

Genetic Justice From Start to Summit

February 28, 2023

This two-part online CGS event centers social justice and human rights, presenting voices and perspectives from feminist, disability rights, reproductive rights and justice, racial justice, environmental, and human rights movements and scholars, who will question whether heritable genome editing has any place in a fair and inclusive future. The second day of the symposium included two panels. The first, “Missing voices speak out,” features **Larkin Taylor-Parker, Abril Saldaña, Dana Perls, and Nourbese Flint**, with **Emily Galpern** moderating, and the second, “Genetic justice beyond the Summit,” features **Isabelle Bartram, Milton Reynolds, Maria Ní Fhlathartha, and Katie Hasson**. Live captions and transcript provided by Lori and Kayla of AI-Live [minimal edits made for clarity].

KATIE HASSON:

Welcome. Thanks for joining us on the second day for Genetic Justice: From Start to Summit.

Welcome back to everyone who was here yesterday. We are glad to have any new folks joining us today. I am Katie Hasson, the Associate Director of CGS. I am a woman in my 40s with curly red, chin-length hair and pale skin with freckles, wearing glasses and a teal V-neck sweater with a black and gray scarf.

A few reminders and things we want to make you aware of – we are recording this webinar, and we will let everyone who registered know when the video and transcripts are posted on our website.

Captioning is available. You can click the CC button at the bottom of your screen, or you can view the transcripts externally using the link in the chat. Many thanks to our captioners, Lori and Kayla, and our ASL interpreters, Holly Newstead and Lisa Perry.

Please use the Q&A box for any questions or comments you have for the panel or any other technical issues you may have. You can upload, discuss and respond to other attendees’ questions as well. We will be using the chat box to share some links and other resources. We will make those links available after the event as well.

I would like to acknowledge that CGS sits on the ancestral and unceded land of the Chochenyo speaking Ohlone people. This land was and continues to be of great importance to the Muwekma Ohlone Tribe.

We are thrilled to continue our symposium today, bringing social justice and human rights right to the heart of conversations about genome editing.

Yesterday's panels included Marcy Darnovsky, with an explanation of how we got to where we are today heading into the Third International Summit on Human Genome Editing. We had Dorothy Roberts,

Rosemarie Garland-Thomson, George Annas, and Silvia Yee, who explored opposition to genome editing from the perspectives of human rights, disability rights, and racial and reproductive justice.

That is objection to the prospect that we might use gene editing tools like CRISPR to change the genes and the traits of future children and generations.

It is important to note, again today, that heritable genome editing is very different from the promising gene editing therapies that are being developed to treat existing patients with conditions like sickle cell disease. They raise some important concerns about whether they will be developed and tested ethically, who will be able to access them given their sky-high costs, but they are much more widely supported than heritable genome editing.

Concerns that genetic engineering of future children could undermine universal human rights and lead to a new eugenics, among other dire risks, led more than 70 countries to put policies in place prohibiting heritable genome editing. This includes a legally binding international human rights treaty that has been ratified by 29 countries. It is called the Oviedo Convention.

While it is still the case that many scientists, civil society advocates and much of the public continue to oppose heritable genome editing for its safety, ethical, and societal risks, there are some high-profile scientists and aligned bioethicists who are nonetheless eager to pursue it.

As we heard yesterday, those scientists happen to be very well-placed at the forefront of a small elite circle that, so far, has dominated public conversations on heritable genome editing, as organizers of the Summit and other major committees and reports.

Even though this group has been trying to back away from the early call for “broad societal consensus” that was called for before deciding whether heritable genome editing ever should be pursued, you really cannot escape the call for broad public discussion, engagement, deliberation on this topic.

It has been restated in every major report and by numerous influential bodies. The question really becomes, what kind of public engagement will we have? It cannot just be a matter of checking a box. It cannot be a sidelined exercise that will not have any effect on policy. It needs to be global. It needs to be broadly inclusive. It needs to be robust and meaningful with potential to actually influence decisions. To be all of that, it will need time and resources.

It needs to include and really prioritize participation of organized civil society. When you start from the perspectives of advocates engaged in on the ground efforts to achieve social change, completely different questions and ways of looking at the issue of heritable genome editing are going to emerge.

This is particularly true when there are questions and perspectives emerging from exchanges among a diverse cross-section of civil society, not just one or two token voices.

These kinds of cross-sector exchanges can be so fruitful. I think we saw that here yesterday. I am sure it will be the case today, too. This is one of our main goals in organizing the Missing Voices Initiative,

including our MVI working group and the Gender Justice and Disability Rights Coalition. We wanted to foster these kinds of almost magical collaborations and discussions.

We were also motivated to show that these “missing voices” are not actually missing at all. We wanted to amplify the essential voices and perspectives of this rich network of civil society advocates and scholars who are committed to social justice and human rights.

And in doing so, to show how different conversations about heritable genome editing can be and how limited the official conversations have been by virtue of excluding these perspectives.

As Marcy Darnovsky said in her remarks yesterday, “If social justice and human rights questions are put where they belong at the heart of the debate, it will be very clear that heritable genome editing has no place in the future we want to build.”

Heritable genome editing is not inevitable. There are more groups and broader coalitions than ever before working in opposition. We are going to feature these rich perspectives today and hear more about the coalitions that are building. We will do that in the panels that are coming up.

To start, I would like to turn it over to Emily Galpern who will moderate our first panel “Missing Voices Speak Out.”

EMILY GALPERN:

I am so pleased to be here at this wonderful event with these incredible speakers. I am a consultant with the Center for Genetics and Society. I am a pale-skinned woman with curly, chin-length brown hair and glasses, and a light blue turtleneck.

Our Missing Voices Speak Out panel is a really fantastic group of advocates and scholars who are focused on particular areas of social justice that we want to bring to you today about the debate around heritable genome editing. We will start off today with Larkin Taylor Parker.

Larkin is an openly autistic attorney licensed in North Carolina and Legal Director at Autistic Self Advocacy Network. I will turn it over to Larkin.

LARKIN TAYLOR PARKER:

I am a relatively young, pale-skinned person with short brown hair, wearing a blue and green jacket. I am coming to you from North Carolina from the homeland of the Coharie people.

As you have been told, I work at the Autistic Self Advocacy Network. This situates me working on behalf of a community that can expect to be hit hard by heritable genome editing should this future we are all concerned about come to pass.

Most people on this call, watching this webinar, attending this conference are probably well aware of the history of eugenics that played out in many countries around the world, including my own.

The area where I am coming to you from was particularly aggressive in its program of sterilization. This all happened less than 100 years ago. It was not long ago at all.

Eugenics, as most of us know, inflicted a lot of horrific harms on marginalized peoples, from forced sterilization to institutionalization that broke up families and removed people from their communities.

This was all predicated on the idea that it would make society better. Of course, no one thinks of themselves as the villain. And the proponents of eugenics believed that certain kinds of people were the cause of social problems. Some kinds of human lives were objectively superior to others and society would ideally be made up of certain kinds of people.

And that which kind the individual was was pretty much set in stone at birth.

Unfortunately, even after various revelations about the horrors that these ideas have brought about when taken to their logical conclusion in different parts of the world, they have not gone away.

