

Equity, Sovereignty, and Racial Justice: Beyond Access in Debates about Human Genome Editing September 14, 2022

A roundtable conversation with **Krystal Tsosie**, **Dorothy Roberts**, and **Milton Reynolds**, organized by Center for Genetics and Society and moderated by CGS associate director **Katie Hasson**. Live captions and transcript provided by Nancy G of AI-Live [minimal edits made for clarity].

KATIE HASSON: Welcome all and thanks for joining us today. Center for Genetics and Society is excited to present this round table conversation with Krystal Tsosie, Dorothy Roberts, and Milton Reynolds on Equity, Sovereignty, and Racial Justice in Human Genome Editing. I'm Katie Hasson, the Associate Director of CGS. I'm a white woman in my forties with curly red hair, wearing glasses and a navy sweater. I'll be moderating the discussion today.

A few things to make you aware of first. We are recording this webinar. Captioning is available. If you would like to view the captions, click on the CC button on the bottom of your screen. Many thanks to the captioner and to our ASL interpreters, CM and Lydia. If you have a question for the panel, please type it in the Q & A box. You can also use the Q & A to let us know about any technical issues.

Finally, before we begin, we would like to acknowledge that CGS sits on the ancestral and unceded land of the Chochochenyo-speaking Ohlone people. This land was and continues to be of great importance to the Muwekma Ohlone Tribe.

Today's discussion focuses on human genome editing, particularly on its social context and social justice implications. These are aspects that should be far more central to the high-stakes public and policy conversations about human genome editing that have been intensifying in recent years. We're asking the question: How do we talk about equity in the context of human genome editing? Equity, racial justice, and Indigenous sovereignty have become somewhat more prominent in recent discussions of public health, but have not yet made it to the forefront of discussions about human genome editing.

When equity does enter the discussion, it is most likely to be discussed in terms of economic access, particularly access to gene therapies using somatic editing to treat genetic conditions like sickle cell disease or inherited forms of vision loss. The gene therapies that have come on the market so far carry sky-high prices, hundreds of thousands or even millions of dollars. Clearly, it's important to ask who will be able to access these therapies and whether there's any way to ensure equitable access. But focusing on access to already developed therapies in the market skips over critical aspects of equity, including who is at the table setting research priorities; who is set to benefit from commercializing treatments; and whether marginalized communities will be asked to bear the risks of development and testing of potential therapies, with little, if any, promise of benefit.

And when it comes to the question of heritable human genome editing, that is, editing the DNA of gametes or embryos to change the traits of future children and generations, this concept of "access" is very little help. Heritable genome editing would all too likely increase inequality and

discrimination even -- perhaps especially -- if it were to be widely available. It could even open door to a new form of high-tech, market-based eugenics. Should it have any place in the world we're trying to build?

75 countries already prohibit heritable genome editing, but a relatively small group of enthusiasts have been pushing to develop it. Consequential decisions about whether to permit and pursue heritable genome editing may be made in the very near future. The US and UK National Academies are organizing a third in their series of human gene editing Summits this coming March. In the UK, a few scientists appear to be trying to jump-start a process that could lead to legalizing reproductive gene editing.

The conversations that will shape decisions about heritable genome editing urgently need the voices and perspectives of civil society advocates and publicly engaged scholars -- people whose commitments to addressing histories and social contexts of marginalization, of exploitation, and erasure ideally situate them to anticipate and prevent the societal harms of heritable genome editing. Instead of debates that focus mainly on technical issues and narrowly defined ethical concerns like individual notions of risk and benefit, we need dialogues that raise challenging questions about racism, eugenics, colonialism, reproductive justice, and more.

Today's webinar is part of a series of events and projects, including CGS's Missing Voices Initiative, that aim to amplify the perspectives of scholars and advocates committed to social justice and human rights, and reveal just how different conversations about heritable genome editing look when these perspectives are not only included but centered. Now I would like to introduce our speakers.

