

Feminist Intersections: Reproductive Genome Editing at a Crossroads

March 28, 2023

Katie Hasson: I'm Katie Hasson, the associate director of the Center for Genetics and Society. I'm a woman in my 40s with curly chin-length red hair and pale skin. I'm wearing glasses and a black blouse with a floral pattern.

Many thanks to our captioner and to our ASL interpreter, Holly Newstead.

Before we begin, CGS would like to acknowledge that we work on the ancestral and unceded land of the Ohlone people. We know that acknowledgment is not enough, and we commit to supporting indigenous sovereignty and indigenous-led organizations in our work.

Today's webinar is the third in a series organized through CGS's Missing Voices Initiative, which aims to bring into the conversation on heritable genome editing the essential voices of civil society advocates and scholars committed to social justice and human rights. If you haven't yet seen the previous webinars, including our recent symposium, "Genetic Justice from Start to Summit," we hope you'll check out the recordings and transcripts on the CGS website.

Today, we have a stellar lineup, bringing an intersectional lens to the discussion of reproductive uses of genome editing. By this, we mean altering the DNA of eggs, sperm or early embryos for use and reproduction, resulting in a genetically modified child—also referred to as heritable genome editing or germline modification.

This practice is broadly opposed by civil society advocates and scientists alike, and many in between. It is currently prohibited in over 70 countries. If it were to be allowed, it would roll out in the profit-driven and poorly regulated global fertility industry. This makes it urgent to engage feminist critiques of the industry, from the lack of research into long-term health effects of egg retrieval, to the potential for exploitation in cross-border commercial surrogacy.

We also need to situate these discussions in broader critiques of reproductive oppression and eugenics. All of these would bring needed attention back to the women and pregnant people who would undergo IVF and carry, give birth to, and care for gene-edited babies. This is another way that putting the seemingly missing voices at the forefront can fundamentally change our discussions of this powerful emerging technology.

I'd like to now turn things over to Susan Berke Fogel, the moderator for today's discussion. Susan is a cofounder of the Pro-Choice Alliance for Responsible Research and an attorney and consultant to nonprofit organizations working on reproductive health and rights issues. Thanks so much, Susan.

Susan Berke Fogel: Thank you, Katie. I am a getting-older white woman. I am bald and wearing red glasses and a dark brown shirt and silver jewelry.

You know, it is incredible to think that the first IVF baby was born just 44 years ago. There is so much that we still don't know. We know little about the long-term health effects on women who undergo IVF for themselves or who provide eggs for third parties. We also know little about the long-term health of the babies who were born. After all, they're only 44 years old—they are younger than I am. And still, technology marches on, too often unchallenged.

We, however, are grappling with these technologies in the larger context of tremendous inequalities across the world, at the intersections of gender, race, class, opportunity, environment, disability and power that currently exist. Forced sterilization, coerced sterilization and environmental toxins are robbing low-income women and women of color of the decision-making dignity to decide when and if to have a child. At the same time, the global for-profit fertility industry is offering childbearing options with a menu of trade selections to those who can afford to buy them.

These new technologies are bringing greater disparities across these different sectors. But they are being marketed as “curing disease,” “ending disability,” “parental choice,” “scientific progress,” when they are really the embodiment of the new eugenics, demonizing people with disabilities, and vastly exacerbating the great disparities that already exist.

It is a complicated subject, and we are really glad that you are here for it. Luckily, our panel is ready to take on these challenges. So, let's get started.

Our first speaker is Kavita Ramdas, who is a globally recognized advocate for gender equity and justice, who provides high-level consulting advice and guidance on initiatives to defend democracy and protect human rights, both within the United States and across the globe.

Kavita Ramdas: Thank you, Susan. I am an older woman with silver hair and an Indian bindi on my forehead. I have light brown skin, and I'm wearing a patterned shirt with Indian cross-stitch embroidery. I'm really glad to be with you all today. Salaam and namaste.