We have a tendency to act like we can engineer ourselves out of social problems instead of trying to resolve the conditions that create them. We still equate the causes of certain kinds of social problems to certain kinds of people.

We still have a tendency that can be seen in moments as small as the hope that a baby will be born with 10 fingers and 10 toes.

People's casual comments that they would rather die than end up like that, that there is a view that certain kinds of human lives are inherently superior to others. This is still with us.

And unfortunately, the conversations about what kinds of human existence are valid, are worth having, are worth keeping around are still tending to take place among certain groups, very small, select groups of people to the exclusion of the broader communities and often the people who are going to be most affected by efforts to change what kind of people there are, such as germline editing.

Disabled people are one of the groups that would be hit hard by germline editing, those of us whose disabilities have a genetic component. But we still too rarely get to be part of the discussion about what kinds of diversity are worth having, and what kinds of lives are worth living.

This happens in a number of ways. It happens through academics and researchers who are making these decisions and who are creating the frameworks for what is ethical and what is viewed as ethical in these sorts of technologies, under-emphasizing stakeholder inclusion in the first place.

It happens through a lack of recognition that disabled people, not just the parents of disabled people, not just the caregivers, not just the professionals who work with us, but disabled people ourselves have meaningful interests, have cultures and communities of our own, and might know what is best for our futures.

It also happens through our difficulties gaining access to the kinds of formal professional roles that come with admission to conversations about the ethics of things like heritable genome editing, through employment discrimination, and discrimination in educational opportunities.

This creates a dangerous situation where people who are not really qualified by training or by life experience to evaluate the worth of human experience is very different from their own, are deciding which ones are worthy.

It is easy for all of us, I think, to overlook or misunderstand ways of life that are very different from our own. This is one of the things that make diversity so important, particularly whenever decisions are being made. It is good to have a variety of perspectives.

And with our perspectives excluded, a lot of good information is being left out of the consideration of whether germline editing is something that should even be pursued.

This creates a risk that heritable genome editing will eliminate some very worthy ways of life and will make humanity smaller, narrower, less diverse and less interesting.

It also risks treating the elimination of whole cultures and communities without their consent as aspirational, and stigmatizing people who are alive today as problems to be solved, instead of people who may have needs that we may have to accommodate to allow everyone to be fully included in society – people who may need support in some ways, as all of us do.

EMILY GALPERN:

Thank you so much, Larkin. It is great to have you start us off here on these important places of hearing from perspectives that are not heard and the people who are most affected.

I'm going to turn it now to Nourbese Flint. Nourbese is a reproductive justice activist. She serves as the Senior Director of Black Leadership and Engagement at Planned Parenthood Federation of America in Washington, D.C.

NOURBESE FLINT:

Hello, thank you for having me. I am a brown-skinned African-American woman. I have a multicolored, African print shirt on, long dreads and some very cute earrings.

Please also let me know if y'all are hearing me loud and clear. I am outside now. Just a caveat, I'm not here as my role in Planned Parenthood but more as a reproductive justice activist. I am happy to follow up after Larkin's opening, thank you for that.

I have been thinking a lot about how do I start this conversation that is so big in a small amount of time.

So I will refer to my notes but I have three points I want to talk about. First, I want to talk a little bit about myself. It is my north star – Star Trek – and it's going to come back in a couple of seconds. With

that, I want to live in a world where we have figured out the basic needs of people and humanity, and that we are boldly going to see and have people realize their dreams. And this is where I think reproductive futurism and the causes of Sci-Fi and reproductive justice intersect. And this is where my church, my ministry is – the idea of how science, humanity, and the future can be the happy place.

With that being said, I'm thinking about what does it mean for us to actually think about the future of reproduction? The future of reproductive justice that is inclusive for all of us? So I thought of a story, because people remember things in stories.

So I will ask you all to imagine with me the story. Imagine you are a teacher. In your class you have to grow a pineapple plant. You do not have great soil. You don't have much access to water and there's not a lot of sunlight because it is in the school and there are not many windows.

The plant is not doing so well. Another science teacher comes in and says, "Hey, I see your plant and it is not doing so well. We should make it better. Let us figure out how to make it better." You are thinking maybe we get some better water in here. They say, "No, we are going to change your plant. How we are going to change your plant, is we are going to make it so it never needs any water! And it never needs any sunlight! Actually, let us make it glow in the dark! So you never even need any light".

You are not sure about that and you wonder what it will do for future plants. "Well, we don't really know what it does for future pineapple plants, but it is science so you do not need to worry about that." So you are like, "OK, what does that do if other classes want to have their regular pineapple plants grow?" And they're like, "Well, we actually don't know what that would do to other pineapple plants and other classes. Nor should we care what they are doing. It's science. So we need to do this and it's going to be great."

"Well, alright, we do not know what it will do in the future to other pineapple plants. And we do not know how it affects other folks in our school who are trying to grow plants either, alright. The last question here is, what happens if our conditions change? What happens if all of a sudden we get a lot of sunlight, or there is a whole bunch of water. Will the plant survive in that?"

They're like, "That is not something we can think about because these are our conditions right now. It is science; we do not need to think about that."

I use this story to illustrate the intersections where I feel reproductive justice comes in, but not where we are thinking about a pineapple plant but thinking about a human being. We want to have questions about our conversation like can we have better conditions for people to survive and thrive, like giving the water and making sure people have sunlight, making sure people are solving the "-isms." Instead of thinking of how we are creating the -isms, are solving the -isms, we are looking at making people harder.

That is where I wanted to start our conversation and I have three points that I wanted to get to.

So, one question, when you think about reproductive justice. Let me backup. When we think about reproductive justice, I want to make sure we all have a framework for it. There are whole classes that could be taught around reproductive justice. But for today when I talk about reproductive justice, it's

everything that has to do with having a child or not having a child and being able to treat your family and your children with dignity and a healthy, safe environment.

This is a framework that was created by Black women using a human-rights framework in the 90s. So that's the quick version of reproductive justice. Using that framework, let us think about the first question that comes up. When you think about genome editing, what problem are we solving for?

An ounce of prevention is better than a pound of cure. Are we using genome editing to make us better at normalizing inequities as a natural phenomenon instead of actually addressing the questions? And making people harder instead of the world softer.

How are we addressing white supremacy, climate change, inequity, healthcare, capitalism? Or does genome editing cause us to delay solving those conditions while pushing humanity to be more closer to a perfectionism that is now centered around white bodies, and their current understandings of quote, unquote, "what is right and good."

Instead of this, we don't open a debate to everybody but only for a few people who are in the room. A few scientists that are dictating what constitutes what's advancement.

This is also with a caveat that we are not asking our scientists to be out there in the community, to do the work, and folks to think about ethics and morals and long-term advancements of what this means. We are actually in the space of having folks, and celebrating folks, who do not actually think about these pieces and how the science actually can impact, not only our world of right now but our children's futures for a time to come.

Which goes back to the question that Larkin mentioned, who gets to decide whose lives are worth living?

So the second question I ask is what are we losing? And this goes back to my Star Trek conversation. I say this quite often; I am a big Star Trek person. If you have watched TNG, The Next Generation, we have Geordi La Forge. He is, in this fictional world, the person who is the chief engineer on the flagship Enterprise.