Dorothy Roberts is George A Weiss University Professor; Raymond Pace and Sadie Tanner Mossell Alexander Professor of Civil Rights; and Professor in the Departments of Africana Studies and Sociology and Penn Law at the University of Pennsylvania. An internationally recognized scholar, public intellectual and social justice advocate, she has written and lectured extensively on the interplay of gender, race and class in legal issues and has been a leader in transforming public thinking and policy on reproductive health, child welfare and bioethics. She serves on the Boards of the Black Women's Health Imperative, the National Coalition for Child Protection Reform, and the Center for Genetics and Society.

Milton Reynolds is a San Francisco Bay Area-based career educator, author, equity and inclusion consultant, and activist. His activism has been devoted to disrupting systems of racial injustice with a focus on juvenile justice reform, law enforcement accountability, environmental justice, youth development, educational transformation, and disability justice. Milton's publications include chapters in *Seeing Race Again: Countering Colorblindness across the Disciplines*, the *Handbook of Social Justice in Education*, and the recently released *Leading in the Belly of the Beast*. He serves on the Boards of the California Council for the Social Studies and the Paul K. Longmore Institute on Disability at San Francisco State University.

Krystal Tsosie, who is Diné/Navajo, is an indigenous geneticist-bioethicist at Arizona State University in the School of Life Sciences, currently as a Presidential Postdoctoral Fellow and starting in January 2023 as assistant professor. As an advocate for Indigenous genomic data sovereignty, she co-founded the first US Indigenous-led bio bank, the Native BioData Consortium. Her research centers on ethical engagement with Indigenous communities in precision health and genomic medicine. She also incorporates biostatistics, genetic epidemiology, public health and, increasingly, environmental data science and stewardship. She

currently serves as Global Chair of ENRICH: Equity for Indigenous Research and Innovation. Her work has received extensive international media attention.

Many thanks to our three speakers. Dorothy, we will begin with you.

DOROTHY ROBERTS: Thanks so much, Katie and thanks to CGS for organizing this important panel. I'm really honored to be in conversation with Krystal and Milton this afternoon. I'm speaking from Philadelphia on the land of the Lenape people and I identify as a Black woman with light-brown skin and locks. I'm wearing a green top and bluish-green glasses.

I want to focus my initial remarks on questioning the deep but often unstated assumptions underlying advocacy for human heritable or germline genetic modification. Its promoters argue that selection of human traits -- that's eliminating "undesirable" traits and amplifying those that are "desirable" -- can benefit human societies. But the prominent ethical debates they engage in have focused on the safety and misuse of genetic editing technologies. For example, an influential 2015 article in *Science* by key scientists and bioethicists in this field, including David Baltimore, Jennifer Doudna, and George Church, called for research to "manage the risks arising from the use of the CRISPR Cas9 technology," which they identify as the possibility of off-target alterations as well as on-target events that have unintended consequences. In their view, managing these risks centers on weighing the potential safety and efficacy of gene editing against its potential benefits.

The ethical issues raised in the 2015 International Summit on Human Genome Editing went somewhat further. The International Summit statement by the organizing committee included not only the risks of inaccurate editing but also the difficulty of predicting harmful effects, as well as the possibility that permanent genetic enhancements to subsets of the population would exacerbate social inequities or be used coercively. But still, all these ethical concerns center on the risks of using gene editing technologies in the wrong way. While the inclusion of justice concerns by the International Summit committee is notable, the committee's framing accepts that genomic modification will make human beings better off as long as no one is physically harmed and the technology is available to everyone. It fails to question the claim that human well-being or flourishing will be furthered if the procedures achieve what they're designed to do and are distributed widely. According to this view, as long as the technologies improve and the risk of so-called undesirable side effects or off-target alterations diminishes, gene editing can ethically proceed because it will undeniably improve the quality of human lives. The nature of human well-being is left out of the debate focused entirely on safety, efficacy, and access, not because it's ignored but because it's assumed that gene editing will make people better off.

