

Center for Genetics and Society  
Gene Editing and the Future of Reproductive Justice Webinar  
Tuesday, June 13, 2017  
1:00 p.m. – 2:35 p.m. est

*This transcript was provided by Communication Access Realtime Translation (CART) Captioning, and has been edited by the Center for Genetics and Society for clarity.*

### **Emily Galpern**

Hello everyone, I'm Emily Galpern on behalf of the Center for Genetics and Society. We're waiting a few more minutes before we get started while more people join.

This webinar will be accessible to blind and visually impaired people so we will be audio describing our slides, which means reading the titles and all words on the slides and describing all images. This will also be possible for folks on the phone to know what we are seeing.

Right now, on the slide, it says "Gene Editing and the Future of Reproductive Justice" Webinar; Tuesday June 13, 2017.

Below that, there are pictures of each of our three speakers with their names and affiliations: Lisa Ikemoto, UC Davis; Ruha Benjamin, Princeton University; and Dorothy Roberts, University of Pennsylvania.

Below that it reads: If you need help with Adobe Connect, call or email Leah Lowthorp at 1-510-665-7760 extension 308. On the right side of the screen, if you are online, you will see a box that says, "Troubleshooting." Use this box if you have any issues you need help with on the Adobe Connect platform. We will get started in just a few moments.

We are recording the webinar for those who cannot participate today and for those who would like to see the video later, and will send out the link in the next two or three weeks.

I'd like to turn it over to Nourbese.

### **Nourbese Flint**

Thank you, Emily.

Hello and welcome, everyone, to "Gene Editing and the Future of Reproductive Justice" Webinar. Again, my name is Nourbese Flint, the policy director and, I would say, resident nerd here at Black Women for Wellness in Los Angeles. Black Women for Wellness is a nonprofit committed to the empowerment, health, and well-being of black women and girls. And we use a reproductive justice framework.

In a moment, we'll dive into reproductive justice for those of you who are not familiar with it. But in the meantime, we teamed up with the Center for Genetics and Society, as well as In Our Own Voice: National Black Women's Reproductive Justice Agenda, to bring you this awesome webinar today.

Just to say a little more about the flow of today's webinar: We are going to have a bit of background about reproductive justice, followed by background information on where we are with genetics and gene editing. Marcy at the Center for Genetics and Society, will be doing that followed by our awesome panel of speakers. After, we will open it up for questions and answers. Just as Emily said, use the Q&A box for questions. We will take as many as we can

because of time.

Without further ado, I'm going to hand it off to my colleague, Michelle, to share about what reproductive justice is.

### **Michelle Batchelor**

Hi, everyone. I'm Michelle Batchelor, deputy director here at In Our Own Voice: National Black Women's Reproductive Justice Agenda, and I am just over-the-moon thrilled to be here with you all. It's very rare that I have an audience or an opportunity to talk with scientists and academics because, at In Our Own Voice, our primary objectives and goals are to really lift up and amplify the voices of black women around reproductive justice issues. We do that at a national, regional and state level with eight state partners, one being Black Women for Wellness. You just met Nourbese. We do wonderful things, and it is around the reproductive justice framework. We wanted to give a little background because we do know [that] not everyone on this call may be as familiar with reproductive justice, just as I am not as familiar with genetic editing.

Reproductive justice comes out of a human rights frame and was birthed in 1994—by black women who were responding and participating in the reproductive rights “feminist movements,” that were happening at the time; [and] that were very much focused on abortion, as well as, white-centered, historical feminist movements. It really takes an intersectional look at the lives of [women]—in our case, we're really focused on black women, women of color, women of all nationalities—and the intersections that influence how we choose to create family, our lived experiences, and how that influences what our family makeup [can be], what our community would look like. Using that human rights frame, the principles are: it is the right to have children; the right to not have children; and it's the right to raise your children in safe and healthy environments.

The work that we do within the reproductive justice movement is really trying to work across all of those intersections, and look at economic justice as well as racial justice, incarceration, and how that affects us. Now I think this is a very timely discussion, and I'm looking forward to it because genetics is not something that I have necessarily thought much about in the future, in the technology. I think as grassroots organizers and advocates really trying to affect policy, we're really concerned about what the implications would be using the reproductive justice framework around policy and rights for women, for people, for black women, and how that can be used to improve our health outcome, how it can be used to improve matern[al] mortality rates, as well as the ethical and human rights concerns that we would naturally have.

As we think about reproductive justice and go into this discussion of genetics, hopefully we're keeping in mind how we can marry the science with the advocacy, effectively learning from our history as well as focusing on what we want people to have. I know [that] all of us on this call want people to have lived their best life free from stigma, free from discrimination; and how we can do that while we still move policy forward, mov[ing] technology forward to meet the changing, evolving, lived experiences that we all have.

I'll leave it there.

### **Nourbese Flint**

Thank you, Michelle.

Now that we all are on the same page about reproductive justice, we're going to take

a moment to dive into genetics. Part of the conversation for many of us, when we think [of] designer babies, [include] movies like *Gattaca* or *The Island*, [and] seem like something way far in the future. It's something we don't have to worry about now. But is that really the case? Next we have Marcy from the Center for Genetics to share about where we are and break down “what is gene editing.”

### **Marcy Damovsky**

Thanks so much, Nourbese, and Michelle, and all of you for being here. I'm thrilled to be with all of you today.

A word about the Center for Genetics and Society: We are a public interest organization. Our mission is to work to bring social justice and human rights perspective to the social challenges that human genetics technology and assistive reproductive technologies raise. Gene editing for human reproduction is right at the center of our concerns.

So, as Nourbese said, my role today is to share some quick background with you about what gene editing is, how it's being talked about, who is talking about it, and who is not. The past few years have seen the development, and a very rapid spread, of a new generation of genetic engineering techniques that go by the term “gene editing.” These gene editing tools can be used to add, to delete, or to change genetic sequences in any living organism. They are more accurate and more controllable than previous genetic engineering techniques were, although they are not as accurate and controllable as the “editing” metaphor might suggest. And that's actually an important point.

