

“Eugenics in California and the World: Race, Class, Gender/Sexuality, and Disability”
A Virtual Symposium, Friday & Saturday, June 4-5, 2021

Panel V: Reproductive Genetic Technologies & Social Justice Implications
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Hi, I'm Marcy Darnovsky. I'm recording these comments because a last-minute conflict prevents me from being with you in real time. I wish I wasn't missing the chance to dig into this conversation. Let me start by thanking Milton and Osagie for their flexibility, and Miroslava and Sue for putting together this important symposium.

The focus of this panel is also our focus at the Center for Genetics and Society. We work to bring reproductive, disability, and racial justice considerations to the forefront in public and policy debates about reproductive genetic technologies, especially the ongoing deliberations about techniques to alter the genes and traits of future children.

CGS got its start 20 years ago, when a small but vocal group of scientists was promoting the prospect of so-called “designer babies.” They envisioned “breeding better babies” with a precision that 20th century eugenicists could only dream about. Some openly acknowledged that it would create a world of genetic haves and have-nots. But, they said, that was a price “we” had to pay, and anyway it was inevitable.

Heritable genome editing, as it's now often called, is actually prohibited in some 70 countries around the world. But despite that, and despite it being intensely controversial (including among scientists working on gene therapies for existing patients), other scientists are pushing it, and have put themselves in charge of several high-profile committees issuing recommendations to move it forward.

These days, most who support heritable genome editing say it should be used only for the tiny number of people who can't prevent transmission of serious heritable disease by using existing techniques, and not for genetic enhancement. They argue that eugenics therefore isn't a concern. But there are numerous reasons to question whether any such limits would hold; to think it likely that approving gene editing for human reproduction would throw open the door to a market-based high-tech form of eugenics.

So very briefly, here are some of those reasons.

First, what counts as “disease” is contested, especially from a disability justice point of view. In a recent *Scientific American* [article](#), Sandy Sufian and Rosemarie Garland-Thomson write of their concern “that the use of these “genetic scissors” will, in the future, cut people like us out of existence without others even noticing.” They point out that “the ability to “fix” people at the genetic level is a threat to those who are judged by society to be biologically inferior.”

A second reason for concern is that most countries, including the US, permit so-called “off-label” uses of approved drugs or devices. So if heritable genome editing gets a regulatory nod, doctors would be free to use it for any condition or trait.

A third reason is closely related: those decisions would take place in the commercial fertility sector,

with typical business pressures to find new customers and boost bottom lines. It's all too easy to imagine the marketing campaigns: "Don't you want to give your child-to-be the best start in life? But you must act now, before you get pregnant. This really is a once-in-a-lifetime opportunity."

Right now, several companies are offering a technique that selects human embryos rather than modifying them. Embryos are created through in vitro fertilization; then their genes are sequenced and run through algorithms that spit out "polygenic risk scores" that supposedly predict the chances of particular traits in the resulting child.

One of these companies, Genomic Prediction, started out offering tests for what they termed "cognitive disability," but stopped (for now) because of the pushback. Another company, Orchid, offers what they call "embryo prioritization." They're marketing to all would-be parents, including those with no fertility issues, and despite the invasiveness and health risks of IVF for women. Orchid's founder, interviewed last week in the [LA Times](#), recognizes that what they're doing is controversial. She says, "Fortunately we're living in a free market...no one's forcing you to buy our product."

In thinking about the likelihood of a new market-based eugenics, it's important to note that most traits aren't fully or straightforwardly controlled by genes. The genetic components even of traits like hair and eye color are complex, and that's far more true of traits like athleticism or intelligence. But that might not stop reproductive gene editing from taking off, because even the perception that gene-edited kids would be superior could be a powerful incentive.

Consider the hypothetical wealthy families that would spend hefty sums of money for their children's genetic upgrades. Whatever the biological effect, those kids would be treated as special by their teachers, nannies, and tutors; the belief that they were superior would shape their lives. The benefits of the social privileges showered on them would be attributed to their genetic upgrades. On a broader level, the focus on genes and the individuals or populations who carry them would deflect attention from the social dynamics that perpetuate inequality and discrimination.

Let me wrap up with a quick show and tell. These are magazine covers and illustrations about the prospect of reproductive genetic modification. [SHOW THEM]

I hope you've noticed the traits that all these babies share: fair skin, blond hair, blue eyes. I think these images tell us something important about ideas of hierarchy and worth in today's social and cultural imaginations, and suggest how heritable genome editing would all too likely play out.