Now, this argument that having certain genetic traits and not having others, whether as an individual or as a species, increases well-being, assumes an understanding of what it means for human beings to live well. But the meaning of human well-being embraced by these advocates isn't objective or universally accepted. It's important to dig deeper to see that the concept of human well-being undergirding their claims tends to import socially biased assumptions about what human well-being means in the first place. So I want to stress one particular socially biased assumption underlying these arguments for genetic modification. The dominant ethical framework promotes the traits of socially advantaged groups and individual enhancement rather than social change. By assuming a concept of human flourishing that privileges these interests and discounts the importance of social change, arguments in favor of gene editing can reinforce socially unjust hierarchies, even if the technologies are accurate and even if they're widely distributed.

The idea that gene editing can improve human well-being distracts us from what we know are the most powerful predictors of well-being. For individuals to flourish, they must live in societies that promote their flourishing. People who are enthusiastic about gene editing either assume that those social conditions are already in place, which we know isn't true, or they fixate on what remains to be improved for them, that is, their genomes, or have great faith in the power of changing the biology of individual human beings but little faith in changing the unjust structure of the societies in which human beings live. We need a full and equitable deliberation of the ethics of human genetic modification that includes this foundational question of the very meaning of human well-being. That means it must include the perspectives of groups that are currently disadvantaged most by social inequities.

The public discussion so far has been just the opposite. It has narrowly included scientists, bioethicists and patient advocacy groups, what have been called professional elites. Their arguments in favor of genome modification are based on false assumptions of scientific objectivity and a universal concept of what human well-being is that not only neglect other perspectives but affirmatively exclude them. People with disabilities, poor people, queer people, Indigenous people, people of color, especially women of color, and others at various intersections of these social positions have to be centered and have power in defining the very meaning of human flourishing so we can democratically and justly determine what role gene editing technology should play or should not play in promoting well-being for all of us. The answers from people who have the greatest stake in radical social change will be very different from those who have a stake in the inequitable and unjust status quo -- who are the very people who have been most dominant in these debates about human genome modification. Thanks.

KATIE HASSON: Thank you, Dorothy. Now we'll hear from Milton.

MILTON REYNOLDS: Thank you, Katie. I'm excited also to be in conversation with the other panelists. I'm Milton Reynolds. I'm coming in from present present-day San Leandro, which is actually on the ancestral land of the Muwekma Ohlone people. I'm a chocolatey-skinned Black man with waist-length dreadlocks. I'm sitting in my home office and I'm backed by some dark bookshelves with lots of colorful books and other knick-knacks.

In thinking about these technologies that we're confronted with and the choices that we have to face as a society, I think it's important to situate ourselves within the context of history. In that sense, I'm particularly interested in the history of eugenics. I come into this conversation a little bit differently in the sense that I'm an educator, but I'm working downstream. I'm working with teachers who are teaching high school and middle school teachers primarily. Seeing from this vantage point the importance of starting these conversations early and often, and to help students develop the kind of sophisticated systems-thinking that can intervene in what I've come to refer to as the attribution error. That is, the success of indoctrination into ideas of race that cause us to look to the body as the site of deficiency and intervention rather than the social context in which the body is situated and in which meaning is assigned to it. It's kind of exciting right now. There are opportunities in California in particular to begin this conversation, but it will be a process, not an event. I'm thinking specifically about the roll out of ethnic studies and it being a graduation requirement.

One of the challenges I see, however, is moving away from essentialist understandings of difference and starting to pick up how meaning is assigned to differences. One of the interventions I've been trying to move forward is helping people move away from conversations about race and identity that focus on the individual and to begin to engage with concepts of racialization and identification which help to illuminate the collective consequences or benefits of

these designations. I think as Dorothy astutely said, some of the bigger questions that are in the backdrop of this conversation is who benefits and who will be the bearer of the consequences.

We're living in a political moment. We're still in this pandemic in which we can see that the differential experiences of racialization and identification have had profoundly differential impacts on communities, with Indigenous communities, poor people, disabled people, and people of color bearing a significant burden. It's hard to imagine that in a society that is predicated on these notions of essential difference can actually engage with these technologies in a way that won't reproduce the very sets of outcomes that we see and that we have been taught to believe are rooted in biology.