He is good, he's a Black man, and he is also blind. He is badass, right? Solving things all the time. In this round of genome editing, does Geordi get to exist and does the diversity he brings with being able to see things in different ways, from being born blind, get to still exist as well? The creativity, the thoughts, the ideas in this world. Does that still exist for Geordi when we are creating the idea of what is good and right now and not giving space for people who have a variety of different diversities of how they currently lack space to enter the conversation.

This is particularly important when I think about the world in the future of Star Trek. It is a world that exists where we did not change the people, we changed the environment to make sure people were able to thrive in those environments.

The last piece and the last question I want to throw up for our conversation is do we create new forms of segregation, with the thinking about genome editing, that people who have more money can engineer their children to be faster, smarter, healthier, or whatever those things are in the world now, while creating a literal different cast of people because of resources.

This is a piece that again takes us out of thinking about our current condition of now and how we celebrate where we are now and what is right, and not think about how maybe we solve the issues that we have or that are impacting us now, that the idea of what things are good might change.

I will leave with this because I know I am reaching time. As we are talking about and thinking about where I sit in Alabama, where I am at right now – in the civil rights movement place with a lot of history – and we think about where we were 50, 60, 70 years ago or even a couple hundred years ago and where we are now in terms of what we think about and how we think about what is good and what our society is and what our ethics are and what our morals are.

Imagine if we had created genome editing in that time where Black folks, certain people like myself, were in bondage and the idea of what is right and good – would I still be able to have these conversations?

I know my time is up but I just wanted to offer up those questions as you think about how this intersects with the space of reproductive justice and the future of our species. We have important questions to be asking of ourselves and of our science community before we leap into what could be our new future.

EMILY GALPERN:

Thank you so much Nourbese for bringing those great stories and analogies and your personal experience.

Our next speaker is Dana Perls. She leads international and national regulatory and market campaigns on biotechnology and genetic engineering from a different perspective, not human biotechnologies but plants and agriculture with the food and agriculture team at Friends of the Earth.

DANA PERLS:

I am a white woman in my 40s. I have shoulder-length, curly, reddish-brown hair. I am wearing a blue shirt with a black jacket.

Nourbese really cued me up well with the example of plants and what if we could replace a natural plant with one that does not need water or sunlight?

It is actually what we are seeing in the world of environmental genetically engineered organisms.

What we are seeing in this conversation is mirror of what we are seeing in the environmental and agriculture sector. We are seeing a new generation of genetic engineering technologies intended to

artificially redesign life. Everything from algae and yeast cells to crops, insects, and, as we are discussing, people.

I want to ask and offer: What are the trends? What are the risks? Whose voices are represented? Are we addressing the real environmental and agricultural problems?

We are seeing in the environmental space this attempt to fix with quick techno-fixes for very complex problems. There is a mismatch of how we are trying to address very complex climate change, biodiversity loss.

We are seeing a deregulation trend at the federal and international levels. We are seeing government and corporate avoidance of public engagement. No public engagement required for new genetically engineered animals onto the market for human consumption. No assessment or public engagement about new genetically engineered crops to be released in agriculture, not even public engagement about mass releases of genetically engineered mosquitoes into communities in California or Florida.

Some of these applications look like virus-resistant pigs, synthetic biology, soil microbes, herbicide-tolerant corn. Something akin to germline editing is a controversial technology intended to change an organism so that it always passes on genetically engineered traits such as an auto-extinction trait in insects. This would be passed on to all future generations of the organism until it changes the entire population forever. This is called a gene drive.

We are hearing repeat promises. The same stories as the first round of genetic engineering. That we are going to feed the world, we are going to have drought-tolerant crops, pesticide-resistant insects and crops. But these technologies, rather than fixing the system, are focused on changing individual organisms to withstand the very problems we have created.

Rather than fixing the soil contamination from pesticides, we design crops to be resistant to certain pesticides. Rather than fixing factory farming and the problems we see within factory farming with animals, we try to change the animal to be virus resistant, heat tolerant, no beaks or horns.

There are a number of risks and concerns with almost no discussion with the general public or even front-line communities, despite these technologies permanently affecting all of us.

We see irreversible contamination of ecosystems. From genetically engineered crops, insects, genetically engineered pollen and trees. We see health problems unknown and risky potentials, detrimental health impacts on people including from increased use of pesticides.

We are seeing socioeconomic risks, including on farming communities, fishing communities, and indigenous communities who are not at the table. We have ethical problems. Who gets to decide whether our world and nature is permanently engineered for all of us? Is this being decided by a small group of corporations that are unchecked by government or communities?

The voices at the table represent big agribusiness, agrochemical companies. Many of which are the very companies responsible for the problems that we are now trying to address.

This deregulation trend of our government agencies is highly problematic and continues to exclude the number of voices that can do risk assessments or name what is most appropriate for problems impacting communities.

There is an incentive to rush new technologies to market, regardless of their ecological utility, ahead of appropriate and transparent assessment and oversight, ahead of public engagement. These applications are protected by patent rights and confidential business information, making it nearly impossible for advocacy organizations, other scientists, the general public to understand the information that can permanently change nature, including agricultural systems, for all of us.

As we've heard, it is really crucial within the environmental space as well that we are evaluating these technologies at a multidisciplinary level using the precautionary principle, looking at solutions that actually and truly address complex problems. And for that, we need all of the voices at the table, including and especially the front-line communities most impacted.

Thank you very much.

EMILY GALPERN:

Thank you for bringing in another realm around environment and agriculture and food and illustrating the parallels between biotechnologies that are related to humans and plants and the environment. The crossovers are so important.

Our last speaker is Abril Saldana. She is a sociologist at the University of Guanajuato in central Mexico and she is currently exploring bioethical principles practices and regulations on human genome editing and stem cell research in Latin America. I will turn it over to Abril.

ABRIL SALDANA:

Thank you very much for inviting me. I am a Mexican woman in my 40s, almost 50s. With chin-length, wavy dark brown hair. I am wearing glasses and a white blouse.

As Emily was saying, my concern regarding the future of human genome editing centers on the global divisions that are so often attached to decision-making in the context of controversial and high-stake technologies applied to human and as Dana Perls so rightly stated, non-human life.

how countries of the global North and South are differently positioned and represented in the discussions. When I say countries, I mean populations. And when I say populations, I mean the diversity of populations contained in nation states. Especially in countries with histories of colonization.

One of the things that worries me the most is that acknowledging the needs and complexities of public engagement is not enough to proceed with human genome editing or any other technology. We need to

engage a diversity of voices, languages – that is very important, languages – and positions, and take into consideration the hierarchies within the geographies of knowledge production.

Histories and legacies of colonization still shape the way countries and communities are placed when it comes to making decisions over the use of breakthrough technologies, the resources and technologies available to develop, to implement and to monitor national and international regulations. But also, and most importantly, nations and populations are differently positioned when it comes to paying the price of global decisions when these decisions are taken without proper inclusive discussions and consultations.

How will the colonial perspective look, when it comes to genome editing? First, it will require including the voices of stakeholders but also understanding that these are not homogenized, not the same. When it comes to engaging civil society, Indigenous people, disability groups, patient groups or the LGBT community, we must first understand the diverse history experiences, organizational capacities, and positions found within and across these communities, along the North–South divide.

