

Parents may one day be morally obligated to edit their baby's genes

As genetic editing becomes a reality, some say it would be wrong not to use it to cure disease

BY **TINA HESMAN SAEY** 7:00AM, NOVEMBER 28, 2017



BETTER BABIES If CRISPR/Cas9 or other gene-editing technologies are ever approved for use in human embryos, parents may one day feel as if they have to use genetic enhancements to give their children the best life possible.

A doctor explains to a young couple that he has screened the pair's in vitro fertilized embryos and selected those that had no major inheritable diseases. The couple had specified they want a son with hazel eyes, dark hair and fair skin. Then the doctor announces that he has also taken the liberty of eliminating the "burden" of genetic propensities for baldness, nearsightedness, alcoholism, obesity and domestic violence.

The prospective mother replies that they didn't want those revisions. "I mean diseases, yes, but ..." Her husband jumps in to say, "We were just wondering if it's good to leave a few things to chance."

But the doctor reminds the would-be parents why they came to him in the first place. They want to give their child "the best possible start."

That's a scene from the movie *Gattaca*, which premiered 20 years ago in October. But thanks to recent advances in gene-editing tools such as CRISPR/Cas9, genetic manipulation of human embryos is becoming reality.

Soon, designer babies like those described in the film may even become morally mandatory, some ethicists say.

Gattaca's narrator tells us that such genetic manipulation of in vitro fertilized embryos has become "the natural way of giving birth" in the near future portrayed in the film. It has also created an underclass of people whose parents didn't buy those genetic advantages for their children.

Until recently, that sort of fiddling with human DNA was only science fiction and allegory, a warning against a new kind of eugenics that could pit the genetic haves and have-nots against each other. At a symposium sponsored by the Hastings Center on October 26 before the World Conference of Science Journalists in San Francisco, ethicists and journalists explored

the flip side of that discussion: whether parents have a moral obligation to make “better” babies through genetic engineering. Technology that can precisely change a baby’s genes is quickly becoming reality. This year, scientists reported using **CRISPR/Cas9 in viable human embryos to fix mutations that cause heart and blood disorders**. CRISPR/Cas9 acts as a molecular scissors that relatively easily and precisely manipulates DNA. Scientists have **honed and developed** the tool in the roughly five years it has been around, creating myriad “CRISPR” mice, fish, pigs, cows, plants and other creatures. Its use in human embryos has been hotly debated. Should we or shouldn’t we?

For many people, the fear of a class of genetically enhanced people is reason enough not to tinker with the DNA of the human germline — eggs, sperm, embryos and the cells that give rise to eggs and sperm. By all means, correct diseases, these folks say, but don’t add extras or meddle with characteristics that don’t have anything to do with health. A panel of ethicists convened by the U.S. National Academies of Medicine and Science also **staked out that position** in February, ruling that human germline engineering **might someday be permissible for correcting diseases**, but only if there are no alternatives and not for enhancements.

But the question “should we?” may not matter much longer, predicted the Hastings Center’s **Josephine Johnston** at the symposium. As science advances and people become more comfortable with gene editing, laws prohibiting tinkering with embryos will fall, she said, and it will be up to prospective moms and dads to decide for themselves. “Will editing a baby’s genes be mandatory, the kind of thing you’re supposed to do?”

For **Julian Savulescu**, an ethicist at the University of Oxford, the answer is yes. Parents are morally obligated to take steps to keep their children healthy, he says. That includes vaccinating them and giving them medicine when they’re ill. Genetic technologies are no different, he argues. If these techniques

could make children resistant to infections, cancer or diabetes, then parents have an obligation to use them, he says.

For now, he cautions, CRISPR's safety and efficacy haven't been established, so parents shouldn't subject their children to the risks. He also points out that this sort of editing would also require in vitro fertilization, which is prohibitively costly for many people. (And couples could pretty much forget about having the perfect baby through sexual intercourse. Designer darlings would have to be created in the lab.)

But someday, possibly soon, gene editing could become a viable medical intervention. "If CRISPR were safe and not excessively costly, we have a moral obligation to use it to prevent and treat disease," Savulescu says.

Using gene editing to cure genetic diseases is something retired bioethicist **Ronald Green** of Dartmouth College can get behind. "I fully support the reproductive use of gene-editing technology for the prevention and elimination of serious genetic diseases," Green said at the symposium. "If we could use gene editing to remove the sequences in an embryo that cause sickle cell disease or cystic fibrosis, I would say not only that we may do so, but in the case of such severe diseases, we have a moral obligation to do so."

But that's where a parent's obligation stops, Green said. Parents and medical professionals aren't required to enhance health "to make people who are better than well," he said.

Savulescu, however, would extend the obligation to other nondisease conditions that could prevent a kid from having a full set of opportunities in life. For instance, children with poor **impulse control** may have difficulty succeeding in school and life. The drug Ritalin is sometimes prescribed to such kids. "If CRISPR could do what Ritalin does and improve impulse control and give a child a greater range of opportunities," he says, "then I'd have to say we have the same moral obligation

to use CRISPR as we do to provide education, to provide an adequate diet or to provide Ritalin.”

Green rejected the idea that parents should, or even could, secure a better life for their kids through genetic manipulation. Scientists haven’t identified all the genes that contribute to good lives — and there are plenty of factors beyond genetics that go into making someone happy and successful. Already, Green said, “the healthy natural human genome has enough variety in it to let any child successfully navigate the world and fulfill his or her own vision of happiness.” (A **version of his remarks** was posted on the Hastings Center’s Bioethics Forum.)

Many traits that would help a person make more money or have an easier life are associated with social prejudices and discrimination, says **Marcy Darnovsky**, the executive director of the Center for Genetics and Society in Berkeley, Calif. People who are taller and fair-skinned tend to make more money. If parents were to engineer their children to have such traits, “I think we would be inscribing those kinds of social prejudices in biology,” she says. “We get to very troubled waters very quickly as a society once we start down that road.”

Creating a class of “genobility,” as Green calls genetically enhanced people, would increase already staggering levels of inequality, Darnovsky says. That, says Savulescu, “is the *Gattaca* objection I often get.”

Yes, he acknowledges, “it could create even greater inequalities, there’s no doubt about that.” Whenever money is involved, people who have more of it can afford better treatments, diets and healthier lifestyles — and disparities will exist. “However, this is not inevitable,” Savulescu says. Countries with national health care systems could provide such services for free. Such measures could even correct natural inequalities, he argues.

Johnston worries that genetic manipulation could change family dynamics. Parents might be disappointed if their designer baby doesn't turn out as desired. That's a variation of the old problem of unfulfilled parental expectations, Savulescu says. "It's a problem that deserves attention, but it's not a problem that deserves banning CRISPR," he says.