I think the importance of broadening the discussion is a critical intervention, and I see that again as a process rather than an event. I spend a lot of time thinking about the sets of structures that are available to us, and which we might invite young people and the general population into these conversations such that they're at the decision-making table or at least to inform that rather than being on the menu. They didn't decide to be recipients of these technologies and yet they will be foisted upon them.

I think we have to move people into those decision-making situations earlier and to keep people informed. I think the conversation about social justice and the consequences of heritable genome editing are interesting to people, but I think when I query people, the interest is oftentimes focused on the benefits again rather than the consequences. So again, we have to unsettle the sets of assumptions that are driving the preoccupations with difference. I think it's actually by collapsing some of the silos between science and the humanities and doing that early and often that will bring people who are interested in these technologies into the histories and the social context out of which these technologies are informed, or at least the questions that are driving them are informed, in such a way that it raises these ethical and moral questions earlier in the discussion rather than late.

These are complex issues, and I think the complexity is best dealt with time on task rather than simplification. I think when we oversimplify these issues, we lose the ability to understand them. The consequences, again, will be broad-reaching. So I do think there's time, and I think there are emergent structures in which we can have these conversations. And like so many of you, it's time to invite others into them. I look forward to hearing from Krystal. I'll leave it with that and look forward to a lively conversation. Thank you.

KATIE HASSON: Thanks, Milton. Now we'll hear from Krystal.

KRYSTAL TSOSIE: Hi, everyone. My name is Dr. Krystal Tsosie. I have long, dark-brown hair and wearing some black and white earrings, a tan-colored shirt, and pink-rimmed glasses. I'm sitting in my home office with a blurred background. Most importantly, I am drinking from a yellow coffee cup which happens to be one of my favorite mugs. I am a Diné woman of the Navajo Nation, and I'm currently calling in from the homelands of the O'odham and Piiposh in what is now called Phoenix, Arizona. I'd like to introduce myself in my traditional Navajo language.

[Introduction in Navajo] Good morning. I am Red House clan, born for Mexican Peoples' clan. My other clans are Bitter Water and Many Goats. I have prepared a written statement, but I'm going to actually switch back and forth to a more impromptu format. I want to note that while my views that I'm going to talk about come from an Indigenous perspective, I do want to state that

all Indigenous peoples are different and therefore my views are reflective of my own experiences.

As an ethicist, it pains me to hear this oft stated trope, which states that genetic technology is outpacing our conversation related to ethics. It's a really incorrect statement. Let us consider a little bit about the background. This is where the genetics part of me comes in. For decades, nay well over a century, scientists and philosophers within "Western" academic institutions have debated the ethical limits of genetic modification and its larger implications for humans, including whether it should even be done. Long before current gene editing technologies came into place. So the current questions surrounding gene editing and gene therapies really are not new.

In terms of the potential for manipulating biological material, the proverbial writing has been on the wall for quite some time. For instance, if we're talking about the ramp-up towards current gene editing tools, before CRISPR-Cas9 systems were in place, we had precursor biotechnical innovations. We had the early splicing experiments of the '60s and 1970s created after the recombinant DNA after discovery of site-specific cleavage of restriction enzymes.

Kudos, by the way, to the captioner!

We have other gene editing mechanisms such as zinc-finger nucleases, transcription activator-like effector nucleases (TALENs). These are 1985 and 2009. This is well before now what would constitute this current era of gene editing. So really the trajectory relating to gene editing and therapies has always been self-evident.

At a certain point, however, we must be asking why researchers have not been centering ethics during the entirety of this technological evolution, commensurate with the pursuit in advancing the pace of the innovation. Further, if researchers within Western science fail to adequately contemplate these ethical questions with other academics across disciplines, then what engenders this current phase of including Indigenous peoples who have historically and continually been disenfranchised in genomics as research subjects in these discussions now?

Ethical conversations related to gene editing have long been occurring. The question is: Do those empowered in science care to listen? This is where I want to speak a little bit off-the-cuff in that Indigenous peoples have always been scientists and have always been geneticists. We have exercised centuries of genetic modification that have led to the current mono-cultural agricultural modifications, and we see the results every day when we go to our grocery store.