I would like to begin my comments following on the framing that Susan has given. As somebody who did not grow up in the United States, I think it's really important for us to situate this whole conversation within a larger reality of power dynamics that exist across the globe, between those who have had power and who have exercised that power in the rest of the world, particularly in colonial forms. I think it is very difficult for people to understand that, just as the first IVF baby is only 44 years old, the first country to become independent post-1940, post Second World War was India from colonial rule—India and Pakistan together. That is only 75 years ago. Most countries in the African continent gained their freedom much later in the 60s.

That relationship of power between the countries that have had and that have not had vast economic, military, and political power over other countries has meant that the relationships have translated into almost every sphere, including the spheres of reproductive rights, of reproductive choice, and the ways in which we envision our futures.

Some examples of that: The fact that it makes it very easy to look for surrogates in countries where women struggle to find any kind of adequate employment or fair pay; the fact that it makes it possible for people in much of the developing world to see surrogacy as some form by which they may make sure that their families can eat or that their own existing children have the chances to be able to go to school and have a better future.

These complex realities are something that I think we rarely take into account when we are discussing this because, for the most part, these conversations are happening in the Global North, where your technology has already gone to a point where people are feeling like “This is a question of choice” or “This is a question of what I want for my children.”

One more aspect of this is that there is a huge way in which the questions around genetics are

used to propose using women's bodies in the Global North to really be seen as baby manufacturers. What do I mean by that? Some years ago, in Germany there was a campaign to bring more Indian guestworkers in on visas to be able to work in the computing sector. The right wing mobilized against this with huge campaigns with signs that said, "Kinder statt Inder"—women should have children instead of us hiring Indians.

This is not that far away from, "We shall not be replaced." There is almost an obsession with trying to increase birth rates amongst nations where they feel that the ethnic majority is losing its majority, and therefore that needs to be replaced with pushing women to actually bear children and thereby advance the objectives of the nation state. I think that this is a deeply macho understanding of what it means to be a nation and is deeply grounded, both as Susan talked about, in issues of eugenics, as well as in ideals around racial superiority.

I want to say two more words about where I am in my work, which has been primarily in the field of philanthropy. I am deeply concerned that philanthropy tends to not think about the intersections between these different areas of work. If you are a philanthropy that funds science, you are rarely thinking about women's rights. If you are a philanthropy that funds women's rights, you are rarely thinking about science. You are not thinking that gender and equity are built into almost every single thing that you do.

I think that there is a long history of, particularly in the country that I grew up in, in India, where the foreign foundations—the Rockefeller Foundation and Ford Foundation—that were involved in supporting population control in India, trying to bring the birthrate down, in the 60s, were viewed with great suspicion by women's right movements and through an understanding that this was a way to control the birth of brown people.

So, let me end by saying that I think there is also a deep resistance in the Global North to thinking about ways in which they can decrease consumption and look at population more as a way to basically have control over what the rest of the world consumes, rather than decreasing their own amounts of consumption. I look forward to discussing this with my panelists next. Thank you, Susan.

Susan Berke Fogel: Thank you so much. So much to think about. Our next speaker is Amrita Pande. She is a professor and the chair of the department of sociology at the University of Cape Town. Her research revolves around globalization and the intimate, with a focus on reproductive labor and new reproductive technologies.

Amrita Pande: Thank you, Susan, and thank you, Kavita, for that. I am going to follow immediately from what Kavita just said. I am Amrita, speaking from my home office in Cape Town, South Africa. I'm a woman with brown skin in my 40s. I have a chin-length curly brown, partly gray hair. I'm wearing a blue-green jacket. First, I really do want to start by thanking Katie and the CGS team for inviting me to be a part of this stellar panel and for building this community around some very urgent questions.

What I want to do today is, in some sense, connect my work on the global fertility industry with the potential use of heritable gene editing for reproductive purposes, essentially what Susan outlined and Katie outlined, germline editing at the stage of IVF. As Susan and Katie have hinted at, there has been a long list of past and current eugenic practices in many parts of the world, which bear adequate testimony, I think, to the fact that the desire, the temptation to genetically modify the future generation in a hunt for an assumed perfect race, perfect baby, perfect future generation, is not mere dystopia.