When we turn to considering [the] use of gene editing in human beings, there are two distinct categories to keep in mind: There's somatic gene editing and germline gene editing. In somatic gene editing, when used as a gene therapy, the aim is to treat existing people with certain conditions—, people who are sick. These changes would hopefully treat, [and] help the person being affected, but would not be passed down to any descendants of that person. Clinical trials of gene therapy using the older genetic engineering method, started in 1990, but, until recently, there has been very little success.[I]n fact, [there have been] some tragic outcomes of those experiments. Now with new techniques, more promising results may be emerging and we can be hopeful about that.

In contrast to somatic gene editing, germline gene editing refers to modifying the gene in eggs, in sperm, or in very early embryos. It's used for reproductive purposes. These changes would be passed down to any future generations. So what that means is that these changes would be reflected in every cell of the body of a child that was produced after these techniques were being used, and also in any of that child's descendants in the future.

Genetically engineered animals have been created this way. You get the glow-in-the-dark bunnies and the goats that can lactate spider silk in their milk, and so on. But germline editing for reproduction has not been attempted in human beings, and that prospect, and the conversation about it, is the main focus of our webinar today.

The best known of the gene editing tools is called CRISPR/Cas-9, which has received a lot of attention [in] the past couple of years. In addition to greater accuracy, it's inexpensive, easy to use, and customizable. There's been a particular focus, including by the media, on the prospect of using CRISPR in fertility clinics for human reproduction. In other words, to determine the gene, and thus determine the traits, of future children and future generations.

The slide that is now showing is the cover of the August 2015 issue of *The*

*Economist* magazine. This is just a few months after CRISPR burst on to the scene. This is one of a number of very similar magazine covers and illustrations. The title here is "Editing Humanity: The Prospect of Genetic Enhancement," and the picture shows a white baby playing with letter blocks, with the letters A, T, G, and C. It shows multiple arrows pointing to various parts of the baby's body. So the arrow pointing to the baby's leg reads "sprinter;" the one to the baby's hair reads "no baldness," the one to the head reads "high I.Q.;" and the forehead "low risk Alzheimer's, breast cancer, strokes;" to the left eye, "20/20 vision;" to the right ear, "perfect pitch." That's the promise that's being made— or the threat that's being made— about germline gene editing for reproduction.

This prospect raises a number of concerns. First: the safety. There is a major issue of off-target edits or inaccurate edits, And this could lead to all sorts of negative outcomes. Even if a child who had been genetically modified seemed healthy at first, they could develop serious problems later on, and sometimes [these problems] might only manifest themselves in subsequent generations.

The second point is that some people argue that germline modification should be permitted, but limited to [the] prevention of transmitting serious inherited diseases. This argument, which is presented as a "medical" argument, is tenuous at best. There are other ways to accomplish the same thing to have children not affected by serious genetic inherited diseases.

Also, it seems dubious that germline modification could be restricted in the real world to serious medical conditions for a number of reasons. For starters, how would you distinguish therapy from an enhancement? What would count as a disease or a disability or normal human variations? Who would draw these lines?

These are questions that also come up around existing prenatal technologies that are able to identify fetuses or embryos with certain conditions. Historically, as well as currently, many assert that selecting against conditions, for example Down Syndrome and other disabilities, reinforces negative and discriminatory attitudes about disability rights and justice. It's likely that human gene editing for reproduction would have the same effects— probably magnified.

Additionally, we need to consider the commercial pressures that would come into play if germline editing for reproduction was to be permitted and marketed by fertility clinics. The assumption that there are "bad genes" and "good genes" would inevitably reflect existing prejudices; and this could all too easily lead to a future of genetic "have's" and "have not's," — a world in which our already shameful social inequalities and discriminations are magnified. So those are, very briefly, some of the arguments against the human gene editing for reproduction.

I want to end with a few words about existing policies. Internationally, gene editing for human reproduction is actually already prohibited by law in more than 40 countries, and these are countries that protect reproductive rights, and that include most nations of the world with advanced biomedical sectors.

Gene editing for human reproduction is also prohibited by a binding international treaty. This slide shows the cover of a report on that treaty, which is called the "Convention on Biomedicine and Human Rights," which the slide shows. Underneath that, [it reads] the "Oviedo Convention," [which is] another name for this treaty, and its additional protocols.

Domestically, the NIH and FDA recently confirmed they won't fund or approve proposals for germline modification for reproduction. But the U.S. has no law that prohibits it—,

even though public opinion in the U.S. has, for years, been consistently opposed to this, especially for enhancement or the creation of designer babies. There are also vocal advocates for moving in this direction, especially in the U.S. and the U.K.

So the final point I want to make is the conversation. One landmark of this conversation was a big conference at the end of 2015 put on by the National Academies of Science and Medicine. [There were] 500 people in Washington, D.C. for three days, including Ruha Benjamin, whom you will hear from [and] was invited to speak about disability rights there. I was invited to talk from a public-interest perspective. But, overwhelmingly, the attendees were scientists and there were very few others—public policy advocates, social scientists, justice-oriented organizations, people with disabilities who were included either as presenters or even in the audience.

In a concluding statement, the summit's organizing committee called for what they termed "broad societal consensus" before any use of human gene editing for reproduction. But unfortunately, since then, there have not been any significant efforts toward engaging the public. Then in February of this past year, another National Academy committee issued a report on gene editing that pretty much dispensed with the call for consensus and recommended that human gene editing reproduction could proceed with certain limits.

All of these, and a bunch of others, will be discussed by our speakers. I'm going to turn it back to Nourbese; and ask Nourbese, Lisa, Ruja and Dorothy to enable your webcams please.

Thanks a lot.

### **Nourbese Flint**

Thank you, Marcy. You left in a great space in talking about genetics, gene engineering from the policy, and the fact that we don't have many other folks—many of the social science and reproductive justice folks—in the room. That is why we have this awesome panel today to bring that perspective.

Now none of our speakers need to be introduced. Their work speaks for themselves. They are superstars in the world of academia. I am super honored to first introduce our first speaker—for some of those who might not know—Dr. Ruha Benjamin, who quite literally has her own cheering section here at BWW. We love her work. Ruha Benjamin is an Assistant Professor in the Department of African-American Studies at Princeton University. In 2016-2017, [she was the] Fellow of the Institute for Advanced Studies. Her work examines the social dimensions of science, technology, and medicine, with the particular focus on the relationship between innovation and inequity. She earned her Ph.D. in Sociology from UC Berkeley and completed fellowships at UCLA's Institute for Genetics and Society and Harvard Science, Technology and Society programs.

