



Genetic Engineering of Humans

Roberta Berry talks about the ethical and public policy implications of genetic engineering of humans.

Roberta Berry is an associate professor of public policy and director of the Law, Science & Technology Program at the Georgia Institute of Technology. Her research focuses on the legal, ethical, and policy implications of life sciences research and biotechnologies. Berry presented her research on the public policy aspects of genetic engineering of humans at the 2005 annual meeting of the American Association for the Advancement of Science. Also, she is writing a book under contract with Routledge on the ethical and policy implications of genetic engineering of human beings. Berry has both a juris doctorate and a Ph.D. in the history and philosophy of science.

What is the time frame within which genetic engineering of human beings could be technologically feasible and safe?

Though genetic engineering of human beings may seem the stuff of science fiction, researchers have already created human artificial chromosomes for use in creating transgenic animals or in gene therapy administered to living humans. Some observers believe gene modules copied from known natural genes that seem to predispose humans to certain desirable features could be inserted on these synthetic chromosomes and introduced into a human ovum or zygote. These observers believe that research toward accomplishing safe genetic engineering of human beings in this way could get under way in the near future, while others maintain that such a step is still many decades away, if it ever could be feasible.

Nevertheless, the public policy debate about genetic engineering of humans is likely to intensify over the next 10 years.

Why is it difficult to understand and address the policy and ethical issues surrounding genetic engineering of humans?

One of the chief difficulties in understanding and addressing the policy and ethical issues surrounding genetic engineering of humans is the novelty of this. We've never before had the opportunity to revise our biological constitution in this way. So it's difficult to find a framework for addressing this. We might be able to think about a new medical technique or a machine that is new to humans, but we've never encountered a novel technology to remake human beings as the subject matter of the technology. For all of us, whether we draw on a religious or secular ethical framework, this tests our ability to find policy guidance, let alone address it in a personal way.

For some it may be an easy personal choice. It will fit into other interventions they think are right or wrong. But then they must decide whether, as a matter of policy, they favor subsidizing or restricting the technology. For many, the novelty and complexity of it will make

it hard to get a handle on what it involves — the possibility that we could revise genes and features of humans. Some will decide that the technology should be given completely free rein. Others will decide that this area is God's domain, not a place where humans should be acting. But still, it's difficult to know within a diverse community whether it's appropriate to prohibit others from genetic engineering of humans.

What are the key policy issues, and why do you anticipate they will be controversial?

The policy issues related to genetic engineering of humans will look familiar to us — they will look like the issues related to new medical procedures. They will be issues of risk and benefit, and the safety of human subjects in research. But then we will face the fact that defining the benefits of this technology is value-laden. People may disagree. It won't be a simple matter to say, 'It's better to be taller rather than shorter, or it's better to have a strong memory than to be forgetful.' People will disagree about the relative importance of features and about the deeper questions of human relationships — how we treat each other. Should we devote ourselves to conscious efforts to design people according to a set of criteria for superiority? What is a superior human being? We'll draw upon past experience with eugenics and treatment of people with disabil-

ities and with various ethnic affiliations. Is there any human who can know and say that certain qualities are superior?

What role will the U.S. Constitution play in the public and personal debate?

There are two senses in which the U.S. Constitution may play a role in the public policy debate about genetic engineering of humans. For one, there may be those who want to have access to the technology and likely will make claims under substantive due process if there are efforts to restrict or prohibit access. One way to do this will be to invoke the Constitution in claims by individuals against those trying to regulate the technology. That's a use of the Constitution to challenge the validity of regulation.

Another role for the Constitution is as a resource in response to the problems of novelty and complexity. One of the ethical and policy resources we have is to say, 'OK, we disagree because we're a diverse society, yet we live in peace.' We accept the fact that we will disagree, yet we in the United States share a common political heritage tied to the Constitution. There is a set of norms and values embedded in it that are foundational, even if we disagree about how they're applied.

We agree on a commitment to our shared welfare. There's no monarch telling us what to do to fulfill the monarch's dreams. We the people give certain powers to the state to regulate for our mutual welfare.

Interview by
Jane M. Sanders

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I look at the shared foundational norms, or values, in the Constitution and how they potentially influence the ultimate policy formation and regulatory scheme in both senses — as a matter of constitutional law and as a resource for public dialogue. We do this with the debate we keep having about what liberty means and in the equality debate such as with affirmative action in educational settings. We have these dialogues on the general welfare and the promotion of science and the useful arts when they start to threaten other values.

We have this store of policy discussion and working things out surrounding certain issues. We can look to these discussions because they all draw upon these norms, which will be evoked by the genetic engineering debate. Then we can start to chip away at the novelty challenge, make it a more familiar problem.

With this issue, we won't reach just one conclusion after a three-month debate. This is going to be an ongoing debate for our lifetimes and the lifetimes of our children, who likely will be the first generation to face the prospect of deciding whether we want to use this technology.

Why would parents want to genetically engineer children? Will they ever be comfortable with the risk?

Those who are working on the technology for genetic engineering of humans think the risk will ultimately be minimal, especially when compared to the potential benefits. Parents with a genetically influenced disease may

find the risk/benefit tradeoff acceptable. They could, through in-vitro fertilization, engage in genetic engineering to ensure their future child won't suffer from the disease.

But there are those who will say, 'If you're willing to do that, why not engage in genetic testing of pre-embryos to determine whether they might get the genetic disease? Then discard those that are predisposed.' In this case, the therapeutic use of genetic engineering is not that appealing. I'm not sure if there will be a subset of individuals who will not discard embryos, but will engage in a genetic engineering procedure when the risk/benefit tradeoff seems OK.

Another group of people who are more likely to address the risk/benefit tradeoff are those that subscribe to arguments that we should be attempting to improve our biological endowment in the same way we have with other attempts to improve ourselves. For example, pregnant women eat a good diet, go to the doctor and take vitamins. Parents want the best possible development of their child's natural endowment. We've not frowned upon this; we've supported this.

So, the argument goes, if I find a technology that's just as reliable, say, as inoculation, then why shouldn't I take the next step and fiddle with the genetic endowment that my child will have and provide a greater prospect of improving the capabilities and health of the child? This argument claims that

genetic engineering belongs on the continuum that starts with providing better health and education. Whatever the risks, the benefits exceed them.

How do you believe the outcomes of other public policy debates — such as stem cell research — will affect this debate?

My hope is that we will draw on the debates about issues like stem cell research to inform the debate surrounding this issue and others. There will be a positive interaction in the sense that we're all trying to find the lines and definitions for our personal and policy lives for the best resolution for now in light of the shared norms in our political community and our personal beliefs.

But I worry that we will not have an open and reflective debate. You have people with firm beliefs that will retreat into

camp separated from each other.

I hope we can debate it within the shared foundational norms in our Constitution and find common ground for the framework of the debate. I'd like to see a wide variety of people thinking about this to arrive at a resolution. I don't want this to evolve into isolated encampments in which people hold their own views and won't listen to others.

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