In today's world, advocating for a technology which aims to genetically modify future generations in a world that is becoming increasingly unequal, divided, politically conservative and right-wing, as Kavita was pointing out, is acutely dangerous. Yet, we find media, scientific communities, academics, and the professional elite celebrating these new technologies as if they are miraculous. Although many of these advocates have recently—and this was quite evident at the summit—they started taking cognizance of the moral and ethical quandary of such technology, almost always, these critical questions—what we think are critical questions of justice—are dismissed by simply drawing a boundary between safe/unsafe, good/bad use of these technologies and, of course, responsible and rogue scientists.

Accepting this binary, I think, is simply naive. While advocates of these technologies believe and would have us believe that heritable genome editing would benefit society, let's just call a spade a spade. Heritable genome editing is not about celebrating our unlimited choices as individuals. It is about eliminating undesirable traits in our future generation. I want to focus on these undesirables, what these undesirable traits are likely to be, based on my experience of researching on and working with intended parents or clients—whatever you want to call them—and professionals in the global fertility industry.

I have worked quite a bit with gestational surrogates and cross-border gestational surrogates and egg providers across the world, but I'm going to focus mainly on racialization and the inherent whiteness of this industry. But it goes without saying that the fundamental base of this industry is to select out disability. We can talk about that in the discussion.

For the past decade—actually more than that now, almost two decades—I have been trying to fully understand the transnationality of the fertility industry by conducting research in three related sites. I think it is important to quickly talk about what these sites are because they will give you a kind of hint as to the transnationality of the process now and the way that the market has flushed into the Global South.

The three related sites that I have worked with are the preparation of egg providers by global egg agencies in South Africa; the egg retrieval and making of embryos in a global fertility clinic in India; and finally the transfer of embryo into the womb of a gestational mother in either Cambodia or Ghana.

The intended parents who I have interacted with in these global fertility clinics are predominantly international. Essentially, these global egg banks and clinics are satellite spaces with little to do with local laws, national laws, or even the national intended parents. So, what is relevant for our conversation here is what these satellite spaces, what I call global fertility clinics, have allowed in the name of choices, desires about the future generations.

What is really critical for us to understand is that these choices are not individual or innocuous, but they are fundamentally shaped by coloniality, post-coloniality, and, if I may just steal Sarah Ahmed's phrase, a desire for proximity to whiteness.

I am recalling this interview with *Wired*, where our very own Marcy provided some great provocations, where sociologist James Hughes remarked that he is not worried about choices of eye color and hair color, as that is not going to increase inequalities in our society. Hughes, I believe like many others, believes that such technologies can improve our life as long as they are controlled democratically. This belief actually resonates with the whole genre of scholarship on what is called liberal eugenics, biopolitics that is allegedly driven by individual choice rather

than by the state. But what we are seeing in the global fertility world is that this binary between the so called “old eugenics” and new or liberal eugenics is actually very misleading.

States by allowing the fertility industry to operate unhindered are essentially reaffirming existing structures of inequality and legitimizing new forms of race- and gender-based inequalities. I will give you some quick examples because I don't have much time.

What I noticed here in the human egg industry in South Africa, where I am located right now—and South Africa feeds very much into the global fertility industry—the entire human egg industry that feeds into the global world is inherently white. What an irony because this is 95% a Black African majority. In fact, in the global fertility world, I'm yet to meet even one Black African egg provider. This inherent desirability of whiteness, what I call inherent desirability of whiteness, is reproduced in a few ways.

Did I hear something from Katie about my time? Okay, time is up. Okay, so I will just summarize by saying it in two ways. One, which is very familiar to all of us, is that intended parents want a racial match. The most interesting thing is that many intended parents from Asia actually want strategic hybridization. That is, they want white mixed-race babies. What these desires give you is more than a hint as to what traits are considered socially undesirable and what traits are considered desirable. This is what is happening right now. It is not speculation or dystopic fiction.

Susan Berke Fogel: Oh my, yes, thank you. Our last but absolutely not least speaker is Alana Cattapan. She is the Canada research chair in the politics of reproduction and assistant professor in the department of political science at the University of Waterloo. She studies gender inclusion and policymaking, identifying links between the state, the commercialization of the body, and reproductive labor.