Ruha is the author of numerous publications including, *People's Science: Bodies and Rights on the Stem Cell Frontier*, and is a recent recipient of the 2017 President's Award for Distinguished Teacher at Princeton.

Because I could spend a whole webinar just laying out the great work of the women on the panel, I'm going to stop there and let Ruha take it away.

### **Ruha Benjamin**

Hi, everyone. So glad you could join us today. A big thanks to the Center for Genetics and Society, to Black Women for Black Women for Wellness, and In Our Own Voice.

They show wonderful foresight in gathering us here today and thinking about issues that may not be on all of our radar. I think by the time something hits the headlines, in the *New York Times*, it's almost too late to start shaping the conversation and start shaping the debate. So it's really important to actually engage issues that we might not immediately see as directly connected to what's normally on our plate in terms of what our concerns are and our interests are.

I was thinking for today: why is it important for people who are in the sciences, working in social justice, to really hone in on this nexus around genetic engineering? What does it mean to people across the spectrum in terms of the kinds of things you care about?

One of the answers I was turning on is this idea [of] how we answer the question around which lives are worth living, which lives are worth bringing into being, and also, by implication, which lives are worth extinguishing. How we answer that question at a biological level has direct implications for how we answer it in terms of the sociology of it—in terms of society. It directly relates to how we invest in housing, how we invest in food, how we invest in education.

When we're talking about genetic engineering, it's not like this esoteric field that is going to impact us down the line. Precisely how we begin to theorize and conceptualize what the answer to this—which lives are worth living—has implications for the things that we're working on right now. This is why the foresight of these organizations to get us together to begin talking about it and opening up the conversation beyond what I experienced in DC at the International Gene Editing Summit.

To begin that conversation, one of the things I thought I would do is think about not how the conversation is being framed, but what are the assumptions in the “preframe”: the preframe of science, broadly speaking, but also the preframe of genetic engineering. What is taken for granted as ideas that we all somehow agree on when, in fact, we haven't had a conversation about it? There's been no widespread debate or deliberation. So I thought, in my opening comments I would just highlight a couple of these assumptions—a couple of these ideas that are part of the “preframe” of genetic engineering.

One of the things that I experienced on a routine basis, as often one of the only social scientists in conversations around all kinds of innovations, is the refrain [that] the public needs more scientific literacy in order to even begin the conversation. So often, it's framed as a deficit: what the public lacks, and how we have to meet that lack before we can engage as equal partners in thinking about the state of investing in a particular field or a particular technology. Often, what I'm struck by is there's not an equal conversation, an equal kind of prioritization around how scientists and other kinds of experts would need to also develop a social literacy in order to adequately engage in this conversation. So we think about what is social literacy. You know, some of those elements. And I was thinking of just a few things that might go into a social literacy around genetic engineering. And it relates to other fields as well.

One of the key kind of starting [points] at the foundation of the conversation—and that the reproductive justice movement really has been at the forefront of contributing and moving public discourse to engage—is troubling the very idea of “choice”: “choice” as a straight forward “good” that has the same kind of effects and meaning for people along the social spectrum when we know, in fact, our personal choices can often reinforce dominant systems, or they can in some ways undercut them, depending on what we're choosing to do in our own lives.

This relates to some of Marcy's points early on that you think about choosing

particular traits for a child. We do that already in terms of giving certain kinds of lessons or enhancements in terms of social opportunities. But with genetic engineering we're talking about often, especially germline genetic engineering, making choices for future generations. In many ways, sedimenting our current biases and our current ideals into people who have had no choice in the matter.

Reproductive justice, the entire movement, helps us in science understand that choice is not a simple kind of ideal that we can take for granted. We have to open up the black box of choice and say, "whose choices are being prioritized and idealized?", and unpack and trouble choice discourse, more broadly.

The second element of social literacy that I see as related to the conversation is often the way that the strict boundary between good uses of genetic engineering and bad uses of genetic engineering are drawn. We are often presented this as part of the preframe of the conversation as very clear-cut: We are not going to do the bad things and we are going to invest in the good things.

One thing Marcy mentioned is that in many ways you can't control—once you let it out of the bag—whether things are going to be used for good or bad. That's one element. But another element is that even the kinds of things we would put on either side of that boundary. Enhancement, we wouldn't choose kids that are going to be taller or shorter, eye color, racial melanin count, and so on. We wouldn't do that. Those social traits we wouldn't invest in. But we would invest in things that have to do with debilitating illnesses that would go on the good side. Those would be the therapeutic uses, the good uses.

And in fact, the boundary between therapeutic good, enhancement bad is quite porous. That really becomes evident when we start to engage the disability justice movement in the conversation where many of the things we might put on the bad side are actually things that people have pride in and do not want to see extinguished. It essentially troubles the common sense that we have developed around this boundary between enhancement and therapy. That's the second element of this social literacy.

The idea that in fact, if we decide that we will only use genetic engineering for good therapeutic uses, we are likely to construct therapeutic justifications for the things we want to see happen. I can unpack that idea a little bit perhaps in Q&A, but the point being that the line is not stable. It's not a dark boundary. Things move on either side of that boundary. We are quite innovative in terms of justifying what we want to do. If we see that a particular justification has traction, then we often we can find ways to employ that for the things we want to do.

The last points that I will not go into in more depth, but want to put on the table as part of enhancing our social literacy around science broadly speaking—genetic engineering specifically—is really for us to be quite honest and tackle the commercial context in which this is happening. People are motivated by all kinds of things. Yes, helping people who suffer from debilitating medical conditions is certainly a primary motivator. But, there are all kinds of things that we wouldn't say are about the public interests but are more about private interests that we need to keep on the table and become very honest about talking about and engaging in the conversations.

The last element of social literacy that I would highlight is really expanding our notion of what governance of scientific technologies and technologies of all kinds can look like. I do not think that those who are producing the technologies can be the only ones to define the risks and benefits around investing in them. One way to think about this is that the risks that scientists know best are not the only risks. There are social risks, political risks that other kinds

of experts, including people who work in reproductive justice, are better equipped to articulate and put on the table. They have to be taken just as seriously as the medical risks that scientists define as important.

