The Ends Don’t Justify the Genes

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Is there anything wrong with causing someone to be paralyzed, or blind, or deaf? If so, then sit up and take notice.

On March 31 the Sunday magazine of the Washington Post featured a cover story on a couple who have intentionally produced a child who cannot hear. The couple themselves are deaf and lesbian, so when a sperm bank would not provide them with a deaf donor, they found one themselves. “We wanted to increase our chances of having a baby who is deaf,” one of them explained. And they succeeded—their baby is “quite deaf.” They claim their attempt to maximize their happiness was legitimate. But was it?

As we learn more about the human genetic code and develop tools to change it, this situation raises a huge question that society needs to answer soon: Is it ethical for parents to force their children to have genetic traits that will be harmful to the child but beneficial to the parents? Most people would have no problem with parents correcting a genetic problem in a baby, so that the baby will not have to suffer from some disability. But what if the parents want to cause the baby to have that disability?

Two responses. First, all people including parents should be free to pursue their desires—but not in ways that prevent others from pursuing theirs. “All people...should be free to pursue their desires—but not in ways that prevent others from pursuing theirs.”

We expect an even higher standard from parents: they should be seeking the greatest well-being for their child, even at some cost to themselves. But at a minimum, parents ought not to disadvantage their child so that they, the parents, can benefit. Even the staff member at the National Association of the Deaf quoted in the Post article honestly acknowledges the core problem with being deaf: “You don’t have as many choices.” The couple in this situation have intentionally limited the choices of their child by imposing the disability of deafness, and that is unethical.

And the issue here is not about being supportive of people who are deaf or otherwise disabled. There are several deaf people in my extended family and my daughter heads the Sign Language group at our high school. I enthusiastically affirm the dignity and rights of people who are deaf. Deaf people, however, are not in danger of losing their rights in this case. This is not a “deaf rights” but a “human rights” case.

The basic issue here is whether or not there are ethical limits to what parents can impose on a child. Before genetics became a factor, the importance of limits was clear. We have not allowed parents to force young children to do hard manual labor ten hours a day so that the parents can have a more affluent lifestyle. If we now say that parents can cause their children to be without hearing, then we are saying that parents’ preferences are all that matters. They can cause whatever harm to their child they wish, as long as they get enough benefit from doing so. Now is the time to draw the line.
physician of wrongdoing. He was provably correct, and that is my point. The discussion of PAS is so emotionally laden with pro-choice autonomy language that it is little, if any, relevant to the legal community to pursue even the most blatant of violations of patients’ wish to be left alone, especially, when they may rob patients of their autonomy.

Conclusion

After four years of the “Oregon Experience,” I am even more convinced than ever that Oregon’s “assisted suicide” of radical suicide is my expressed in a suicidal “death with dignity” is nothing more than a grand illusion. It is, after all, a grand illusion to believe that one can really control the time and means of his or her death. This illusion has been born out repeatedly, as problems with the safety and efficacy of PAS, as well as with obtaining truly informed consent for such a procedure and ensuring that it is performed only voluntarily, have been documented. Instead of embracing autonomy, we would all do well to recognize that the death we die is a result of the death lived throughout one’s life—whether it is a death to sell or a death for self.


Editor’s Note: The U.S. Department of Justice has issued the most recent challenge to physician-assisted suicide in Oregon. The Department plans to appeal the April 2002 override of Attorney General John Ashcroft’s declaration that doctors who write lethal prescriptions for their patients would lose their license to prescribe controlled substances. Ashcroft’s declaration would have essentially rendered physician-assisted suicide in Oregon illegal.

The Power and Peril of Genetic Technology: Reflections on Spider-Man

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The recent movie Spider-Man has exceeded all expectations, both from a business standpoint and as an entertaining “comic book movie” filled with lots of action, enjoyable humor, and romance. Although it did not turn out to be a profound movie, Spider-Man raises some interesting issues relevant to bioethics—namely, genetic enhancement and the unrestricted pursuit of scientific advancement. High school “science geek” Peter Parker gains “super spider powers” after he is accidentally bitten by a genetically altered spider during a school trip to a science institute. Millionaire scientist Norman Osborn becomes Spider-Man’s nemesis, the “Green Goblin,” after participating in an unsuccessful experiment in order to secure continued medical funding for his research. Through a superhero action movie, Spider-Man introduces viewers to biotech dilemmas, perhaps paving the way for societal acceptance of emerging biotechnologies.

Peter Parker becomes Spider-Man by accident, and (unlike some superhero) remains one of us. It is not Peter’s fault that the science institute was genetically altering spiders, nor did he have a desire to claim super powers. By contrast, Norman Osborn unscrupulously pursues human-enhancement experiments for military purposes and in an unamenable way characteristics other than those he sought to engineer. Though Spider-Man deals with the use of power, it offers a (subtle) warning about the quest for power.

This comparison, though, raises a larger issue. How ethical is it to impose character on people that are not necessarily harmful, but which they may not want? Does everyone want to be a man? Of course not. Does everyone want to be white? Reasonably so. It is ethical for parents internationally to force their child to be something that he or she may not want to be?


Parents (or anyone else) must not be allowed to impose, genetically or otherwise, a harmful characteristic on their child.

First, the situation of the deaf couple and child underscores the more serious need to keep parents from making genetic choices that harm their child. But it also prompts us to consider the different wrong we do by intentionally forcing a child to have a characteristic that the child may not want.


In the end, perhaps only genetic interventions people would want can ethically be imposed on children. Included would be those interventions that prevent fatal diseases—but there are other categories that meet this criterion as well. Identifying them is a task in which all should participate, and for its outcome we will profitably affect us all.

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News from the Field

Belgium Legalizes Assisted Suicide

Belgium has become the second country in the world to explicitly legalize assisted suicide. The law passed by the tower house of the Belgian Parliament by a margin of 81 of 51 with 10 abstentions. Passage had been widely expected since the Belgian Senate approved the bill late last year. (Last year the Netherlands became the first country to officially legalize assisted suicide.)

Belgium’s medical association opposed the bill, saying that it goes too far and that it allows some to commit suicide even though they might not otherwise do so for the 4 years. In contrast, in the Netherlands, the Belgian law does not allow anyone to seek assisted suicide. According to the BBC, the country’s Christian Democrat party may challenge the law to the European Court of Human Rights.

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