this way:

Onset is insidious. Personality changes (obstinate, moodiness, lack of initiative) frequently antedate or accompany the involuntary choreic movements. These usually appear first in the face, neck, and arms, and are jerky, irregular, and stretching in character. Contractions of the facial muscles result in grimaces, those of the respiratory muscles, lips, and tongue lead to hesitating, explosive speech. Irregular movements of the trunk are present; the gait is shuffling and dancing. Tendon reflexes are increased. . . . Some patients display a fatuous euphoria; others are spiteful, irascible, destructive, and violent. Paranoid reactions are common. Poverty of thought and impairment of attention, memory, and judgment occur. As the disease progresses, walking becomes impossible, swallowing difficult, and dementia profound. Suicide is not uncommon.

The illness lasts about fifteen years, terminating in death.

Huntington’s disease is an autosomal dominant disease, meaning that it is caused by a single defective gene located on a non-sex chromosome. It is passed from one generation to the next via affected individuals. Each child of such an affected person has a fifty percent risk of inheriting the gene and thus of eventually developing the disease, even if he or she was born before the parent’s disease was evident.

Until recently, Huntington’s disease was especially problematic because most affected individuals did not know whether they had the gene for the disease until well into their childbearing years. So they had to decide about childbearing before knowing whether they could transmit the disease or not. If, in time, they did not develop symptoms of the disease, then their children could know they were not at risk for the disease. If unfortunately they did develop symptoms, then each of their children could know there was a fifty percent chance that they, too, had inherited the gene. In both cases, the children faced a period of prolonged anxiety as to whether they would develop the disease. Then, in the 1980s, thanks in part to an energetic campaign
by Nancy Wexler, a genetic marker was found that, in certain circumstances, could tell people with a relatively high degree of probability whether or not they had the gene for the disease. Finally, in March 1993, the defective gene itself was discovered. Now individuals can find out whether they carry the gene for the disease, and prenatal screening can tell us whether a given fetus has inherited it. These technological developments change the moral scene substantially.

How serious are the risks involved in Huntington’s disease? Geneticists often think a ten percent risk is high. But risk assessment also depends on what is at stake: the worse the possible outcome the more undesirable an otherwise small risk seems. In medicine, as elsewhere, people may regard the same result quite differently. But for devastating diseases like Huntington’s this part of the judgment should be unproblematic: no one wants a loved one to suffer in this way.

There may still be considerable disagreement about the acceptability of a given risk. So it would be difficult in many circumstances to say how we should respond to a particular risk. Nevertheless, there are good grounds for a conservative approach, for it is reasonable to take special precautions to avoid very bad consequences, even if the risk is small. But the possible consequences here are very bad: a child who may inherit Huntington’s disease has a much greater than average chance of being subjected to severe and prolonged suffering. And it is one thing to risk one’s own welfare, but quite another to do so for others and without their consent.

Is this judgment about Huntington’s disease really defensible? People appear to have quite different opinions. Optimists argue that a child born into a family afflicted with Huntington’s disease has a reasonable chance of living a satisfactory life. After all, even children born of an afflicted parent still have a fifty percent chance of escaping the disease. And even if afflicted themselves, such people will probably enjoy some thirty years of healthy life before symptoms appear. It is also possible, although not at all likely, that some might not mind the symptoms caused by the disease. Optimists can point to diseased persons who have lived fruitful lives, as well as those who seem genuinely glad to be alive. One is Rick Donohue, a sufferer from the Joseph family disease. “You know, if my mom hadn’t had me, I wouldn’t be here for the life I have had. So there is a good possibility I will have children.” Optimists therefore conclude that it would be a shame if these persons had not lived.

Pessimists concede some of these facts, but take a less sanguine view of them. They think a fifty percent risk of serious disease like Huntington’s appallingly high. They suspect that many children born into afflicted families are liable to spend their youth in dreadful anticipation and fear of the disease. They point out that Rick Donohue is still young, and has not experienced the full horror of his sickness. It is also well-known that some young persons have such a dilated sense of time that they can hardly envision themselves at thirty or forty, so the prospect of pain at that age is unreal to them.