### **Nourbese Flint**

Thank you, Ruha. I'm sure there's a lot to get into during the question and answers there. To keep us flowing, we next have Dorothy Roberts, whose book, *Killing the Black Body*, sits on every black woman's book stand, including my own. Dorothy Roberts is the George A. Weiss University Professor of Law and Sociology at the University of Pennsylvania, with appointments in the law school and the departments of Africana Studies and Sociology. Her books include *Killing The Black Body: Race, Reproduction and the Meaning of Liberty*, *Shattered Bonds: The Color of Child Welfare*; and *Fatal Invention: How Science, Politics, and Big Business Recreate Race in the 21st Century*. She serves on the Center for Genetics and Society Advisory Board.

And with that, take it away, Dorothy.

### **Dorothy Roberts**

Thanks. Well, thanks to everybody for joining this really important conversation and to all that helped to organize it. I'm really thrilled to be part of it and to share the conversation with my co-panelists who are all such great experts on this topic and dedicated to reproductive justice.

I want to reinforce what Ruha said about examining the assumption that underlies the science. Often science is described as an objective field that doesn't take into account social biases, free from all the pressures of society and politics. Gene editing falls into a similar trap where there are many social assumption that are hidden. What we know about hidden social assumptions is that they usually benefit the most privileged people in society; and harm the least privileged. That is very true about the debate over gene editing.

I'll focus on a few other points about it—beginning with the way in which the role of “justice” is framed by the dominant view that has been prominent in the debate over gene editing. That has really been controlled by the scientists. From their point of view, the main issues are making gene editing safer, and more accurate, and more accessible. As long as no one is physically harmed by it, and it can be made more accessible to more people, it's seen as being “just.” The only problem with justice regarding gene editing, according to the view is making the technology safer, and more accessible, and more accurate. But this assumes that there's a universal conception of human health and well-being that everybody shares and that gene editing, if it's safe and accurate, is going to further that.

A reproductive justice approach refutes this idea that there's some objective universal project and progress in technology; and it can pave the way in which gene editing imports on social assumptions and hierarchies. First of all, one way in which gene editing does this, is that it operates in a context of longstanding oppression of women, of poor people, queer people, and people with disabilities, and in particular the devaluation of black mothers.

We can look to the history of birth control as an example of what we can expect with gene editing: where birth control technologies, like gene editing, were proclaimed to be inherently liberatory and all that was important was increasing access to these technologies. But what history shows us is that they actually have been used for decades to deny black women and other women of color the right to have children. If you don't take into account this



systemic devaluation of black mothers and the way in which these technologies have been used as forms of population control, you are not addressing the *true justice* in reproductive technology. A major point of reproductive justice is that technology should not be used to deny women the right to have children, especially when that denial is based on unjust hierarchies of race, and class, and gender.

Secondly, the advocates of gene editing rely on changing the biology of individuals rather than changing the unjust structures of societies in which human beings live. The people who have dominated the debate over gene editing have a vested interest in the belief that the reason why socially disadvantaged people have problems and are suffering is because of their inherent trait. So the answer is to change their inherent trait rather than to change society. Gene editing focuses on individual enhancement rather than social change.

Well, there's a big difference in the viewpoint of people who are oppressed by social structures, and people who are privileged by them. People who are privileged by them have more of a stake in keeping them the way things are. You're not going to get a debate about gene editing or a view about the ethics of gene editing that takes into account its role in perpetuating social structures rather than rely on biological changes, if you don't include the voices of the people who have a stake in social change.

Right now, the dominant voices are people who don't have that stake in social change. Obviously, the debate would be very different if we included at the forefront the voices of people who understand. This is what reproductive justice stands for—understands that humans' well-being and freedom relies on an equal society—not on tampering with biological differences.

Thirdly, and relatedly, gene editing operates in the context of increasing neoliberal reliance on the market and the stripping of state support for human well-being. Gene editing relies on a market-based procedure that focuses on changing individual's biology rather than relying on state-supported, people-led changes in society that provide generously for all people, humans, well-being.

The reproductive context of this reliance on the market has meant giving women the responsibility of ensuring the genetic fitness of their children. For example: eliminating genes that fit for children with disabilities rather than ending discrimination against people with disabilities. It's led to pressuring women to use genetic technology in order to enhance dominant views of genetic fitness.

Women of color are the most vulnerable to this kind of exploitation both for them to use gene editing to control their children's traits; and it's not at all true that providing more access to women of color is going to provide us more freedom if it just means that it will enhance the pressures on women of color in order to use these technologies to produce the children that the state believes would be less of a burden on it.

It also can be used to exploit women's bodies, especially women of color's bodies, to be used in the reproductive marketplace. A reproductive justice approach reveals what might look like freedom of choice to use genetic editing, as Ruha pointed out, is actually the perpetuation of unjust social structures and hierarchy. If we focus on dismantling unjust structures and hierarchies as the main way to achieve reproductive justice, the ethics of gene editing looks very, very different. That's why we need to be at the forefront of debate about the ethics of these new technologies.

I'll end there.

## **Nourbese Flint**

Thank you, Dorothy. I just want to remind folks that there is a question and answer box, if you have any questions that come up. We have one more panelist and then we'll get into that space.

Our final speaker is Lisa Ikemoto. Lisa's the person's whose work I turn to when I'm personally looking for how to talk about reproductive technologies and people of color's bodies, and I'm super appreciative of having someone right here in California, in our backyard, who is a leading mind on this work. Lisa is a Martin Luther King Jr. Professor at UC Davis School of Law. She teaches bioethics, reproductive rights, law and policy, and healthcare law. She uses a critical race feminism to examine how race, gender and class shape the development and use of emerging biotechnologies. Her recent work addresses reproductive tourism, the way in which human-gametes use links the fertility and biotechnology industries and the privatizing effects of informed consent.

Phew, that was a lot. Go ahead.

Lisa, take it away.

## **Lisa Ikemoto**

Thank you, Nourbese. I want to echo everyone else's thanks to Black Women for Wellness, In Our Own Voice, and the Center for Genetics and Society.

To pick up the conversation, I'm going to take the gray critical questions that Ruha and Dorothy raised—the framing questions—and also the threads that they identify, trying to bring us down to the ground. I'm going to focus on how the use of CRISPR or other genetic modification tools for germline modification purposes might come to be distributed.