Alana Cattapan: Hi, everybody. Thank you Susan. I will start by saying I'm coming to you as a settler and uninvited guest on the traditional territory of the Anishinaabe, Haudenosaunee, and Neutral peoples and what has come to be called Waterloo, Ontario, in Canada. I am a white woman in my late 30s, with shoulder-length brown hair, wearing a beige lace blouse and a black blazer. Behind me are full-ish books on a brick wall and I'll probably be drinking from a colorful mug throughout. Thank you for having me. I'm really pleased to be part of an esteemed panel. I am thankful for the participants but also to CGS for inviting me. I will say that a lot of the remarks that I'm going to make overlap a great deal with what has already been said from Katie, Susan, Kavita, and Amrita. Hopefully I do not repeat too much.

I am a political scientist, and my work in this field has largely focused around the feminist approaches on reproductive and genetic technologies and how we involve often excluded communities from conversations about how we govern these things. At the heart of my work are concerns about reproductive autonomy and justice, and how to engage in the governance of reproduction in ways that are not only ethical but also address our responsibilities to future generations.

So, heritable genome editing as we all know, as we've been talking about, is the most recent in a long history of reproductive and genetic technologies for which there is a renewed call to engage because they are now possible. And with the assumption that because they are now possible, they might offer some sort of benefit to human society. It is, as someone said before, a real cart-before-the-horse situation.

It is important to recognize from the outset that this is a technology for which there is no clear medical need. There are already genetic testing interventions that—they raise their own set of concerns—but can intervene to prevent certain genetic conditions without modifying the germline. So, from the outset, we may not need heritable genome editing at all. In fact, I would argue and many of you would argue that that is the case.

I have a few concerns that I will outline in the time I have. The first is about who gets to decide about how we proceed with heritable genome editing. As Amrita said, as our very own Marcy has outlined before—really beautifully, Marcy, in your introduction to the Missing Voices Initiative programming prior to the start of the last international summit on genome editing earlier this month, the statements and reports of scientists and bioethicists that have organized these large international summits reveal an understanding that it is that community that will attempt to articulate when it is appropriate for human germline editing to proceed, for heritable genome editing to proceed, shifting commitments to obtaining “broad societal consensus” and later “public engagement.” Then broad scientific consensus suggests that self-regulating scientists believe that they are at the helm of determining the conditions under which heritable genome editing could be permissible. The rest of us are not seen to be part of that conversation, and this particularly excludes people with disabilities who have a tremendous stake, as we all do in this intervention.

I want to highlight that this also doesn't even mention, and I haven't heard this conversation much, although somebody mentioned it earlier, the providers of the gametes and egg donors in particular, who will in the short-term undergo unnecessary ovarian stimulation and extraction to have their eggs removed for use in genetic editing. There are concerns about the consent of those people, about the modification of their germline, their genes. Where are they in this conversation?

To paraphrase Donna Dickenson's work on embryo research, the lady vanishes again and again.

In the wake of this Third International Summit on Genome Editing, it seems strange to keep entertaining the conversation as to whether it is necessary to keep talking about whether to pursue heritable genome editing at all. It is true that the possibilities enabled by CRISPR-Cas9 and subsequent uses of that technology, in at least one case to create children—probably more, I assume—necessitated another look as to whether longstanding prohibitions on heritable genome editing that have existed in more than 70 countries should be revisited because it was worth looking at whether the concerns that informed those prohibitions in the first place have been addressed in the meantime. It is clear that they have not.

Heritable genome editing continues to be unsafe, unnecessary, and to pose a significant threat to the value and diversity of human experiences. And it is already prohibited in many places.

My second concern here is about the persistence of this conversation and that we are already in that conversation working to set up exclusion and legitimating the possibility of judging which lives are worth living. I'm not going to rehearse this too much. Amrita did a really tremendous job and others have before me. But some of these conversations about potential future permissibility and regulatory oversight revolve around an attempted distinction between therapeutic editing versus edits to the genome for purposes of enhancement. Editing the germline, this conversation about whether or not to proceed, provides a framework for these discussions, a site in which to make determinations around what traits and experiences and potential disabilities are desirable and undesirable, and what counts as healthy.