More empirical research on the psychology and life history of sufferers and potential sufferers is clearly needed to decide whether optimists or pessimists have a more accurate picture of the experiences of individuals at risk. But given that some will surely realize pessimists’ worst fears, it seems unfair to conclude that the pleasures of those who deal with the situation simply cancel out the suffering of those others when that suffering could be avoided altogether.

I think that these points indicate that the morality of procreation in situations like this demands further investigation. I propose to do this by looking first at the position of the possible child, then at that of the potential parent.

Possible Children and Potential Parents

The first task in treating the problem from the child’s point of view is to find a way of referring to possible future offspring without seeming to confer some sort of morally significant existence upon them. I will follow the convention of calling children who might be born in the future but who are not now conceived “possible” children, offspring, individuals, or persons.

Now, what claims about children or possible children are relevant to the morality of childbearing in the circumstances being considered? Of primary importance is the judgment that we ought to try to provide every child with something like a minimally satisfying life. I am not altogether sure how best to formulate this standard but I want clearly to reject the view that it is morally permissible to conceive individuals so long as we do not expect them to be so miserable that they wish they were dead. I believe that this kind of moral minimalism is thor-
oughly unsatisfactory and that not many people would really want to live in a world where it was the prevailing standard. Its lure is that it puts few demands on us, but its price is the scant attention it pays to human well-being.

How might the judgment that we have a duty to try to provide a minimally satisfying life for our children be justified? It could, I think, be derived fairly straightforwardly from either utilitarian or contractarian theories of justice, although there is no space here for discussion of the details. The net result of such analysis would be the conclusion that neglecting this duty would create unnecessary unhappiness or unfair disadvantage for some persons.

Of course, this line of reasoning confronts us with the need to spell out what is meant by “minimally satisfying” and what a standard based on this concept would require of us. Conceptions of a minimally satisfying life vary tremendously among societies and also within them. De Rigeur in some circles are private music lessons and trips to Europe, while in others providing eight years of schooling is major accomplishment. But there is no need to consider this complication at length here since we are concerned only with health as a prerequisite for a minimally satisfying life. Thus, as we draw out what such a standard might require of us, it seems reasonable to retreat to the more limited claim that parents should try to ensure something like normal health for their children. It might be thought that even this moderate claim is unsatisfactory since in some places debilitating conditions are the norm, but one could circumvent this objection by saying that parents ought to try to provide for their children health normal for that culture, even though it may be inadequate if measured by some outside standard. This conservative position would still justify efforts to avoid the birth of children at risk for Huntington’s disease and other serious genetic diseases in virtually all societies.

This view is reinforced by the following considerations. Given that possible children do not presently exist as actual individuals, they do not have a right to be brought into existence, and hence no one is maltreated by measures to avoid the conception of a possible person. Therefore, the conservative course that avoids the conception of those who would not be expected to enjoy a minimally satisfying life is at present the only fair course of action. The alternative is a laissez-faire approach which brings into existence the lucky, but only at the expense of the unlucky. Notice that attempting to avoid the creation of the unlucky does not necessarily lead to fewer people being brought into being; the question boils down to taking steps to bring those with better prospects into existence, instead of those with worse ones.

I have so far argued that if people with Huntington’s disease are unlikely to live minimally satisfying lives, then those who might pass it on should not have genetically related children. This is consonant with the principle the greater the danger of serious problems, the stronger the duty to avoid them. But this principle is in conflict with what people think of as the right to reproduce. How might one decide which should take precedence?

Expecting people to forego having genetically related children might seem to demand too great a sacrifice of them. But before reaching that conclusion we need to ask what is really at stake. One reason for wanting children is to experience family life, including love, companionship, watching kids grow, sharing their pains and triumphs, and helping to form members of the next generation. Other reasons emphasize the validation of parents as individuals within a continuous family line, children as a source of immortality, or perhaps even the gratification of producing partial replicas of oneself. Children may also be desired in an effort to prove that one is an adult, to try to cement a marriage or to benefit parents economically.