I believe that if and when genomic modification of human embryos, eggs, and sperm rules out, it will likely do so for fertility clinics as an add-on service to in vitro fertilization. I'm going to start by providing a sketch of the fertility industry. I'm going to be using broad strokes with some qualifying language but little nuance, which means I'm going to be generalizing quite a bit, in order to just set up the picture.

The fertility industry, which is based on the use of assistive reproductive technologies, is a multibillion dollar industry. This goes to the point about commercialization that Dorothy and Ruha have both raised.

Typically, when we look at the use of assistive reproductive technologies from the outside, what we see is the doctor, the intended parent or parents, and the beautiful children who are conceived through technology use. The industry includes many other actors and it's important to keep those in mind. Of course, there are the people who provide sperm and eggs for other use—people called donors—despite the fact that most of them are paid; the women who provide surrogacy services; and then there are the sperm banks, the egg agencies, surrogacy centers, genetic testing labs, embryology labs, drug companies, professional organizations like the American Society for Reproductive Medicine, lawyers, and credit agencies among others.

The fertility industry is primarily, but not wholly, for profit. The services are priced as luxury goods as Debora Spar's work has shown. Many, but not all, of the centers and agencies that are the glue of this industry offer their services in ways that commodify humans and their attributes, including race, religion, SAT scores, athletic ability, hobbies, and body mass index, just to name a few.

The use of these technologies reflects tensions in how we define family or the

families we accepted as "normal." There have been battles over access by people who are single, by LGBT folks, by people with disabilities. Access by people of color and lesbian and gay intended parents has been created more by formation of niche markets than by inclusion of mainstream markets. On the other hand, the industry has enabled family formation outside of the traditional marriage base by the so-called 'opposite sex family model,' and so has challenged, in that way, obligatory understanding of family.

In the meantime, practices in the fertility industry reinforce and expand strategized reproduction. Shelley Collins showed how race, gender, class, immigration status marked out and limit the roles that women from different groups can play in reproduction and family. Her work focused on who were the nannies and who were the mothers. Obviously Collins' work also reminds us the stratified reproduction has a long history and has taken different forms in the U.S. In the present time, we often use assistive reproductive technology in ways that defines specific limited roles for people who are participating in reproduction and family formation. We call them egg donors, sperm donors, surrogates, and intended parents. And the first three are situated as third parties, largely by contract, and therefore clearly situated as non-family.

The fertility industry is globalized and fosters reproductive travel, a form of medical tourism. The major destination spots tend to be characterized by highly gendered social structures and economies, weak regulation, and developing nation status. It's no surprise that when we hear about reproductive travel or these major destination spots, they include places like India, or, more recently, Mexico. The industry is dependent, in other words, on inequality.

That being said, the U.S. is a major destination spot in part because of weak regulation but also because of at least three other factors I want to mention. The first is inequality, resulting from availabilities of women and financial need and ability of others to pay at luxury good prices. Number two: the racial and ethnic diversity of our populace that makes it possible to offer eggs, sperm, and surrogates of every race for differing prices. And, three: lack of restriction on genetic testing and selection, including sex selection.

While most who use in vitro fertilization are not necessarily rich, there's an economic access divide. Because the labor markets are structured by race and gender, it means that single women, especially women of color, and lesbian couples, are the least likely to have economic access to fertility services.

The 21st century has the family normalized practice of selecting attributes like SAT score and pricing people with those attributes. The way in which these technologies are offered keeps the idea of biological race alive and profitable. In addition, we've accepted with little question the role of commercial sperm banks and egg agencies in screening out donors based on social criteria, including disability, and punitive medical criteria. These practices all wrapped up in an explanation that makes the supply in demand, market language, the rhetoric of gift, health, love, responsibility, and most of all the language of choice. Neoliberalism of free market individualism frames the practices and the way we see the issues.

Now I'm going to move us down to gene editing and how it might roll out. Imagine that CRISPR has been used to modify several in vitro human embryos; and as a result a baby has been born, apparently a healthy baby. Current U.S. law prohibits the FDA from reviewing proposals to modify human embryos, although as Marcy mentioned at least 40 other countries are prohibiting this use. For now, that effectively bans any genetic modification of human embryos. My hypothetical seems a little unlikely but the law in the U.S. is part of an appropriation bill that requires annual renewal. So the law could change in any renewal year.

Given the fact that we have medical tourism, those who want in vitro fertilization with genomically modified embryos could go to another country.

Here's an example, not with CRISPR, but another genetic modification technology. In 2016, Dr. John Zhang announced the birth of the first baby born after conception with a modified embryo. The technology used was maternal spindle transfer, titled mitochondrial transfer. I won't explain that technology now. It's a different tool and a different type of genomic modification than CRISPR. Because U.S. law prohibits this in the U.S., the New York-based team sent the intended parents to the New Hope clinic in Mexico and the justification was "therapeutic" —they used this line that Ruha referred to earlier.

The focus of the 2016 announcement was that the procedure was a success and the baby was healthy. There was no significant evidence offered to show that, but almost immediately mitochondrial replacement was offered or improved in a number of other countries. The New Hope clinic itself announced plans for 20 more mitochondrial replacement babies; and in the Ukraine, mitochondrial replacement was used not to address disease but as a fertility method, thus, dropping the therapeutic justification. This new technology, unapproved in many countries, became commercially available within weeks.

I think this illustrates a likely pathway for germline modification by CRISPR. Germline modification would become an enhanced form of genetic selection offered as an add-on service to in vitro fertilization, to those who can't afford it. That would widen the door for eugenic selection.

Eugenics has a long history and has taken different forms in the U.S. over the years and most of them, the idea of the 'social good' has justified imposing reproductive control to achieve social control over certain populations—most often defined by race, disability, poverty, and national origin. But eugenics can also result from privilege of purchasing genetic choice.

Even if genetic modification is not used to create so-called "designer babies," it's still likely to be used in a setting that feeds the idea that biological race is real and that perpetuates stratified reproduction.

I'll end there. Thank you.

### **Nourbese Flint**

Thank you.

First I want to thank all the speakers for giving us that background and laying the foundation for a conversation for us to have. With that being said, we are moving into our question and answer. I want to take a little bit of moderator's privilege and ask my question, or a couple of questions, first. Again, just to remind folks, use the Q&A box on your right-hand side on your compute, in order to put in questions.