It's really interesting that when I, as an Indigenous scientist, [express] my views related to exercising pause and caution related to gene editing, that I get accusations that I am anti-science and anti-progress. There are some racist underlying notions on this. I'm not going to give that attention at this point. But I do want to address this narrative of the fact that just because peoples or disempowered peoples are against or exercising caution and concern, it doesn't mean that we are fundamentally, unilaterally against the incorporation of these technologies in our communities. In fact, I think this should be a good thing, whenever peoples are just expressing concern about how these technologies are going to be utilized. Because if we are not, one, we are fundamentally ignoring some power dynamics that have caused some harms onto our communities. But then also, by not listening, we are potentially going to repeat past ethical harms. So we really need to think about whether or not we are just looking at the same extraction that we have seen before but utilizing new genetic tools.

There are a number of projects that are meant to increase the inclusion of diverse populations in genomic technologies, and this is meant to discover “undiscovered” genetic variation, to lead to genetic technologies. What unfortunately can happen if we're not careful about our language is that we almost equate peoples with rare variants -- or peoples from small populations that have not historically been studied in genetics -- with being fonts or fountains of undiscovered variation. So I've seen this translate in publication language in terms of describing Indigenous peoples as just a treasure trove of undiscovered genetic variation, as if studying us becomes equatable to the lost scientific frontier or last scientific frontier. We have to really make sure we're not objectifying the same individuals that we're hoping to include.

I also want to state that we really need to think about whether or not these gene editing tools will truly “democratize” genomics. The term democratization of technologies is something that I take issue with because any system that benefits most will still disenfranchise minoritized groups. The system of “benefits most” is one that will continue the further erasure of small populations like Indigenous peoples. So we should be advocating for equity as opposed to democratization, and these two terms are not synonymous. We also have to understand that biomarkers from disenfranchised peoples in the Global South have been made openly available and publicly available, and the entities to benefit first have been drug companies and pharmaceutical companies, and the people to benefit last have been the very same Indigenous peoples that provided that data to begin with.

It is really interesting. In 2007 a *New York Times* reporter went back to a small tribe in the Amazon and basically asked this community, what was it that researchers promised you in exchange for your DNA? And they basically said, we were promised medicines and therapies. And they were shocked to learn that access to the genomic information was being sold for \$75 to \$85 a vial by researchers. And this is directly analogous, or there are some parallels, with the story of Henrietta Lacks whose HeLa cells and cervical cancer cells have been used without her or her family's expressed knowledge and consent, and have been used to advance oncological and a number of biomedical innovations. But only recently has Johns Hopkins University and Medical Center come to even try to incorporate her descendants into that conversation. So we really have to consider when we're talking about the extraction of biological materials for advancing science, who are the peoples that are benefiting first?

I'll state one other story. I've been really honored to be a co-founder of the first Indigenous-led biological data repository in the US. We, unsurprisingly, were asked by drug companies for access to our database. It's interesting, though, because we asked drug companies, front and foremost, how about this for an interesting concept: Why don't you use Indigenous people's DNA to study the conditions that affect Indigenous peoples? We already knew the answer to this question, which was that Indigenous peoples in the US constitute about 3 percent of the general population. So effectively, we don't constitute a profitable enough segment in order to warrant using our own people's data to study the conditions that affect us first. So this should give us pause about where the interest is, especially when we consider that technological innovation in private and public interests, which are increasingly becoming more partnered with for-profit companies, tend to be driven with this profit-driven motive. We should be concerned about this profit model when we're talking about whether or not the benefits of the technologies really are going to be translated to the people that provide the data first.

Finally, rather than going into a lot of things about off-target effects or narratives, [I'll mention] genetic narratives about evolution and evolutionary adaptation -- which sometimes, unfortunately, are misused against Indigenous peoples, because then you have this biologization of what constitutes “normal.” There are a lot of questions, unfortunately, about

what constitutes “normal” and a “normal background” and “returning to normal” when we talk about incorporating gene therapies.