In this, it harkens back, I suppose, to colonial and imperial discourses imbued with scientific racism about who gets to count and who gets to decide what kind of traits and ideas are desirable. Amrita has covered this quite well. Desirability, though, is a moving target that tends to land on those most marginalized and one that is often centered and will continue to center on people with disabilities.

Katie, I see you and I'm really quickly going to say one more concern. I want to address not just the whether, but the how. If this debate about whether we are going to engage in heritable genome editing continues, even though it remains prohibited in many countries, and it seems it will—there is a persistence amongst those advocating for its use—and there's this continuing push to allow heritable genome editing, we can't stop the conversations about whether it should be permitted, but we also need to start talking about what it might look like to engage as ethically as possible together.

Katie signaled to this in her introductory remarks, but there needs to be a meaningful conversation about the governance, and more specifically, the economic model in which heritable genome editing may occur.

As others have mentioned, the international fertility industry is worth billions of dollars. This is compounded by potential economic incentives related to the patenting of genetic technologies and their potential use. It is entirely possible—it is probably occurring already—that the use of heritable genetic modification will be a site of private medicine and private profit, rather than a site of global collaboration, and if this is in some way going to benefit humanity, a site of potential shared benefit.

If the persistence of the scientific community in pushing towards heritable genome editing is successful, the model here matters. It is critical that the incentives of neoliberal capitalism and the maximization of profit do not inform decisions about what kinds of genetic editing is permissible, and that the perceived benefits are not just a site of profit built on the backs of future generations. Katie, I see you and I will stop there. Thank you so much for having me.

Susan Berke Fogel: Thank you so much. So much to think about. What we would like to do now is to invite our three speakers to react to what we have already heard before we open it up for maybe some questions. How about if we just do a roundtable and start again with Kavita.

Kavita Ramdas: Thank you so much. I neglected to add my thank you to the Center for Genetics and Society. I'm so proud to serve on their advisory board. A few reflections that I don't have the depth of academic knowledge and research studies that my other two amazing colleagues have put forward, but I think I will say that in a career of almost 30 years of working within the U.S. and global philanthropy, a few things come to mind that make me really quite concerned when I hear about the degree to which this is such a challenge. One, my colleague Elisa Slattery, who I believe is on the webinar and worked with me at the Open Society Foundation, was one of the few people at the Open Society Foundation, and indeed at any foundation, to understand that the fundamental work that we do in reproductive health and rights must be grounded in a connection to an understanding around research and a connection to work in science.

It has been a very difficult indeed for an organization like CGS to raise funds because the people who fund women's rights, who are funders of women's rights, are basically active in supporting what they considered to be women's movements on the ground. And yet, our

inability to see that the women's movements on the ground don't have the ability because of the power dynamics that I spoke about earlier, that often they are excluded from places of science. Both Alana and Amrita have made that point. When you are excluded from those spaces, you don't even know what is being discussed. How can you be having a movement that is taking that on as a major issue?

So, it really behooves foundations who have money, who have resources to really make those connections.

In a similar way, an analogy that I will give to this is that it took women's movements a very long time before they connected with economics. My other colleague, Dr. Marina Durano, who worked with me as a feminist economist, will tell you that it was in the "*Ni una menos*" movement in Argentina, which began with issues of bodily safety and women arguing about the safety of their bodies. It didn't take long for that movement to realize that Argentinian debt and what it meant for individual Argentinian women was as much of an issue for a feminist movement as questions of violence and reproductive rights.

So, I would urge us to begin to think in a very different way because I think the issues that both Amrita and Alana are putting on the table cannot remain in the academy, cannot remain in the hands of scientists. In order for them not to be stuck in that space, they must in fact be connected to women's rights movements on the ground. That will take financing, that will take support for organizations like CGS, and it will take a much more intersectional approach to understandings of power, science, and economics. Thank you.

Susan Berke Fogel: Amrita, do you want to respond to what you have heard?