My question goes for all the panelists but I'm going to start with Lisa and I'll work my way backwards. All of you talked about reproductive justice and social justice folks not being at the table. But I'm wondering who is at the table? Who are the folks making these decisions, and if there's any insight on the framework —or if there's any framework at all— that they are using in trying to make these decisions about what technology should be moving forward?

I'll start with you, Lisa.

### **Lisa Ikemoto**

I'm sorry. I thought you were asking Ruha.

Who is at the table? So far as Marcy mentioned, it seems like it has been primarily

scientists at the gene editing summit; and since then it has been interesting. I think from that perspective of institutional science, the belief seems to be they're being more inclusive than others, and that may be true. But that's a comment on how previous conversations have taken place.

So it's true that there have been people like Ruha speaking up, and Dorothy, and certainly many of us. Many others of us have been trying to get our voices in the door. But the formal conversations are largely taking place indoors within those institutions.

I don't know if anybody wants to add anything to that.

### **Dorothy Roberts**

Well, I'll add one aspect of it. In my limited experience being part of the conversation as part of the stem cell research program in California and part of the Standards Working Group looking at the ethics of that, I have found that the voices that are added outside of science—the “regular people” that will be affected by gene editing— tend to be patient advocates.

I think there's a sense that there are scientists; and then there are people who will be affected by gene editing, and those people are patients and their advocates. The people who are turning to them are carefully selected ones who are looking to gene editing as a way of addressing certain diseases, illnesses, disabilities. They almost are used in a way to shut down criticism of gene editing because they are not scientists. They are people who have very sympathetic situations. But they are not the disability rights movement that questions more critically the way in which gene editing can be used to discriminate against and devalue people with disabilities, and substitute for ending that discrimination.

That's just one piece of how I've experienced the debate supposedly “widening,” but widening to people who support the idea of gene editing as a solution for illness and disease and disability as opposed to more critical voices.

### **Ruha Benjamin**

And I would underscore Dorothy's last comment. Another way to think about it is that the public is included often; but it's a highly curated public and one that often has to pass a litmus test of already fully supporting the agenda as it has been given.

There's often a very low tolerance for raising these critical questions among those—and this is not simply about gene editing, but grows out to research on stem cell research and stem cell initiatives— where there is a public that's included. It is a patient advocacy public that is strongly supportive. There are many good reasons of the science, but it often has the effect of shutting down other counter-publics who might raise other types of questions that are really valid to the conversation.

### **Nourbese Flint**

Because all three of you mentioned this conference that happened, could someone tell us, for folks who don't know what the conference is that it seems like all of you were at, what the conference is? I don't know who would be the best person to speak about it. Maybe Lisa, or Dorothy, or Ruha about this conference that folks were at, where none of us happened to be there but you all were there—the one talking about gene editing.

### **Ruha Benjamin**

Sure. I won't go into it in-depth. It was called the International Summit on Gene Editing, although the extent to which it was international was questioned all along. It was, I believe, co-sponsored by the National Academies of Science, U.K. Royal Society and the Chinese Academy of Science. The names of those might be a little off in my presentation, but a quick Google [search] and you can find the entire proceedings, video proceedings, the text that came out of it online for those who want to learn more about it.

### **Nourbese Flint**

Thank you.

To follow up a little bit on that, this question is for Dorothy. Given the already complicated history around scientific development and women of color's bodies are there any historical precedence that we can look to show if we don't kind of add our voices to this conversation, where it might be going?

And I know you talked a little bit about birth control. Are there any other spaces that we can look at?

### **Dorothy Roberts**

Well, one might be the contest over addressing coerced sterilization, where there was an assumption that increasing access to sterilization would be beneficial to women. That left out the experiences of black women, Latino women, Native-American women, and other women of color who had been victimized by state programs to sterilize them. The involvement of women in color in that debate, and also in advocating for regulations that would end or at least reduce—they didn't work to end it—but at least there was some intervention in what was rampant sterilization abuse of women of color, was critical. That's one historical example.

Another is the way in which the history of eugenics has been co-opted by conservative anti-abortion advocates—even using black women's experiences to shame black women and to promote the view that black women by having abortions, are committing genocide against their own people, promoting the message that black women's wombs are the most dangerous place for African Americans. That was part of a billboard campaign that went up. I know without black women being involved in challenging those efforts—which also included legislation both at the state and national level to restrict abortions by women of color, on grounds that they discriminated against girls or against black children, without the intervention using a reproductive justice focus on these laws and advocacy efforts—many people might be fooled into thinking that denying women access to abortion services, which are medical healthcare services that women have a human right to access, might have thought that this was some kind of social justice effort.

I could give other examples, but those are two where the intervention of women of color, and in particular black women, have been absolutely essential to understanding the social justice implications of the regulation of technologies and access to technologies.

Again, as I was trying to emphasize in my comments, “access” by itself doesn't mean anything if it's access to an unjust structure. In these cases, whether we're talking about access to technologies or restrictions to those technologies, you have to look at what are the underlying social assumptions, and what are the implications; what's the impact for social structures and hierarchies to get to whether they're just or not. They're not either just by themselves. Without that attention they can be, and historically, reproductive technologies have been used to harm and control as much as they've been used to liberate.

### **Nourbese Flint**

Thank you.

There was a question from the webinar. I'm going to read it. "My own experience is that many people—in their research or science elite, as well as regular people who may feel they don't know much—have an instinctive understanding of how complicated it is to talk about the so-called "good" or "bad" uses and how access issues and hierarchies affected. So does anyone know of recent surveys, research, or focus groups, or other opinion work that specifically women and men of color, people with disabilities, and others about their own views about somatic and germline editing? It seems like it would be a rich area to explore."

I'll shoot that one to Ruha.

### **Ruha Benjamin**

I was looking at that question and just thinking, I don't know off the top of my head one survey or research project that encompasses all of that. I've seen much smaller scales, often qualitative studies. But my first inclination is that that would be such a valuable starting point—to have a survey that tries to gauge where people are at.

Then a follow-up question that I noticed coming here on this side panel, is what forums or settings do we see as important for broadening the conversation beyond scanning or surveying the field? One of the things I was thinking about [in] my own engagement with Black Women for Wellness and the ongoing work this organization and others like it are engaged in is that for a genuine conversation, you meet people where they're at.