I do want to state one thing, which is simply the fact that when we're talking about trying to increase access to genetic technologies, let's consider the health care status of diverse populations in the US, first and foremost. My peoples are the Navajo Nation. When COVID hit, for instance, it wasn't due to biologically intrinsic differences in which the pandemic first increased in numbers in our communities. It was because of lack of access to adequate preventative health care. So when we're talking about incorporating gene therapies, let's remember that not all segments of our population have equitable access to these therapies to begin with. If we're going to be talking about decreasing health inequities, let's think first about funding clinics and funding adequate preventative health, creating and training genetic counselors and increasing awareness of these diverse issues at the level of clinical providers. Let's think about equitable data sharing and equitable benefit sharing systems before we talk about how incorporating these gene editing technologies are supposedly going to be the panacea that ends health inequities. Thank you.

KATIE HASSON: Thank you so much, Krystal, Milton, and Dorothy, for these really generative comments. To kick off the discussion, I'd actually like to give each of you two to three minutes to respond to each other's remarks, to address points of connection that you see or pose some questions of your own to further the conversation. Why don't we go in the same order as before, starting with Dorothy, then Milton, then Krystal.

DOROTHY ROBERTS: Thanks so much, Milton and Krystal, for those great comments. To Milton, I just want to endorse his historic viewpoint and emphasize how important history is, especially the history of eugenics. I think there's this tendency to, especially in science but maybe just in general, to say, "Oh, what happened in the past was in the past. We're so much better today. We would never do what happened before." There's a way in which, in science, when you bring up the history, it's almost used as a way of saying, "That was scientific racism, but we're not racist today." So even though there are the same principles underlying eugenics that we can find in some of the arguments for genetic modification technologies today, because we are not like the Nazis, because we're not like the eugenicists of the past, we don't have to worry about it.

I think it's critically important to look at these foundational principles underlying genetics, in connection with what I was saying about the focus that should be on social equity and justice and change, as opposed to innate biological ideas; that's what to me is at the heart of eugenics, the pretense that social inequality is caused by innate differences and therefore we can improve society by improving people's genes. Also, the emphasis on how coercion, the coercion that we saw during the eugenics era and ever since is important; and this is another reason why the widespread use of these technologies does not mean that they're just and equitable, because that widespread use could be forced on people through coercion.

And then, Krystal, I really appreciated as well all the points you made, but I want to highlight a few that really struck me. One is the importance of sovereignty over data and the actual biological materials, which has to be part of our discussions and our action around who has control over not only the debates, but over the actual materials that are being collected. I think maybe we can discuss --later -- ideas about sovereignty. I think they're especially relevant when it comes to Indigenous people. But the idea of control over the materials, I think, as you pointed out with Henrietta Lacks, goes across a number of groups.

I loved your idea and your questioning of what even is considered science and the notion that if you raise issues of social justice, many people will say, "You're not practicing good science." Again, related to what I was saying about these underlying assumptions that some scientists make that they pretend are universal and neutral, but they're not. They're ideological. And so science is an ideological practice. It's not neutral. I found also that that is often used, this claim that you're not being scientific when you point out the ways in which scientific innovations can be used inequitably.

The profit motive, I'm so glad you raised that, the way in which profit has such a strong force over technological innovation. Even the basic research and then the uses of innovation are so driven by commercial considerations. That's something we need to be concerned about. And then, finally, the way in which health inequities are not caused by innate differences in our genes. They're caused by inequities and injustices in our society. I think that also corresponds with the points I was trying to get across, that people who have a stake in social change -- because they are most affected by social inequality -- have to be not only part of the debate but have power over deciding how these technologies are going to be used. Thanks so much, both of you, for your comments and engagement.

MILTON REYNOLDS: Thank you. Yes, sort of building on that, both of your work Dorothy and Krystal, how important it is to question the discourse. This idea of access, to me, is an interesting sort of framework, but it assumes that everybody has equal benefit and that everybody will be treated "samely," as though there's something good about that. It obscures the differential histories and ongoing differential consequences of racialization.