So the voices of these groups must be heard in their own context, their own languages, and particular standpoints. So finally, when it comes to the global governance of human genome editing, we need to problematize the notion and the locus of governance.

What I mean is that we need to zoom out from the nation states by looking at what we call sequence of use that allow or are allowing these technologies to happen or to be applied without appropriate regulation. And what I mean by sequence of use is a transnational movement of actors, such as physicians, scientists, of knowledge, the movement of tools, techniques, patients, and biological material, within but also across countries.

The first baby born after mitochondrial transfer techniques are what they call three-parent-baby happened in Mexico because, according to the US doctor head of the medical team from New York, Mexico was a country with no rules.

So we need to make, also the repro-genetic market accountable beyond national borders, watch closely across review boards in the US and elsewhere. And we need appropriate regulations and measures to do so.

I'm going to stop here to give to give time for questions and discussions. Thank you.

EMILY GALPERN:

Thank you so much Abril. Thank you for bringing in the essential point about different perspectives related to geography and in particular Global North and Global South and the dominant voices of Global North.

What we are going to do now is have an opportunity for the richness of all of the experiences and perspectives of our four speakers to come together – and give you each a chance to respond to each other -- if there is something you would like to comment on after hearing all of the speakers, in addition

to your own remarks. I think we will go in the same order that we started. With Larkin, then Nourbese, Dana and Abril.

Then we will have a second chance to come back around and see if there are some audience questions and comments that you want to address. I will turn it over to Larkin.

LARKIN TAYLOR PARKER:

Thank you. I expected to learn a lot from this group. I certainly have. I appreciate all of the other speakers today. Nourbese's pineapple plant analogy particularly resonated with me.

I really question the wisdom of paring down human diversity at a moment where we face all kinds of unprecedented challenges. That risk often seems understated and under-considered in discussions about heritable genome editing.

EMILY GALPERN:

Thank you, Larkin. Nourbese?

NOURBESE FLINT:

I do not think I have anything to add at the moment other than... OK, I guess I do have something to add. Just the lines of plants, animals, and humans and how it is not a huge leap between what's happening with plants and what they are talking about that is happening with people. And that there is the same kind of reasoning that is happening with plants that is why we are trying to fix people.

But it is not framed in the same type of framework. This is like, "We're going to help people!". But wondering if we need to start with they are not really trying to help people, they're trying to change people in the same way that they changed plants: "Yes, we have to do this to survive." This is one of the pieces I have been ruminating about.

EMILY GALPERN:

Thank you. We want to hear from Dana and Abril.

DANA PERLS:

As you did before, Nourbese, you really drew the connection between plants and insects and animals and human engineering perfectly for me. I do not know if I can say it much better but I want to say to what Larkin and Nourbese was saying is that there is a disconnect between the complex, and really problematic situation that we're in in the environment trying to address contamination, the problems of factory farming, addressing drought and other issues caused by climate change. And there is a disconnect between the genetic engineering proposals and what is actually needed for very complex webs of life and ecosystems.

This is not a machine, right? Ecosystems are not a machine where you can have a plug and play solution.

And as Larkin was naming around the diversity of a population, and this idea that we could attempt to pare down diversity is what we are seeing the environmental sector. That at a time of massive biodiversity loss of animals and plants and insects, we are seeing a push from genetic engineers to reduce that biodiversity to just a couple of different crops, a couple of different insects, the gene drive which is designed to cause the extinction, permanent extinction, of various organisms, including plants and animals and insects.

And so, at a time where we are already seeing biodiversity loss, now there is a push to intentionally shrink biodiversity as well. And with these unassessed technologies we might actually be perpetuating the very problems that we are trying to solve. Thank you.

EMILY GALPERN:

Thank you, Dana. Abril?

ABRIL SALDANA:

I agree with Dana that there are things happening without proper consultation, and I think that the way that these things are happening in the environment and plants, and non-human world, are a very good indicator of what is coming if we do not do something about it, if we do not ask for inclusion. And these things are happening already with some clinical trials, at least in Mexico, that we are seeing without any proper regulation to look over them.

Again, in the case of the first baby born after a mitochondrial transfer technique that happened in Mexico, I think there was probably not enough condemnation around the world. Probably because it was a clinical trial in the hands of a US physician.

He was not a Chinese physician. He was not a physician from the Global South, but he was a US physician so that was probably why the scientific community was not that appalled, as it was, with the case of the CRISPR babies.

After all, as Baylis has argued, the MRT baby is a case of human modification. We must be very concerned about what is happening with these technologies without any consultation and look for what has already happened in the environment with plants and animals to see what is to come if we do not do something about it. Thank you.

EMILY GALPERN:

Thank you. I'm going to bring together a few themes from the panel and bring in a few questions from various places. I think some important things that I'm hearing that cross most of your talks is about the way that these technologies are very focused on technological fixes for social problems, as illustrated by Nourbese's description of the pineapple plant, among things that each speaker said.

And instead of changing the environment and changing social conditions, changing economy and policymaking, we are trying to change people or that is the intent of this technology, and in the case of agriculture, plants and soil etc..

As Abril brought in, there is a lack of regulation generally and lack of corporate and government accountability and transparency. And really underlying all of that is the profit motive, rather than centering people from these technologies. Lastly, the question of – it should not be a question – but whose lives are valued? Whose lives and what kind of lives and people are worth bringing into the world and living?

This is a question that has been unfortunately in our society for quite a long time, and has been brought to different communities about thinking that certain peoples and communities are less worthy than others. That some people with certain traits are less worthy than others.

Each speaker, I think, brought in so beautifully the importance of the diversity and experiences of perspectives of humans and of the environment. With the crucial moments that we are in with climate change, all the more evidence of how important it is that we value the humans we have on this earth, and the earth on which we are living.

So, I think my question, you can address any of those things that I said, anyone on the panel, but I want to refer to something in the Q&A as well which I think is related. Nourbese brought up imagining futures, not just science fiction, which I know she loves, but real futures, and what might that look like in the context we are in now.

The comment in the Q&A was, what is the binding force that could unite the resistance, towards liberation?

And I think particularly referring to some of the things that Abril had mentioned about different constructions, different understandings or visions by different peoples in different geographies. To all of you, really, what is the future you can imagine? How might we get there in a different route than through genome, heritable genome editing?

Abril, why don't you start us off?

ABRIL SALDANA: First, I think that the future that I am imagining is to make a truly global consultation of the future of these technologies.

One of the things that I am worried about is this notion that some people in the Global South are not pro-science because of religion, Catholicism, they are not really believers in science and they will not go for it – science.

If you look at international surveys about if people believe or not in science, you will see that that is not the case. If we look at, for instance, the number of people that were vaccinated during COVID, you will see the Global South, especially Latin America, was very interested in vaccinations.

There are so many prejudices about how people engage with science. And also I think that these technologies, or the future that I am imagining for these technologies, is one where science and scientists are accountable for what they do and they really acknowledge the importance of trust in science. I think this is a moment where we need to really look into the states not only of the technology itself, but in the relation that people have with science.