Amrita Pande: Sure, thanks Susan. I think listening to Kavita again was very helpful, and what Alana was also saying about who gets to make these decisions. It is completely embedded in power dynamics. If you were really wanting to change the frame, you would need to perhaps pivot the center and start looking at it from the point of view of the Global South. As soon as you start thinking about these new technologies from the Global South's frame, then you realize that there are huge opportunity costs of investing in these technologies. Even if they are for research purposes, these opportunity costs are enormous.

Gamete editing, for instance, is likely to benefit only a really minuscule number of intending parents. While the cost of these technologies, whenever they are made available to people for reproductive reasons, are so high that it is unlikely to be accessed by those who need it most. Those demographics, for instance, where infant mortality is the highest.

If the goal at the end is to have a healthy baby or a healthy genetically related baby if you want that, and we want to use these technologies in a way that is most effective and most effective for many, then we must look at the figures. Don't quote me on this, but over five million children under five years of age die annually from preventable and treatable causes, like diarrhea, malaria. We will go a much longer way in allowing intended parents to have and keep healthy genetically related babies if we invested in those. These kind of opportunity cost arguments are really important, and important to bring up in all our discussions with these professional elites.

Susan Berke Fogel: Thank you. And Alana?

Alana Cattapan: I'm trying to figure out how to unmute as usual. There are two pieces I will pick up on from the conversations so far. One is again the question of regulation. How do we decide

who engages in the conversation and the decision-making here? Amrita, when you said democratization, it lit up bulbs in my mind because I'm a political scientist and I want to talk about democracy all the time. Democracy has never been, or a democratic approach, has never been an effective way to protect minority groups, which is why many countries have bills of rights. It's what we have established human rights to protect groups from their governments and from decision-making that might be poor or might be made by masses of people that are not necessarily in favor of protecting human rights of those most marginalized.

And so, democracy is maybe not the way forward here. Perhaps it is not a broad societal consensus that we are looking for but a view that centers those who would be most marginalized in this experience.

I keep thinking now, I wrote down so many notes that make no sense taken out of context. I also want to stress something that has come out of this conversation, which is the desire for genetically related babies. But this entire conversation about human germline genetic modification is about an ongoing committed desire to genetically related babies and ensuring that those babies have desired traits, as many of us have talked about. This is not the only way to build families. There is an ongoing and strong commitment of many governments to certain kind of family forms that we can question, that we can challenge and keep challenging, where we are not prioritizing genetic relationships at the center of our family building.

Susan Berke Fogel: Yes?

Kavita Ramdas: Susan, can I add one more point?

Susan Berke Fogel: Please do.

Kavita Ramdas: I think it is very important to say that quite absent this next level of scientific abilities that would be made possible if this genetic editing of the kind we have been discussing would be possible, we already live in a world where we are deeply influenced by cultural assumptions, by things like son preference. You don't even need this kind of genetic testing because in India right now, we are not even allowed under the law to use ultrasounds to determine the sex of a child because there is such a strong preference for male children that female children are routinely aborted. Amartya Sen has written this important assessment talking about the missing women of India—India is not alone in this. China had a similar experience, Korea had a similar experience.

All I'm saying is if we are going to translate the existing biases of our society that are already deeply gender unequal, then why would we not expect those same biases—whether they are pro-whiteness, whether they are pro-male, whether they are pro-lighter skinned, taller, whatever the predilections are—to translate into this new technology.

And I think even as we see with AI Chat, which is another area not in bioscience, but it is another area, if you have patriarchal and racist attitudes that are already internalized in the algorithms that these new technologies are using, then it really does not matter what unique thing—and ableist actually, deeply ableist assumptions—even with the technology we currently have, we are dealing with a set of choices that people are making because they can see what works or doesn't work and what is privileged in their society.

I want us for second to remember that we are already working in a space in which these assumptions and in which these biases are being internalized, not just in our societies but also

in the algorithms that are just racing forward in every other space, not just in the space of genome editing.