Oftentimes with the way that federal funding is tied to forms of public engagement, we stage events. We stage programs that are meant to have a wide representation, but there's such a strong selection in terms of people who show up to these or who are invited to these—often, these invitation-only public forums—that I think we want to push beyond that level of deliberation and meet people where they're at. [For] example, Black Women for Wellness has a monthly breakfast so that people in my neighborhood of South Central L.A. come to something that community folks are already going to, and connecting the issue of genetic engineering where people care about already.

I think oftentimes if someone is already gung-ho about something like genetic engineering—that is one population, often a very small population. But there's a lot of people for whom this field will impact and have meaning and the stakes are high for them, but that connection hasn't been made yet. I would think that we would want to engage more in terms of people who don't even see this as an issue yet, but who will likely be effected whether they realize it or not.

One way to do that is to have more robust relationships with organizations that have been working in communities all along, and not helicoptering in when it suits our research to find out what people know, as opposed to building these lasting conversations. That's one set of thoughts around that.

### **Dorothy Roberts**

I really, really want to support what Ruha is saying—that surveys are good. That should be a starting point. But this is really an issue of engagement. Many people don't believe they could engage with science because they haven't been given opportunities to do that. There is such myth and mystique surrounding what scientists do in U.S. culture that says they

have absolute authority, and other people can't possibly understand what they are doing. That is such a dominant view that it's important to break through that, as Ruha, other people, science, has done. But it has to be done by engaging with people about the struggles and issues they are facing right now and explaining that it's ok to criticize science.

I think as all of us have been saying, that's one form of knowledge. It's not immune from bias. But there are other forms of knowledge that are just as important. That message is going to take a lot of organizing and movement work to get across in addition to them raising up the voices of people who now have been—understand better how they can participate.

### **Nourbese Flint**

Another question from the webinar participant: “Can any of you comment on how the fetishization of the ‘other’ contributes to genetic modification and gene editing?”

I don't know who would be best to answer that question. Lisa, do you want to try it?

### **Lisa Ikemoto**

I can start. In part, you have to think about who the other is—that's being created by the possibility of genetic selection and genetic selecting out. That's what we're talking about is drawing lines between—it's a question that Ruha introduced at the beginning—who are we saying whose lives are worth saving and protecting, and whose lives are we saying are not.

As this technology is implemented, we have a chance, to push back against the dominant sort of assumptions behind that. I think the opening questions were so important in this conversation.

I think as it stands now, the conversation is assuming that people with serious illnesses and people with certain disabilities are the “other” in this conversation. To build on the history that Dorothy introduced before, idea that we should and could do this has a long history. The choices that we've made over time about whose lives should be protected and whose lives should not may have shifted from time to time.

For example, when I looked at—I've written a little bit about—the coerced and forced sterilization that took place, not during the early 20th Century but primarily during the 1960s and 1970s across the United States. The populations actually varied from region of the country within the United States. For example, on the West Coast, it was largely Latinas who were not receiving public support. In the South, it was largely low-income black women who were receiving public support. In the Northeast, it was more likely they would be Puerto Rican women; and in some parts in the country, including the Midwest, it was more likely to be white, low-income women. So, who is “other,” is just as telling.

I think we have to keep our eye on the ball. Right now, I think the justification that's being used is a therapeutic justification. That may change, and it may change very quickly just as it did in the mitochondrial replacement example that I gave. But because it's shifting, we have the opportunity I think to try to shape that conversation.

### **Nourbese Flint**

Just a follow-up on that question of “who are the others?.” usually, the conversation around gene editing has to deal with, “Ok, then it's going to be eugenics and they're going to edit out people of color” , right? People's worst case scenarios. Is that really the case? There was also a conversation about commodification of people of color's traits.

So this question is to Ruha. Is there another way that we can look at the



conversation when we talk about commoditization of people's bodies? Is it the extreme “only eugenics” based, where they gene edit disabilities and race, or are there other conversations that are just as tangled, and we should be weary of?

### **Ruha Benjamin**

I think the skill set that we need is this kind of adaptability in terms of what we look out for and what should concern us, and not assume that the way in which scientific harms got enacted in the past is the same way it's going to get enacted in the present or future. There's a kind of adaptability to harm so that our critique of it has to be as adaptable.

One of the things I think we should look out for—and there's already a precedent for this but I think one direction that we should really keep in mind—is that often we presume a eugenic harm will be enacted by trying to get rid of undesirable traits, that those undesirable traits will be mapped on to social groups that are already subordinated and already oppressed. That the primary approach will be to lessen that group, lessen those traits. Certainly, there's a lot of precedent for that.

But I think what we also see as a kind of subtext all along that may, in fact, characterize the way in which genetic engineering takes shape in the future, is more along the lines of—again, thinking about this word that the person used in terms of “fetishization”—particular kinds of traits associated with subordinate groups becoming desirable in interesting ways, and therefore commercially lucrative so that people want to capitalize on creating more of that.

We see this in the cultural sphere. We see that in terms of cultural appropriations, for example, in which white culture appropriates those selectively—those particular cultural traits or behaviors that are seen as fashionable at any given moment, and that there's a lot of attention and investment in that. Often the people who originated that or who are the primary protagonists of that do not benefit at all, or nearly as much as the dominant group when they use that.

We might see something similar in terms of how this affects genetic engineering in the way we think of, let's say, a climate change. There's, as I mentioned to my colleagues on the panel here, a new short science-fiction film that takes the premise of climate change and shows that the severe heat makes melanin a highly commoditized trait, so that there are melanin extraction clinics all around the country. Those people who are experiencing poverty sell their melanin to the clinics in order to get some kind of compensation, and the primary people purchasing the melanin are white people. In that case, blackness is not an undesirable trait. It's desirable. It's commoditized, and it's exploited.

I think we see Lisa's work really highlights this in terms of IVF, but we see precedence in terms of the way that scientific harms may present a particular quality or trait as desirable, but the people who have that do not benefit from that desirability. The exploitive context means that they then are a subject to different forms of oppression precisely because what they have is valued. We shouldn't conflate a quality that is valued with the people being valued who have that quality.