This is a very important moment for us to look at the future of society's relationship with science. Thank you.

EMILY GALPERN:

Thank you.

Nourbese, you were talking about imagining futures, do you want to answer that question?

NOURBESE FLINT:

Thank you for the question. I think a couple of pieces. Minorities, we have talked about Star Trek, the things that I would love to see our future work on is what it means for us to actually do a deep dive into the root causes. How do we start solving those pieces with a new set of liberation, like looking at racism, looking at patriarchy, looking at climate change and all the pieces that are causing inequities in our society and reevaluate our conversation and then reevaluate where science needs to go afterward – after we do these things.

I think sometimes we have a tendency to think these issues are so big we cannot solve them. And not understanding the systems and where we live right now. So the structures that we sit in, how we run our society are all of someone's imagination. That is important for us to have a dream and imagination and strategy and to think about what is our future and those things can also be created.

I think the last piece I'm thinking about, we need to start re-thinking about science in the way we teach it. We have a tendency to think science is good, it's how people use it where the problem is.

And being sophisticated in our analysis of how we use science. Just the way we want more kids to understand photosynthesis and have those tools available to them, I think it would also be important to make sure that our folks in STEM have the tools of social justice and ethics and morals to be able to have and think about how their creations are being out in the world. Even the simple question of what is important, what do you want to study is based in our current idea of what is good and right.

There are things we may not be thinking about because the people who are in the room are the ones getting to ask the questions that are based on their framework of what is, again, right and what is good.

EMILY GALPERN:

Thank you.

Dana since you are on screen do you want to comment and then we'll bring in Larkin?

DANA PERLS:

Sure. I'm not sure I have too much to add. But in particular, the vision that we have for environmental and agricultural worlds is one that's ecological, one that is actually healthy for people and the planet, one that uses the known responsible technologies that are agro-ecological, that work with ecosystems, ones that have been used by Indigenous people for many generations. We know from data and international bodies that the best way and the most popular way, effectively, to feed a growing planet is through food sovereignty. Where people have control over their own farms, where they can attend to the land in ecological ways.

We have no data, in fact we have opposite data, to show that the genetic engineering technologies actually work against these goals. They result in corporate consolidation that put farmers out of business. That do not allow people to save their seeds, that contaminate farms, that cause genetically engineered salmon to potentially go extinct.

The vision is that people can live in a world of food sovereignty, can sell their seeds, can tend to the soil in a way that is healthy for that soil. This is a world that does not use genetic engineering and, in turn, is perpetuating the industrial impacts that we are stuck trying to address.

EMILY GALPERN:

Thanks, Dana. Larkin if you have something to add?

LARKIN TAYLOR PARKER:

I agree with the other panelists. I think that we need to remember that our social conditions are often made by human beings and can be changed by them, especially when we work collectively. We need to also have hope. The problems that we are facing can feel too big. That is very true. And, technological change, technological development, and technological development that does not ask questions about "well, we can but should we?" can feel inevitable sometimes. But our collective and individual actions actually do have a lot of power to shape the future.

People who have struggled for liberation in the past have often made positive change, had some success in achieving their objectives even if that success is limited and imperfect. Even at an individual level, on a very small scale, our actions can matter.

I am speaking to you today because in 1920s and 30s North Carolina, nobody called the Eugenics Board. People just ignored this boy who was very conspicuously struggling with literacy. Eventually, he would be my grandfather.

So, the choices that we make together, individually, can actually get us closer to this world that is fit for humanity and nature, as opposed to trying to reshape those things to fit some of our very flawed social systems that we want.

EMILY GALPERN:

Thank you, Larkin, so much.

I want to turn to a little bit of a different angle, though completely related. Larkin, maybe you can start us off on this because you talked about eugenics in your remarks at the beginning. It is another area that overlaps all of the topics that each of you were talking about and really undergirds most of the interest in developing and using heritable genome editing.

Because we have all of you—advocates and some scholars around disability rights, reproductive justice, and environmental justice and global governance and colonialism— I think it is important to look at the history of how eugenics has affected each of the different communities or areas that you work with that we are talking about.

If you might want to talk about that in relation to the history that you know of from your work as well as the connection to heritable genome editing and this question of the future—the just future, the just and equitable future that we are all talking about, if you want to connect those as well.

I will leave it up to you what entry point you have. Larkin, if you want to start us off in relation to eugenics?

LARKIN TAYLOR PARKER:

Eugenics is of great concern to the community I serve. Worry about it, worry about what the future holds for us and whether there will be one, is something that has been around in the autistic community since I first started to get involved in discourse and a little activism in my mid-teens.

It's maybe a lower-level worry as it has become less socially acceptable to talk about a world with no autistic people in it as a good thing, as the end goal than it was 10 or 15 years ago but it is still there and probably always will be.

Looking at what has happened to the number of children born with Down syndrome since the advent of prenatal testing in wealthy countries, says a lot about the value placed upon people with IDD.

Parents do not make those choices in a vacuum. Prospective parents may be exposed to a lot of assumptions about the quality of life for people with IDD. They may know the service systems and a lot of places are widely inadequate.

There is no point in blaming the individuals, but at the same time, my community watches those developments and certainly sees how our lives are valued and whether some genetic marker is found that allow the same thing to happen to us in the future. Whether the threat of heritable genome editing being used to attempt to eliminate autism is something that ever comes to pass, people who are alive right now today definitely see that and feel devalued.

It is hard to feel like society is accepting you and welcoming you when it is still fairly politically correct to talk about the existence of people like you as a bad thing.

EMILY GALPERN:

Thank you for sharing on such a personal level that applies so broadly societally in general.

Dana did you want to respond to this question? About eugenics?

DANA PERLS:

I do not think that I have anything to add at this moment.

EMILY GALPERN:

Ok, bringing in Nourbese, I'm sure has a lot of historical and contemporary knowledge about this issue too.

NOURBESE FLINT:

I think the other piece, the two pieces that I would bring up is one of the reasons why the reproductive justice framework was created was this idea of eugenics. Why the second wave of feminism was fighting for their right to not have children, women of color, and particularly Black women, were fighting for their right to have children. And that's because of the long history in our country of who is valued as worthy and who is able to have children—who would be able to have families.

Not too long ago, whereby the simple act of being Black meant you were considered less than human. In some cases, we are still struggling with seeing the humanity of Black folks. If we are still struggling with just the simple fact of recognizing who humans are and seeing their humanity, the idea of us judging or using the current understanding of who we are, to set that in stone of who we should be, is frightening, and a nightmare for many of us.

We are essentially walking in with bias of the current condition of who is valuable. The history, there is a through-line with eugenics and what science has done and what genome editing can offer if we are not vigilant in our conversation as a way to be more precise.

They will be more larger with the ideas of orchestrating bioengineering hate, bioengineering who is worthy, bioengineering value. This would be the only that I would add. Also, that we talk about it in a way that we need to be better in science. This is also a space that is very fearful. it can be a lot of fear for me, a lot of fear that we could get essentially stuck in a future where I am not seen, and my child is not seen as a full human being.

EMILY GALPERN:

Thank you, Nourbese, again, like Larkin, for your broader comments that you bring so personal, but illuminate the importance of the societal implications. Abril?

