

Bioethics and Law Forum

Choosing Our Children's Future or Choosing Our Future Children?¹

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Another milestone in advancing genetic technologies was reported when a private clinic in Chicago successfully tested embryos for an Alzheimer's gene. The mother has the early onset gene, which will cause the disease to strike her by her late 30s, but the testing allows her to avoid passing it on to her child. This case is interesting because it offers a glimpse of what's coming.

The Human Genome Project's rough draft paves the way for identifying genes for a whole host of diseases. Eventually, we may even begin to understand the genetic influences on personality, intelligence, height, eye color, and the proclivity to be overweight or to eat without becoming fat.

This research will inevitably lead to the possibility of testing embryos, and once tests are available, people will almost certainly want to use them. Thus, we are quite literally at the beginning of being able to choose the types of children we will have, not by manipulating them, but by selecting from a range of embryos and the characteristics each of them carries. All of this raises questions about whether and how to use such technologies.

The woman whose case triggered this debate has been criticized for choosing to have a child she won't be able to care for within 10 years and probably won't recognize at all because of advancing Alzheimer's shortly thereafter. Her story is both compelling and tragic, mostly because she knows what her future holds.

But the rest of us shouldn't feel so smug, since our own lives are full of uncertainty. None of us knows our future. There is no crystal ball that predicts who will be affected by cancer, who will live to be 100 years old, or who will be hit by a bus crossing the street tomorrow. It is especially hard to make the case that the genetic testing of embryos should be denied to a woman who wants to use it to avoid passing a debilitating disease on to her children, when she could get pregnant the "regular" way and run a 50:50 risk of having an affected child.

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Unless we are willing to make the societal determination that people with the gene for early onset Alzheimer's disease ought to be prevented from bearing children altogether—leading us down a path we should fear to tread—it doesn't make sense to effectively force them to roll the genetic dice by denying them access to genetic testing for embryos.

What makes issues of the genetic testing of embryos so pressing is that unlike nearly every other area of medicine, the genetic testing of embryos has no effective oversight or rules, and therefore, no limits. This is because the federal government decided 20 years ago to ban funding for embryo research and therefore lost the opportunity to create rules for it. And since in vitro fertilization—which is the medical technique used to make embryos to be tested—is rarely paid for by health insurance, there is little oversight of its use.

These are all good reasons for why societal discussion and debate on these issues are long overdue, especially since Congress will consider a ban on cloning-related technologies in the next weeks or months. Any policy decision can benefit from full and diverse debate.

In the end, the question is whether individual physicians and individual clinics ought to decide what are effectively societal issues. We are creating a modern-day Wild West environment by avoiding oversight and regulation of the use of genetic testing in combination with assisted reproductive technologies. That's why it's time to rein things in.

Footnotes

¹ A version of this article appeared in Dr Kahn's biweekly column "Ethics Matters" on CNN.com. 

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