

Dignity

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Inside:

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. Being able to make choices is good—but not if our choice takes away the choices of others. My freedom is important; but I am not free to do something that will undermine yours.

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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.

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physician of wrongdoing. He was probably correct, and that is my point. The discussion of PAS is so emotionally laden with pro-choice autonomy language that there is little, if any, resolve in the legal community to prosecute even the most blatant of violations—violations which, ironically, may rob patients of their autonomy.

Conclusion

After four years of the “Oregon Experience,” I am more convinced than ever that Oregon’s “sacred cow” of radical autonomy 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 borne 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 self 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.

A 1984 amendment to the Controlled Substance Act permits federal authorities to take action against physicians who endanger their patients’ health—even if the means by which they do so are allowed by state law. Citing this Act, the Department of Justice maintains that assisted suicide is not a legitimate act of medicine and that federal authority to regulate drugs supersedes state legislative rights. The Department also issued a fact sheet listing moral objections to physician-assisted suicide, which include the American Medical Association’s position that assisted suicide is “fundamentally incompatible with the physician’s role as a healer.”

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Second, we can more clearly see the harm of genetically limiting our children when we consider how we would view the same harm without the genetics involved. Genetic and reproductive technologies and techniques, such as the donor insemination used in this case, are simply tools. We use tools to accomplish things. Whether a use of a tool is ethical depends in part on what we are trying to accomplish with it. If something is wrong, it doesn’t matter what tools we use to accomplish it—it is still wrong.

Preventing a child from hearing harms the child; it limits and disadvantages the child. Wouldn’t we condemn parents who took some tool and intentionally destroyed their child’s ability to hear? If they do the same thing using genetic tools, as in effect this deaf couple did, our opposition should be equally strong. To accept this genetic limiting of a child’s abilities is not only to justify even more harmful genetic limitations. It also justifies non-genetic means to limit a child—for example, destroying the hearing of a child who can hear.

In the *Post* article, the couple try to defend their actions in two primary ways. First, they argue that their life as deaf people is fine, and that their child’s life will also be fine. Even if this were to be true, it misses

the point. Human beings are amazingly resilient, and they can adjust to, and make the most of, even the worst circumstances. But that does not mean that the circumstances are good or are to be sought or caused if possible. People who are brain damaged or paralyzed can still have a good life—but that fact does not mean that we should accept or encourage brain damaging or paralyzing people. Nor should we accept causing deafness.

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Second, the couple maintain that if it is OK for some parents to try to have a black child—because they themselves are black—then deaf people should be welcome to have a deaf child. A problem with this comparison is that blackness itself does not necessarily impose major limitations on people. If society limits people because of their skin color, such limits represent prejudice and are unjustified; they should and can be removed. The limits of deafness, however, are not completely the product of human prejudice and are not all removable.

This comparison, though, raises a larger issue. How ethical is it to impose characteristics 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? Resoundingly no. So is it ethical for parents intentionally to force their child to be something that he or she may not want to be?

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 all 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 if possible, for its outcome will profoundly affect us all. ■

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