ABRIL SALDANA:

I was thinking about the clinical trials of the contraceptive pill developed by Gregory Pincus in 1950s. The trial started in a psychiatric hospital in Boston, and then Pinkus moved to Haiti, Puerto Rico, and Mexico. We have many of these stories, that regardless of the technology we're looking at, they start to be or the clinical trials often happen in places where there is no regulation or the regulation cannot be effectively implemented.

So I think that we need to learn from history, and we need to learn from history because some of these trials, or most of these trials, are justified by a discourse of eugenics. The Pincus trials were justified

because women in these places and in these countries were not protected by law, but they were also perceived as women that should not reproduce.

So I think that we need to be very careful and learn from history and not repeat the same mistakes.

EMILY GALPERN:

Thanks, Abril. We just have about two minutes left. Abril, since you are unmuted and just spoke, I wanted to see if you could you talk for just a few minutes about commercial interests and profit and conflict of interests in patents because I know that is an area that you have focused on and as we are hearing from all of you speakers about the profit motive versus centering people in humanity and justice.

ABRIL SALDANA:

Yes, well, one of the clinical trials that also I am looking at is the uterine lavage, a complicated technology to explain in two minutes, but it is something that is not regulated and that involves participants in Nayarit, Mexico, volunteers that were subjected to very intensive procedures that are, again, not under any regulation by law.

This clinical trial was designed by a company in the US. The ethical board was a commercial ethical board in America.

So things that had happened in Mexico had been overlooked by commercial, or for-profit ethical review boards. So we need to look at how the reproductive and the repro-genetic market is evolving and how can we make accountable these markets and these companies, patents and interests, private clinics, for instance, that sort of promote themselves as very progressive because one of the things that these technologies offer is a very frivolous or superficial image of a progressive technology that will give everyone the opportunity to reproduce as they wish.

But we need to be careful with those discussions and make accountable not only countries but also the market itself.

EMILY GALPERN:

Thank you, Abril for that little tease of a much bigger issue. Your scholarship is so important around this and so many areas here. And I just want to thank all of our panelists, Abril, Dana, Nourbese and Larkin for superb remarks and interactions with each other, all that you bring from the history of your personal and professional experience in communities you're connected to. It makes such a difference to have your voices, that are very central here but unfortunately missing from the larger international and national debates and policymaking. So thank you so much for your comments today and I will turn it back to Katie to take us into the next panel.

KATIE HASSON:

Thank you. Just as we shift into the final panel, I am going to play a little bit more from this video, featuring important reasons to oppose heritable genome editing from people in our network. But we hope you will stay on.

We are going to go through the end of the hour, and we have an exciting panel coming up next that is going to be forward-looking, talking about ways that you can get involved in the issue. The panel will be Genetic Justice Beyond the Summit. We will start that in just a few seconds.

(Music plays)

KATIE HASSON:

Thank you so much everyone. We are coming into this next panel that will feature Isabelle Bartram, Milton Reynolds and Maria Ní Flatharta. This panel is Genetic Justice Beyond the Summit. This is something that really should have been in the name of our symposium, Genetic Justice From Start To Summit, because of course, as we have been hearing, the upcoming summit is not the beginning or end of this conversation.

In this panel, we want to showcase some of the ongoing work and initiatives related to opposition to heritable genome editing and new initiatives that are getting off the ground. We hope to connect you with a range of ways to engage and activate on these issues.

I have spoken a little bit earlier today and yesterday about CGS's Missing Voices Initiative. It is part of our broader work at Center for Genetics and Society to bring together a range of academics and professionals across disciplines, as well as progressive advocacy organizations, including those focused on reproductive and disability rights and justice, racial justice, LGBTQ rights, Indigenous sovereignty, human rights, the environment. You've seen a taste of these over the past few days.

And while you know a few of these organizations focus primarily on gene editing or other genetic technologies, and therefore, they are not often featured in the sort of international or mainstream conversations around heritable genome editing, they do see clearly how something like heritable genome editing would threaten hard-won rights in the cultures of disabled communities, as you have heard. Or how existing sexism, racism, attempted erasure of Indigenous people might shape the development, the marketing and the use of these technologies.

So as these groups are committed to think deeply and work hard to bring a just and inclusive future into reality, they face a range of grave concerns about whether there is a place for this technology in the future we aspire to.

So I am going to introduce our speakers. We will start with Isabelle Bartram. Isabelle is program director at Gen-ethisches Netzwerk, a Berlin-based nonprofit organization advocating for the responsible use and governance of genetics. Thank you, Isabelle.

ISABELLE BARTRAM:

Thank you. I am Isabelle Bartram. I'm usually in Berlin. I am now joining you from my vacation in Switzerland.

I am a white woman, nearly 40 years old. I have dark blonde short hair and red glasses, and I am wearing a gray sweater.

You already introduced me. I am program director at Gen-ethisches Netzwerk or gene ethical network. It is an NGO that was founded over 35 years ago by feminists and environmental activists and critical scientists to observe and report on biotechnological advances that impact society.

In Germany, research on embryos is not allowed. Modifying an embryo to be implanted is also forbidden. So, some scientists use the hype and the enormous promises surrounding genome editing to lobby for a change of this law.

So, they say that Germany should be able to compete with the international research community. The law against embryo research is mostly based on the embryo as something sacred, as a potential human.

I do not agree with this argument and the argument of my organization is more that we fear that a market for eggs would be created, where poor women or other people would be made to “donate” eggs for research with obscure benefit.

Since genome editing was developed, we have warned about the entanglements of science and financial interests of this field that, in our opinion, make it so hard to assess the true risks and benefits of the technology.

We are also very critical of the ableist discourse around heritable genome editing, where scientists and media talk about “healing” every kind of disease and disability. We think scientific advances should serve a common, public good and heritable genome editing is not a goal that will benefit society

We want an international stop on research in this direction. We released a statement on this topic in 2017, and an updated version in 2019 that we also translated to English, that is mostly focused on the medical field.

As a representative of my organization, I am also part of a gender justice and disability rights campaign against heritable genome editing that was initiated by the Center for Genetics and Society and that is part of the Missing Voices Initiative. This campaign is an action coalition of the UN Generation Equality Forum. We are working together with scholars and other civil society organizations, like the Pro-Choice Alliance for Responsible Research, the Autistic Self Advocacy Network, the Disability Rights Education and Defense Fund, the Genetic Support Foundation, and the Sama Resource for Women and Health from India and biorespect from Switzerland.

The goal of this coalition is to centralize gender justice and disability rights in public discussions and policymaking regarding heritable genome editing. Our objectives are to articulate a set of principles grounded in gender justice and disability rights to first inform civil society and public understanding and then also the development of public policy related to heritable genome editing.

Once we have established these principles, we will then develop model policies on heritable genome editing for countries and international bodies that do not already have policies on this topic.

We also want to create tools to assist organizations and scholars working on gender justice, disability rights, and other social justice fields to achieve inclusion of their voices and leadership in public discussions and regulatory deliberations on heritable genome editing.

On top of this, Gene-Ethical Network is also part of an international alliance of civil society organizations that will publish a declaration against heritable genome editing at the beginning of the summit in London.