Alana Cattapan: To build on that a little bit, I just wanted to add that the ongoing biases in society will be replicated no matter what the technology is, as Kavita has just said. So, what we need to be questioning in the present, and this might respond to one of the questions that has come in, to concerns about the uses of technology because there is no medical need. There is no real need, so why pursue it? This is a question I have been grappling with in the last few days as I have been thinking about my remarks today.

There is a strong incentive towards, as I said before, innovation and progress and science. Incentive mechanisms both for the prestige of scientists, but also the desire to do something new, to somehow be moving humanity forward. This language of progress that is again bound up with notions, linear notions of time, but also linear notions of the way “advances”—scare quotes all over that—in the human race.

Here, we need to question the way we structure science. This is not about scientific self-regulation but also incentives in the scientific establishment. What is seen to be prestigious, helpful, funded? That, too, is bound up with notions of patenting and intellectual property and capitalism.

And so, these things can be unpacked. It is possible, with great imagination.

Susan Berke Fogel: Thank you. I am thinking about what you are saying in the sense of what we already have is a global fertility [industry]. Raising these issues of not only where we are now, not only where this technology could take us, where we have a global fertility industry where people are encouraged, who are using provided eggs or sperm, are already encouraged to choose hopeful traits. Right? So, they look at somebody’s bio and whether they are athletic or they are musical or what color eyes they have. And some of this is fed by the desire to have, if not a biologically connected child, a child that looks like us, which is rooted in the biological, right? A child is born, someone wants to know, who do they look like.

So, I would really be interested in the reactions to: “Is this seen as a next step?” Although those choices are not guaranteed because that is not how bodies work, but is this seen as a logical next step? I appreciate Alana particularly using the word dangerous. How do you think about that in terms of how this industry is evolving?

Kavita Ramdas: Amrita, I don’t know if you would like to respond to that first.

Amrita Pande: Yeah sure, I can go ahead, Kavita and Susan, because the way this industry will expand—it has already expanded way beyond the scientific impulse—is what is so dangerous about these new technologies is that even if you want to assume that the scientific impulse was only noble, once it reaches the market it has a life of its own.

In response to what you raised, Susan, and what someone raised in the Q&A, we often want to think of new technologies as modern and as something that we can actually find benefits of. Of course, it’s new. The word new. It is modern. It has to somehow improve human life, and we just have to find ways of regulating it.

And this is the problem. It’s that very often, these kinds of new technologies are so easily legitimized on the ground that it will further human well-being. That it will take care of those

people who are most vulnerable, those suffering the most. But I think it is really important to bring back onto the table this question of what does it mean to improve human life?

Again, I think coming back to pivoting the center and thinking about the Global South, and thinking about what does it really mean to improve human lives? Is that concept of improvement universally accepted? In general, gene editing works to eliminate human traits that are considered to be either a disease or a disability, right? We haven't talked much about disability justice yet. Disease and disability in a sense are seen as traits that diminish human capacity. But, if we were to now foreground disability justice, we would get a very different way of looking at the problem and, hence, different solutions. Diseases, disorders, ability, disability are all politically and socially constructed, and they vary from culture to culture and vary over time. There is no universal definition of disease or disability.

In a sense, eliminating a disease or disability which seems to be the paramount concern, or at least the paramount legitimizing ground for these technologies, is actually about eliminating variation which we cannot support or which is very inconvenient for society. For each disease, actually there are treatments that can make the quality of life worth living. The fundamental of selecting out a variation is that certain traits are just thought to be inconvenient and that somebody just takes this decision that this needs to be eliminated from humanity. It goes back to the question that Alanna asked. Who takes these decisions, and who do we allow to take these decisions? It is basically a lack of will for social change which is legitimizing such extreme action.

Alana Cattapan: I'm being very cautious about intervening, but I wanted to just add to what Amrita has just said about the centering of disability justice, and this is also to answer one of the questions that came in the chat. There is no medical need for this. If we think about disability justice at the center of our conversations, and that a variety of human experiences are not just valid but welcome in this world and contribute substantially. But also, people don't need to have genetically related children. There is a strong desire on the part of many, that is something that is part of our social construction of gender to be certain. Genetically related children is not a medical need. There are also other options. A lot of the work that I do and Amrita does centers around people's desire to have genetically related children. There are options for some people. These are not economically available, there are problems with those models, and there are also genetic testing technologies, there are problems associated with those. But there are many other options to heritable genome editing. There is simply, again, no real need for this.

