

# A REPRODUCTIVE JUSTICE PERSPECTIVE ON GERMLINE MODIFICATION

## OVERVIEW

Creating genetically modified humans was once hypothetical—the stuff of science-fiction. Now, it's an urgent matter of social justice. Germline modification (also known as heritable genome editing or gene editing for reproduction) would almost certainly open the door to a new kind of eugenics, and women's bodies would be the primary vehicle.

Mainstream debates about germline modification rarely mention pregnant women or people, or acknowledge the links to the oppressive systems and expectations that affect all people's reproductive "choices." These discussions perpetuate assumptions that having a child with a disability is unquestionably something to be avoided and reinforce beliefs that it's better to bring people into the world who are taller, slimmer, and "fairer." They also reinforce the valuation of genetic relationships over other forms of kinship.

The risks raised by germline modification intersect with the concerns of other movements, including reproductive justice, racial justice, disability rights, LGBTQ rights, environmental justice, and health justice. **Reproductive justice advocates can play a key role in preventing a high-tech eugenic future where some people's genes are deemed more valuable than others'.**

## WHAT EXACTLY IS GERMLINE MODIFICATION?

Gene editing, in general, refers to making changes to the DNA of any organism. The best-known gene-editing tool is called CRISPR-Cas9.

Using gene editing in human beings to treat diseases in an existing adult or child is called somatic genetic modification or gene therapy. These changes only affect the person being treated and are not heritable. When safe, effective, and accessible, gene therapy to treat diseases is widely supported.

By contrast, germline modification changes the DNA of embryos, eggs, or sperm. Any of these changes would be passed down from generation to generation.

Germline modification is highly controversial. It poses unknown health risks for pregnant women and people. It also poses risks to the health of future children and generations, as well as consequences for their identity formation as people "designed on demand." It also has the potential to increase inequalities and open the door to a new form of eugenics.

More than 50 countries have banned germline modification. The United States currently has some "soft law" and agency policies related to the technology, but no national or state laws prohibit it.



## HOW WILL IT BE USED?

If germline modification were to be approved, it would likely start with clinical trials, then roll out in fertility clinics, and eventually be marketed as an “add on” to in vitro fertilization.

Germline modification is often presented as a “great promise,” a way for people to avoid passing on genetic diseases to their children. But existing methods already allow this (for those who can afford it), without using an unsafe and untested procedure that would basically be risky human experimentation.

## WHAT ARE THE LINKS TO REPRODUCTIVE JUSTICE?

The development of this technology is taking place in the shadow of history, in which scientific research was used to control the reproductive lives of women, trans, and nonbinary people. If allowed, its use in the for-profit fertility industry would make it unlikely that equity, safety, or ethics would be prioritized.

Germline modification could exacerbate reproductive, racial, and disability injustice by:

- Recreating—in new ways—population control methods aimed at women in general and at poor women and women of color in particular;
- Reinforcing oppressive societal assumptions, such as beliefs that some lives are more worthy than others, and that it is parents’ responsibility to ensure the genetic “fitness” of their children;
- Pressuring pregnant women and people to abort fetuses with genetic conditions;
- Exacerbating existing inequalities and discrimination;
- Creating new forms of injustice by encouraging those who can afford it to “design” their children with supposedly “superior” genes and traits; and

- Requiring a large supply of human eggs for continued research, exposing women and people who provide them to known and unknown risks.

## REPRODUCTIVE JUSTICE ADVOCATES CAN CHANGE THE CONVERSATION!

Because the reproductive justice movement recognizes how people’s lives are affected by the multiple contexts in which they live and makes visible the ways that women, trans, and nonbinary people have experienced reproductive oppression, we are uniquely positioned to talk about the dangers of a technology like germline modification.

As reproductive justice advocates, organizations, and scholars, we can encourage our movement as a whole to:

- Counter genetic determinism;
- Call for political, economic, and social transformation rather than technological fixes;
- Challenge the advancement of a high-tech eugenic future in which some people’s genes are deemed more valuable than others’;
- Challenge ableist assumptions of germline modification and existing technologies;
- Highlight health risks for women and people who would carry genetically modified fetuses, and for genetically modified children and future generations;
- Oppose any attempts to position women’s bodies as the primary source of irreversible alteration of the human genome; and
- Invite our allies from other social justice movements to engage with the complexity of issues posed by germline modification.