Are there alternative ways of satisfying these desires? Adoption or new reproductive technologies can fulfill many of them without passing on known genetic defects. Replacements for sperm have been available for many years via artificial insemination by donor. More recently, egg donation, sometimes in combination with contract pregnancy, has been used to provide eggs for women who prefer not to use their own. Eventually it may be possible to clone individual humans, although that now seems a long way off. All of these approaches to avoiding the use of particular genetic material are controversial and have generated much debate. I believe that tenable moral versions of each do exist.

None of these methods permits people to extend both genetic lines, or realize the desire for immortality or for children who resemble both parents; nor is it clear that such alternatives will necessarily succeed in proving that one is an adult, cementing a marriage, or providing economic benefits. Yet, many people feel these desires strongly. Now, I am sympathetic to William James’s dictum
regarding desires: “Take any demand, however slight, which any creature, however weak, may make. Ought it not, for its own sole sake be satisfied? If not, prove why not.” Thus a world where more desires are satisfied is generally better than one where fewer are. However, not all desires can be legitimately satisfied since, as James suggests, there may be good reasons—such as the conflict of duty and desire—why some should be overruled.

Fortunately, further scrutiny of the situation reveals that there are good reasons why people should attempt—with appropriate social support—to talk themselves out of the desires in question or to consider novel ways of fulfilling them. Wanting to see the genetic line continued is not particularly rational when it brings a sinister legacy of illness and death. The desire for immortality cannot really be satisfied anyway, and people need to face the fact that what really matters is how they behave in their own lifetime. And finally, the desire for children who physically resemble one is understandable, but basically narcissistic, and its fulfillment cannot be guaranteed even by normal reproduction. There are other ways of proving one is an adult, and other ways of cementing marriages—children don’t necessarily do either. Children, especially prematurely ill children, may not provide the expected economic benefits anyway. Non-genetically related children may also provide benefits similar to those that would have been provided by genetically related ones, and expected economic benefit is, in many cases, a morally questionable reason for having children.

Before the advent of reliable genetic testing, the options of people in Huntington’s families were cruelly limited. On the one hand, they could have children, but at the risk of eventual crippling illness and death for them. On the other, they could refrain from childbearing, sparing their possible children from significant risk of inheriting this disease, perhaps frustrating intense desires to procreate—only to discover, in some cases, that their sacrifice was unnecessary because they did not develop the disease. Or they could attempt to adopt or try new reproductive approaches.

Reliable genetic testing has opened up new possibilities. Those at risk who wish to have children can get tested. If they test positive, they know their possible children are at risk. Those who are opposed to abortion must be especially careful to avoid conception if they are to behave responsibly. Those not opposed to abortion can responsibly conceive children, but only if they are willing to test each fetus and abort those who carry the gene. If individuals at risk test negative, they are home free.

What about those who cannot face the test for themselves? They can do prenatal testing and abort fetuses who carry the defective gene. A clearly positive test also implies that the parent is affected, although negative tests do not rule out that possibility. Prenatal testing can thus bring knowledge that enables one to avoid passing the disease to others, but only, in some cases, at the cost of coming to know with certainty that one will indeed develop the disease. This situation raises with peculiar force the question of whether parental responsibility requires people to get tested.

Some people think that we should recognize a right “not to know.” It seems to me that such a right could be defended only where ignorance does not put others at serious risk. So if people are prepared to forego genetically related children, they need not get tested. But if they want genetically related children then they must do whatever is necessary to ensure that affected babies are the result. There is, after all, something inconsistent about the claim that one has a right to be shielded from the truth, even if the price is to risk inflicting on one’s children the same dread disease one cannot even face oneself.

In sum, until we can be assured that Huntington’s disease does not prevent people from living a minimally satisfying life, individuals at risk for the disease have a moral duty to try not to bring affected babies into this world. There are now enough options available so that this duty needn’t frustrate their reasonable desires. Society has a corresponding duty to facilitate moral behavior on the part of individuals. Such support ranges from the narrow and concrete (like making sure that medical testing and counseling is available to all) to the more general social environment that guarantees that all pregnancies are voluntary, that pronatalism is eradicated, and that women are treated with respect regardless of the reproductive options they choose.