Kavita Ramdas: Maybe just to add one other piece that is important here is to remind us—somebody said in a question, it was in the chat and then it was removed—saying that there was a medical reason to have it because it makes it less difficult for people who have IVF. I guess that I would say that, again, this is not an easy thing to say for anyone who has been through the process of wanting to become a parent and what it involves. There are people who have deeply strong feelings about this, absolutely.

In a global sense of the issues that have to be dealt with, it does seem that in a world where the vast majority of poor children on this planet literally don't get, as Amrita said earlier, don't get clean drinking water or food to eat. Forget about the point that those are that the things that cause them to get malaria or diarrhea or whatever. It does seem very strange that who is being privileged is essentially between the 1 to 5% of our global economy who are then enabling themselves to have all these choices, which nobody in the bottom 25%—forget about the bottom 25—even 50% of the world is not going to be able to have those choices at all.

So, I'm not saying that this is an easy discussion for us to have, but that is why began by saying it has to be situated within the existing power dynamics between those who have and those who don't have. To be very honest, from what we have seen through this pandemic about how big pharma doesn't really care about the needs of those who are most in need. They actively made sure that people in South Africa didn't get access to the vaccine in enough time. We have had that experience with HIV-AIDS. We have had that experience in every single instance where large private, profit-making companies have essentially privatized medicine and have privatized healthcare.

So, way before we get to the fancy technologies of editing a gene, you are already in a deeply unequal world in which there is profit driving the outcomes of these companies and not the well-being of either people or planet.

Susan Berke Fogel: We have only just a couple of minutes left, and we have a couple of questions in the Q&A. Whoever wants to jump in. The question is, "Please explain how heritable genome editing enables people to have genetically related children." It doesn't. But these two conversations are important at the same time. Because the desire to have genetically related children is part of what leads people to want assisted reproductive technologies in the first place.

But, the second question is, which I'm hoping someone can answer, "I agree with the point of disability and genetically related children. I'm not so sure these points can be extended to diseases in general. For example, if these technologies would result in less prevalence of a genetically inherited form of cancer, would we think about them differently?" Somebody want to respond to that in our few minutes left?

Alana Cattapan: I will try. This is something to think about for sure. It's a really good question. I think that there is general consensus that experiencing cancer is not tremendous, not great, to put it mildly. It is unclear in experiences of genetic modification, when we're talking about heritable genetic modification, that the attempted editing of the germline will result in situations of benefit, or potential, in this case a reduction in the prevalence of disease for future generations. The only way to know that is to engage in an experiment with future generations rather than focus on perhaps other ways to prevent or intercede that aren't heritable.

I don't have what I would say is a satisfying answer to your question, but there are considerations here in terms of the autonomy and capacity of future generations and the decisions that we are making for children in the future as well as concerns about human experimentation that is intergenerational. Again, not satisfying at all, but perhaps some issues to contemplate.

Susan Berke Fogel: Thank you. We are going to wrap this up. I guess I will just add, one other thing is that there are other ways, if we think of how many conditions are actually caused by environment, by toxins, I would like us to see us eliminate those causes of harmful conditions before we move forward with more of this—and a whole other session on epigenetics and how that affects our bodies, but we are running out of time. This has been amazing. So much to think about, and I want to hand it back to Katie to kind of wrap up for us.

Katie Hasson: Thank you so much, Susan, Alana, Amrita, Kavita, for your insights, for this provocative discussion. Clearly, there is so much more we can talk about, and we are so grateful to all of you for being here for this conversation today.

Many thanks also to our ASL interpreter, to our captioner, and really to everyone behind the scenes at CGS who has been working so hard to bring this event and all of our previous webinars together. We really appreciate all of you attending today and at our previous events. If you are new to the Center for Genetics and Society, we encourage you to check out our website, geneticsandsociety.org. You can also follow us on Twitter and Facebook and learn more about our work. Thanks again, everyone, and goodbye.