We are called the Coalition to Stop Designer Babies. The declaration can be found and signed at coalitionstopdesignerbabies.net.

The members are: Stop Designer Babies UK, that is currently campaigning against the planned legalization of heritable genome editing in the UK. The Alliance for Humane Biotechnology from the U.S. and also the Center for Genetics and Society and also biorespect from Switzerland and Sciences Citoyennes from France and GeneEthics from Australia.

Our main arguments are that designing children's genes runs counter to accepted basic visions of diversity and inclusion and equality of all vulnerable individuals and minority groups, and allowing heritable genome editing would exacerbate existing social inequalities.

We also think it would be contrary to human dignity because it reduces human beings to the status of designed and optimized consumer objects. We think it is not ethical to submit a child to the severe health risks of genetic modification just to preserve 100% biological relatedness.

We are concerned about the exploitation of and health risks to those that are sources of eggs for research to make heritable genome editing possible.

Thanks for listening.

KATIE HASSON:

Thank you, Isabelle.

Now we will hear from Milton Reynolds. Milton is an educator and activist in the San Francisco Bay Area. He is the founder of Milton Reynolds Consulting and on the advisory boards of the Center for Genetics and Society, the Paul K. Longmore Institute on Disability at San Francisco State University and the anti-eugenics project from Small Beginnings. Thanks, Milton.

MILTON REYNOLDS:

Thank you Katie, and thanks for the opportunity.

As you heard, my name is Milton Reynolds. I am a middle-aged black man with salt-and-pepper dreads that are waist length and a beard that is certainly more salt than pepper, and I am coming you from the unceded ancestral land of the Ohlone People.

I will keep my remarks relatively short so we can get into some exchanges. This conversation is resonating with me a great deal today. As recently as last Friday, I was in a conversation with the California Coalition for Eugenic Memorialization. There were at least three women in that room who had been subject to sterilizations themselves.

When we talk about eugenics as something in the past, I think we do ourselves a distinct disservice. We have to begin to think about eugenics as a present commitment and in many cases a sustained commitment to these notions of human improvement. But recognizing that this project of human improvement is one rooted in fallacies.

Everybody is fine the way that they are. We can start with that.

There are some things to be excited about. I will list a few of them and hope we can delve more deeply.

There is a growing awareness of this history. When I go back to some of the work I was doing in terms of inviting educators into this history up to 20 years ago, there was very little recognition of this history. To the extent it was recognized, it was typically associated with the Holocaust.

That is actually a really important point of connection. It is a critical history to understand, but it is also important to understand that it is part of a much larger history. When we begin to look at the impact and scope and consequences of eugenics on a broader transnational level, what we understand is all nations in which eugenics was implemented have a distinct and different trajectory of these ideas, but there are also some universal elements or things that are important to observe.

One of the challenges of dealing with this history and connecting the past to the present is the complexity of these issues. It is really layered. It is layered in ways that causes us to have to think about how we disentangle these notions of categorical disposability from institutions that impose, or serve differential value on people? How do we also interrupt the habits of minds that invite us into essentialist thinking that assert this notion that biology is destiny?

Biology is not destiny, but those are seductive ideas. One of the reasons they are seductive is because they are simplistic. They are as dangerous as they are simplistic because by virtue of causing us to let the body as the site of deficiency, it prevents us from connecting the body, our bodies, into the larger context in which meaning is being assigned or imposed.

Dana and Larkin and so many people in yesterday's panel had made clear how dangerous those narrow observations and that narrow focus is.

When we begin to actually scope out and look at the broader impacts of eugenics, we can actually see these patterns of normalized disposability are actually normalized. We can see through the COVID pandemic how particular communities bore disproportionate harms. Even the legacies of eugenics caused some people to be suspicious of scientific support and help.

Recently even in the NFL there was an effort to do compensation for traumatic brain injuries. We saw eugenic arguments being leveraged in order to advocate for lower compensation for African-American athletes who were "already less intelligent."

We see disability continuing to be framed as pathology, something to be resolved rather than learning how to accommodate and shift society.

There is my timer. I'll just go a minute or two more.

Even in terms of resource allocations, we can see situations like Standing Rock and fight for water or Flint when entire communities are seen as disposable and put in the crosshairs of change.

A couple of ideas I will just lift up really quickly. We need to challenge the framing of eugenics as purely historical and begin to utilize the historical thinking skills and frameworks such as change and continuity to follow the ways in which eugenics gets rebranded and normalized and the work that it does.

In my own work, I have shifted the discourse away from race and identity to racialization and identification in order to speak to the ongoing preoccupation with assigning and imposing value. Inviting people into that kind of language invites them to also look more broadly and look at the context and to ask different kinds of questions.

We also need to center the voices of those most marginalized. I think back on the work that has been done over the course of the past several years, From Small Beginnings, but also the work that Center for Genetics and Society has done for so many years, and centering the voice of those most harmed or marginalized.

One of the culminations from the Small Beginnings project was a weeklong Anti-Centennial in which we centered the voices of BIPOC folks and people of color specifically Indigenous and African-American voices and queer voices and voices of the disabled. What we came out with was a fundamentally different understanding. And we also brought in artists and culture makers. Those kinds of provocations and understandings of the history from that vantage point makes it clear that eugenics is alive and well.

How do we think about putting in place structures and systems to invite people into these conversations early and often, so they are not seduced by the ongoing efforts to market these kinds of projects for improvement, as though we are all going to be consumers with equal access or that even the ideas themselves are worthy of exploring.

I look forward to talking with the rest of you. Thank you for my time and it has been a great conversation, let's keep it rolling.

KATIE HASSON:

Thanks Milton for those comments. I am excited to get into conversation as well to talk about some of these themes of challenging thinking and coalition building.

First, we will hear from Maria Ní Fhlatharta who is a legal researcher, policy advisor, and human rights advocate. Previously Maria worked on the Real Productive Justice Project at the Centre for Disability, Law and Policy at the University of Galway.

Thanks Maria.

MARIA:

I was listening to Milton and totally forgot that I was going to have to speak afterwards.

To start as a visual description, I am a very pale white woman with long dark hair. I am wearing a pink jacket that I have found out does not have pockets, so I now hate it. There is a wall and a bookcase behind me, as is now custom in Zoom calls.

I will talk a bit about coalition building and what it means, or what is necessary to have inclusive movements, particularly within these spaces and to make these conversations even possible.

I come from an academic and activist background. I have, I suppose, been an activist on disability rights for a long time, also abortion rights and LGBT rights in Ireland. But I also work on a lot of these issues academically. I generally am always wearing two hats, or feel like neither an academic nor an activist at any one time.

I am going to focus on what we need to build a kind of more inclusive movement around some of these things. It is interesting, particularly existing in those in-between spaces as a disabled person, a lot of the time you are in conversations where your value is called into question by people who have no understanding of your life.

I think sitting between the reproductive rights movement and the disability rights movement, which is where I will draw the lessons I'm going to talk about today, it is quite interesting. It is an interesting space to be, but I am also very grateful for the other disability rights activists who sit between those spaces.