I was struck by something you said, Krystal, in terms of thinking about Indigenous populations as a fount of variance, and thinking about the extractive nature of that; as if there's some cache of genes, and if we can get at them, we'll all be better. Yet none of the profit approach dismisses the importance of allowing people to benefit from their own genetic material, the research that might be done on that. I do think it's very difficult to disconnect the technologies from the economy.

When we look through the lens of eugenics, we understand that this designation of fitness was purely for the purposes of extraction or elevation. So who was to be extracted from and who was to benefit from those extractions. It's something that's still very much with us. It's hard not to see the parallels, particularly here in Silicon Valley, between these narratives of everybody gaining access and our shared benefit. When we look back through the rearview mirror on technology and what it's done to the region as well as to society, it's clear there have been differential harms and clearly differential benefits. The benefits accrue pretty narrowly, and the consequences accrue far more broadly.

I think that's what we have to be worried about, because similarly we are the product. While they may be offering services, we are in fact the product. I think some of the history of what's been done to particular populations already makes that clear. So how do we not just sound the alarm, but help people understand the historical continuities between the patterns? Because I think it is about being able to interpret the patterns that allow us to make more informed decisions. When we're able to see these systems functioning, it should, over time, allow us to see and hear each other differently, right? So we're not anti-science. We're talking about the very particular impact of science on our collective experience, both in the past but also in the present. The question about it is really, is this going to be the same in the future? Unless we change the folks who are at the table and the framework of the conversation, there's a rocky road ahead. The overpromising and under-delivering is also a pretty consistent pattern within

the eugenic framework. The utopian society it offers never emerged, and that's because the assumptions that undergirded their beliefs were false from the get-go. You can't build a stable house on the foundation of sand. That's just the reality of it. I'll leave it at that. I'd love to hear your thoughts, Krystal.

KRYSTAL TSOSIE: Thank you, thank you both. I was really honored to go after both of you, because you two definitely set up a foundation for what I was able to say, which is speaking from personal experience. Thank you so much.

I definitely resonated with everything that both of you stated. I wish we had a whole other conversation to just talk about the narrative related to genomics and genetics with race, because that is something that I feel -- especially in the last couple of years -- has been one that I don't think people have interrogated with really any good outcomes in terms of how to move forward in a good fashion. To your point, Milton, about needing to increase educational awareness, that's something that, talking with scientists, we don't do this very well in terms of communicating outside of our disciplines. It's something we can improve upon when we talk about public engagement and awareness related to these complex scientific issues.

Let's just think about in terms of the biologization of what constitutes indigeneity or Indigenous identity. There's a huge confusion about what constitutes an Indigenous person and who defines it, and there's a huge misconception about just DNA and genetic ancestry testing in terms of those types of assumptions and definitions, and has absolutely nothing to do with biology. It has everything to do with social definitions by the community. Also, underlying all of these complex issues is the politics of whether or not a colonial government even wants to recognize the rights of Indigenous peoples to exist. Those rights get tied to resources in treaties. I feel like this is part of the larger complex issues when we talk about the rights of any community to sort of self-define who belongs to them and then also who has the right to collect information from them to create a scientific narrative that's fundamentally about them.

And I do want to give adequate attribution to disability communities in this because the motto "not about us without us" comes from that community. There's a lot of parallels between what I see in terms of Indigenous data sovereignty and also the sovereign right of patient advocacy groups to self-define who belongs to them and who can benefit from them. So I really -- seven minutes left, I'll just leave it there. Thank you.

KATIE HASSON: Thank you. This is great. So many good points were brought up, but I think as we're coming close on time, I would love to bring it around to something that each of you mentioned in different ways, which is what will it take to change the current conversations around gene editing in particular? How do we change the folks who are at the table, the framework of the discussion, and who has power of decision making or control over decisions? How can we prioritize bringing in these voices and perspectives that are out there? These voices that are not missing. These points are being made. These conversations have been happening for a long time. But why aren't they sort of defining who's at the table and what will it take to get there?