### **Nourbese Flint**

There is several questions about what can we do as listeners, as scientists, as academics, as healthcare professionals. Ruha talked a little about diving into communities and linking up with communities. But is there any conversation or space in which folks who are

listening can get engaged? Or how would they do that? And what demands should we be asking healthcare professionals, scientists, and academia with this conversation?

I'll leave that there, and I'll shoot that first to Dorothy Roberts.

### **Dorothy Roberts**

Well, I think organizing on a number of levels is important. One level that we talked about a little bit just a moment ago was working with organizations that are already promoting social justice in various ways. I think this webinar is an example of three organizations getting together to address the issue of gene editing and reproductive justice.

I firmly believe that it's much more effective for people to work collectively than individually. I think individually we can all become more educated by reading what's available on gene editing and the critiques of gene editing, but it's really important to work with organizations that are already either focused on reproductive justice or genetic issues like the organizations organizing this.

But also, and this is a key aspect of reproductive justice, is connecting with organizations that are not focused on those particular topics, but we understand how they are addressing interlocking forms of oppression. Organizations that are dealing with criminal justice, for example, disability rights, economic justice, health justice. All of those intersect with gene editing, and all of those movements can be harmed by a focus on gene editing as the solution to social inequality. That's the sort of broad way of talking about it, but I think that collaboration among social justice organizations on this issue is really key.

### **Ruha Benjamin**

Do you mind if I add a little footnote?

### **Nourbese Flint**

Go on.

### **Lisa Ikemoto**

Yes.

### **Ruha Benjamin**

I strongly support that idea of collaborative work—groups working on different things coming together around this. One thing I feel like we could all do, as soon as we get off of this call, no matter what our spheres of influence is, is to really begin to seriously tackle the kind of scientific exceptionalism that prevents people from engaging this in the first place.

One way that I tend to think of it is, people don't feel like they need training as an economist to have a voice when it comes to things that have to do with work and employment and economic issues. There's not a sense that "If I'm not an expert, if I don't have degrees in this, I can't say anything meaningful about it." We don't do that with other things. We don't think, "Oh, I need to be trained in political science to have any worthwhile ideas about what's happening in politics." No. Everyone feels the implications and what stakes are. They have something to say. I think we need to do that same kind of cultural work in terms of shifting discourse, shifting out how people feel they can meaningfully contribute and say, "You don't need a degree in this in order to contribute meaningfully." It won't be the same contribution as a scientist or as someone trained in this particular field, but you have something meaningful to

contribute to the conversation.

I think that that kind of shift—we have to begin to do it no matter our sphere of influence. Otherwise, we will continue to run up against this idea that “I’m not a scientific person. I’m not a sciency person.” Right? “That’s too heavy; I can’t get into that.” The reluctance. The ambivalence. The fear, even to even tread into these conversations.

I think that something we can all begin to do is tackle that scientific exceptionalism to say that we all have a meaningful stake in this and so we all need to be able to think. In fact, we might even think someone who is not trained as an economist would have something different and worthwhile, something completely different than someone in that field would have. It’s a valuable contribution precisely because you’re not trained in it. You can see things that that person cannot. I think we can make a similar shift to say precisely because this is not your entire livelihood that’s caught up in the advancement of the field, you may have more objectivity towards contributing to this than someone who is trained in that. It shifts the stakes in terms of who should be talking about this.

### **Lisa Ikemoto**

I just want to add one more thing to cap that. Ultimately, these questions are not about science and technology. They’re about people. They’re about us and our lives, how we’re valued.

### **Nourbese Flint**

So with that, because I know we’re at time, I wanted to give about 30 seconds to each panelist if they had any final thoughts to share with us as we wrap up this webinar. Again, thank you. I will do another thank you in a minute. I’ll start with Lisa. Then we’ll do Dorothy, and Ruha.

### **Lisa Ikemoto**

[In] my last 30 seconds, what I would go back to is that maybe what’s different about the questions that we’re facing now that we haven’t seen as clearly in history is that it’s highly commercialized. In the market, there’s a very big slippage between desire and all the way to need. We make that transition very easily as consumers in the market. That’s part of what happens with these technologies. The industry relies on that. We should be challenging that.

### **Dorothy Roberts**

I would say that even though there are lots of changes in how our society is organized, and how science operates, and the technologies, there is a basic philosophy of gene editing that is consistent with prior ways of thinking that we’ve seen cause all sorts of harm. That is the reliance on changing individual’s biology instead of changing unjust social structures. That’s the aspect of reproductive justice that I think is so important to add to this debate and to how we’re going to deal with these technologies in the first place—that reproductive justice focuses on changing society in order to ensure human rights and well-being—not changing individual’s biologies. I think if we keep that framework in mind, it will help us think much better and act much better about the ethics of gene editing.

### **Ruha Benjamin**

I guess I won’t use the whole 30 seconds. I’ll just use three words that come out of

some current discourse, especially through social media when we talk about these issues. That is, “trust black women.”

### **Nourbese Flint**

I want to say a big thank you to the panelists, to the fellow co-sponsors, the Center for Genetics and Society, and In Our Own Voice National Black Women's Reproductive Justice Agenda. Of course, again, this is Nourbese from Black Women for Wellness.

I do want to plug the books again. We have Ruha Benjamin's book, *People's Science: Bodies & Rights On The Stem Cell Frontier*. I actually have it right in front of me. Dorothy Roberts', *Fatal Intervention*, and *Killing the Black Body*.

I'm also looking at the book, too. Right? *Fatal Invention*. And *Killing the Black Body*. Lisa, you can find her information and great work online, particularly around egg donorship.

I thank you for being involved in this conversation. I know we didn't get a chance to get to all of the questions, and we need to have more spaces to have these conversations. Another shameless plug, Black Women for Wellness with the Center of American Progress will be hosting a science, science fiction and comics preconference, for October 4, in New Orleans-- right before “Let's Talk About Sex Reproductive Justice Conference.” More details about that soon.

This is one of the conversations we wanted to talk about—linking the science fiction and science intersection—particularly with a social justice lens. Again, this conversation has a lot to dive into. We hope you will come back. We hope you plug into your organization.

Please stay on for a couple of minutes afterwards. You will see a survey that pops up when we close out. If you can take the survey, if you'd like more details, connect to the organization, pop your email in there and we can get you connected to some of the organizations doing this work.

With all of that, thank you, again. And, next time.