Notes

1. This paper is loosely based on “Genetic Diseases: Can Having Children Be Immoral?” originally published in Genetics Now, ed. John L. Buckley (Washington, DC: University Press of America, 1978) and subsequently anthologized in a number of medical ethics texts. Thanks to Thomas Mappes and David DeGrazia for their helpful suggestions about updating the paper.
2. I focus on genetic considerations, although with the advent of AIDS the scope of the general question here could be expanded. There are two reasons for sticking to this relatively narrow formulation. One is that dealing with a smaller chunk of the problem may help us think more clearly, while realizing that some conclusions may nonetheless be relevant to the larger problem. The other is the peculiar capacity of some genetic problems to affect ever more individuals in the future.


5. Why would we want to resist legal enforcement of every moral conclusion? First, legal action has many costs, costs not necessarily worth paying in particular cases. Second, legal enforcement would tend to take the matter in question out of the realm of debate and treat it as settled. But in many cases, especially where mores or technology are rapidly evolving, we don’t want that to happen. Third, legal enforcement would undermine individual freedom and decision-making capacity. In some cases, the ends envisioned are important enough to warrant putting up with these disadvantages, but that remains to be shown in each case.

6. Those who do not see fetuses as moral persons with a right to life may nonetheless hold that abortion is justifiable in these cases. I argue at some length elsewhere that lesser defects can cause great suffering. Once we are clear that there is nothing discriminatory about failing to conceive particular possible individuals, it makes sense, other things being equal, to avoid the prospect of such pain if we can. Naturally, other things rarely are equal. In the first place, many problems go undiscovered until a baby is born. Secondly, there are often substantial costs associated with screening programs. Thirdly, although women should be encouraged to consider the moral dimensions of routine pregnancy, we do not want it to be so fraught with tension that it becomes a miserable experience. (See "Loving Future People.")

7. It should be noted that failing to conceive a single individual can affect many lives: in 1916, nine hundred and sixty-two cases could be traced from six seventeenth-century arrivals in America. See Gordon Rattray Taylor, _The Biological Time Bomb_ (New York, 1968), p. 176.


13. To try to separate the issue of the gravity of the disease from the existence of a given individual, compare this situation with how we would assess a parent who neglected to vaccinate an existing child against a hypothetical viral version of Huntington’s.

14. _The New York Times_, September 30, 1975, p. 1, col. 6. The Joseph family disease is similar to Huntington’s disease except that the symptoms start appearing in the twenties. Dick Donohue was in his early twenties at the time he made this statement.

15. I have talked to college students who believe that they will have lived fully and be ready to die at those ages. It is astonishing how one’s perspective changes over time, and how ages that one once associated with senility and physical collapse come to seem the prime of human life.

16. The view I am rejecting has been forcefully articulated by Derek Parfit, _Reasons and Persons_ (Oxford: Oxford University Press, 1984). For more discussion, see "Loving Future People.

17. I have some qualms about this response since I fear that some human groups are so badly off that it might still be wrong for them to procreate, even if that would mean great changes in their cultures. But this is a complicated issue that needs its own investigation.

18. Again, a troubling exception might be the isolated Venezuelan group Nancy Wexler found where, because of inbreeding, a large portion of the population is affected by Huntington’s. See Revkin, "Hunting Down Huntington’s.

19. Or surrogacy, as it has been popularly known. I think that "contract pregnancy" is more accurate and more respectful of women. Eggs can be provided either by a woman who also gestates the fetus or by a third party.

20. The most powerful objections to new reproductive technologies and arrangements concern possible bad consequences for women. However, I do not think that the arguments against them on those grounds have yet shown the dangers to be as great as some believe. So although it is perhaps true that new reproductive technologies and arrangements shouldn’t be used lightly, avoiding the conceptions discussed here is well worth the risk. For a series of viewpoints on this issue, including my own “Another Look at Contract Pregnancy,” see Helen B. Holmes, _Issues in Reproductive Technology 1: An Anthology_ (New York: Garland Press, 1992).