MILTON REYNOLDS: I think for me it's really about breaking orthodoxies. I think about Chimamanda Adichie's "The danger of a single story." In many respects we're suffering the consequences of a single story of eugenics, right, in which a particular experience of eugenic racialization is assumed to be representative of the broader collective. It is an important story. I don't want to get that wrong. But racialization is a context-specific endeavor. I think it is the illumination of those histories and an interrogation of those histories that's super important. Over

the course of the last several years in the pandemic, as you probably know, Katie and others, there have been a number of different convenings around the history of eugenics, and many of them have been transnational. I think it's in the context of these transnational discussions that we can actually understand how critical these conversations are and the importance of having conversations not just transnationally but across disciplines, because they've also been multidisciplinary conversations. It was through these series of exchanges that it was made abundantly clear that eugenics is alive and well. Moving eugenics out of something of the past into talking about it as something that's present will give us an opportunity to deepen and complicate the discussion. I think it will also invite others into the discussion.

There are some efforts underway to attend to reparations, a movement here in California [in response to] eugenic sterilizations. I do think, as the conversation grows, there will be more opportunities to pull people in. I look forward to organizations like the Center for Genetics and Society and others to really be convenors and to find ways to move these conversations more broadly and to bring other folks to the table. I think that work is essential. Thank you.

KATIE HASSON: Thanks.

DOROTHY ROBERTS: I agree that there has to be more education efforts, which CGS is great at, including this convening here, to educate the public and raise consciousness to counter the narrative that genetic technologies are just this unadulterated benefit and that we don't need to question some of these underlying assumptions. But then we also have to figure out how to actually have an impact on the development of these technologies and their use. I think we have to look to ways in which movements have always organized to have an impact on politics. You know, protests and legislation and all the various ways that we organize to make a difference. Milton mentioned reparations, and some of the work that's been done for reparations of the survivors and those we've lost as a result of sterilization abuse and other kinds of eugenicist policies that continue today. We have seen ways in which there's been a real, concrete impact, and we have to learn from those and continue those as well.

KATIE HASSON: Thanks.

KRYSTAL TSOSIE: Thank you. I think that, Dorothy, the topic related to reproductive justice is so intertwined, especially in the current political sphere. This reminds me of what you said in terms of eugenics and the comment that reproductive justice is -- a lot of people don't realize that in the '70s -- about the same time that we were deliberating about the Belmont report, which is foundational to how we conduct human subjects research in this country -- at the same time, we had the Family Planning Act during the Nixon administration. Indigenous women who were seeking care through the Indian Health Service were, without their consent, being sterilized. That has affected a whole generation -- generations of Indigenous women and families.

I think the central point is that science has to come to a sense of humility if they want to engage the communities that they want to engage. To your point, it involves a reckoning with the past, like truly reckoning with the past instead of just trying to sweep it under the rug and asking everyone to get along. Because the other thing we have to think about is not in terms of who are we inviting to the table but whether or not they are being empowered to have a voice. I think this has to do with how scientific expertise is being defined. One comment that I've made in a recent paper about ethics and genetics is it's often the researchers who are defining the rules of engagement of what constitutes ethics. That to me is a huge conflict of interest. So we really have to come up with [solutions] -- in terms of humility and ensuring that we're not just

prioritizing the same people to be agents, and really questioning, from the communities themselves, what it means to have advocacy in these spaces.

KATIE HASSON: Thank you so much. Many thanks to Krystal Tsosie, Milton Reynolds, and Dorothy Roberts for this fascinating conversation and so much food for thought. I'd like to thank our ASL interpreters and captioner and all of you who are attending. Special thanks to Emily Galpern for her work in organizing this event and Emily Beitiks of the Longmore Institute on Disability for stepping in heroically to provide some behind-the-scenes help on the webinar today, to keep things running smoothly. This event has been organized as part of CGS's [Missing Voices Initiative](#), a group of advocates and scholars bringing social justice and human rights voices and perspectives to ongoing and highly consequential discussions about heritable genome editing. We'll be hosting our next event in November: "Forging New Disability Rights Narratives about Heritable Genome Editing," and we'll be sure to send you information about that event soon. We hope you will join us. If you're new to CGS, you can learn more on our website, geneticsandsociety.org.

Thanks so much, everyone, and goodbye.