A lot of the time when we are talking about different things, we end up talking about things that are specifically harmful to disabled people. A lot of the time in the bioethics space we talk very positively about the Oviedo Convention as something that is useful, as we have done at different points in this call. The Oviedo Convention holds provisions that are directly contrary to disability rights. With regards to consent, it's actually specifically contrary to the UN CRPD. And while disability activists were supportive of it initially because it was better than what had gone before where you are allowed to override disabled people's consent without any participation and Oviedo does mandate that disabled people should participate in decisions about them, it does not actually acknowledge that these choices are disabled people's rights to make for themselves, which is particularly difficult when you apply to the context of reproductive justice and reproductive rights, where disabled people are so often denied the rights to make their own decisions about their own reproductive lives.

I'm going to talk about two things that are necessary. One that the disability community needs in order to be able to participate effectively in some of these contested spaces and difficult discussions, and two, what wider communities need to do in order to ensure that disabled people can meaningfully participate within these spaces.

We talk a lot about, the importance of inclusion, but we sometimes ignore that for disabled people to participate fully in civil society there has to be a disabled people's movement to participate. And a lot of the time, we are talking about these things in spaces where a disability rights movement has been unsupported, or marginalized or maybe does not exist in the fullest sense possible in the way that other human rights movements exist.

Around the time on the referendum on abortion, even Ireland has a long history of disability rights, when we had our abortion referendum, there wasn't any feminist or groups that were engaged specifically on this issue and they had to be created. A lot of the time when we need to say we need to

include disabled people, we need to see if there is a disabled community that is able to participate, and they need to be supported.

Milton talked about eugenics being a current issue. Over the last four or seven years, we've seen several attempts for further laws to allow for the involuntary stabilization of disabled people.

In the Netherlands where the disability movement might not necessarily be strongly engaged in those issues, this law passed and we now have further involuntary sterilization of disabled people.

In Indonesia where there is a strong disability feminist movement, the law that was introduced which would have allowed for further sterilizations of disabled people failed. That provision was removed because they were able to oppose it effectively.

Disabled people need the space to actually unpack, to be able to engage, unpack and have these conversations themselves within their own movements. That is something that is really important because if you look at things like abortion or some of these other issues, they are particularly contested spaces for disabled people to exist in.

Disabled people are not a monolith. Disabled people are rarely only disabled; they have other identities that might impact how they feel about the specific issues.

I recognize that that took way more time than I thought it would, I will cut it short and look at what coalitions need to happen because it is quite exciting to see the coalitions happening around the Missing Voices Initiative, but also other coalitions that exist in this space where you see people working across movements.

It is not enough to simply say that we want to include disabled people or we want to include marginalized voices, there needs to be some mechanism to ensure that we are doing this effectively—just one is to ensure that access is met without controversy or a fight.

We are seeing a massive move right now towards moving back to in person events without facilitating hybrid. It is quite nice to be online without having to argue that as an access need. Although no one wants bring me from New Zealand, to be fair, it is way too far away. The actual buildings that we use, physical access, language interpretation, but also resources for people who are more marginalized within the disability community. Easy to read is very rarely produced for these kinds of events.

It would be great to see more, particularly given what Larkin said earlier, to see more inclusion of people with IDD. We also need to go beyond tokenistic involvement.

A lot of the time, we look for that acceptable person and this is kind of true across groups. Look for that acceptable, often tokenistic person who may not be connected with their community. I think that this is something that is really important, particularly that representation alone is insufficient if someone is not connected with the wider community and isn't necessarily representing the voices of that wider community. And I think this is where organizations of persons with disabilities and other activist collectives need to be included, rather than just single individual voices.

The last thing I'm going to touch on because I'm totally out of time is that non-disabled people also have to do the work. This is something that's been clear throughout the work I've done on reproductive

justice and disability, where they might be happy to argue for what they already believe in terms of disability rights, that if you want to include disabled people within that movement, you also have to have some of those uncomfortable conversations with themselves. Larkin touched on this really well earlier when they talked about the different biases that people have, they may not have ever interrogated before and that just are a consequence of living in the world in which we live.

People who are aiming to include disability also have to have those uncomfortable conversations and see where their biases are and make sure that they do recognize the equal dignity and inherent worth of disabled people. So I'm totally out of time. I'm sorry that that ended up being a bit of a rush job. Apologies.

KATIE HASSON:

Thanks so much, Maria. As we've done on the other panels, I would like to give each of the panelists a chance to respond to what they've heard from the other speakers. I think we have some amazing themes here along the lines of how centering marginalized voices can change the conversation but also that it requires a certain level of challenging current thinking. But there is also a lot of exciting and challenging work in coalition building. I would love to hear from Isabelle first, then Milton, then Maria.

Perhaps, one or two minutes of response. Thank you.

ISABELLE BARTRAM:

Thank you. I wanted to say that Milton's remarks really resonated with me in the sense that what he said about we need to change the framing of eugenics. It is not just the historical thing of the past but that there are people today that were affected by eugenics and still are affected.

Because often in debates on this topic it is seen as something that happened before, but now it is something completely else. When I talk about the subject in Germany, eugenics was very much talked about like something from the Third Reich, that happened during World War II. It is very hard to get it into conversations. Milton is very right, there are universal elements of these eugenics ideas that persist today.

To what Maria said, I found it interesting, the point of how can disability communities be effectively included. This thing that there needs to be a disability rights movement to connect to. If it is not there, then you have to do the work of activating people.

My organization did this successfully in regarding to noninvasive prenatal testing, but on this topic I found it hard, because it is such a supposedly abstract topic, to really get a disability rights movement or organization involved to see that this is an important issue. I want to get better on this, so this really spoke to me.

KATIE HASSON:

Thank you, Isabelle. Milton?

MILTON REYNOLDS:

Yes, so there was a question in the box asking about the shift of rhetoric away from racism and it is very intentional. The purpose is to help people think about the context in which these ideas are being generated.

So briefly, the challenge in the United States of racism in the post-war period is framed as an individual, moral or ethical framing, rather than being able to understand systems and structures that assign differential value to people and normalize extractive ideologies and eliminationist ideologies.

The shift in rhetoric is actually really important. It's important in terms of the work I do because even the notion of the individual sort of robs people of their agency. When we talk about racialization and identification, we can also speak to how different communities have navigated that and the kinds of knowledge stores, skills, and competencies that are developed in these processes of navigation.

It is our shared understanding of each others' struggled histories, struggled knowledge that make us more powerful as a collective. So organizing efforts have to be intersectional, we have to bring different people to the table. Not because we want "all of the right faces in all the right places" but because there are deep stores of knowledge and strategies rooted in those different communities' struggles throughout history.

We do not have to reinvent the wheel, but we have to create the mechanisms and the structures that provide the resources for these sustained conversations so that we can build relational capital as well as intellectual capital together. We're going to need because these issues are coming down the pike. They are here already so how do we think together collectively and confront this juggernaut which has never gone away in the first place?

I'll leave it at that and will pass it over to Maria.

MARIA NÍ FLATHARTA:

Yes, I'm thinking about specific communities as well. When you're looking at individual communities who are supposed to be represented so they themselves are intersectional. A lot of times, we have situations where you have what ends up being a very privileged representation of the specific marginalized group if that's possibly the right way to say that.

You will have organizations that will tend to be white, wealthy people from a marginalized group. I say this is a white, financially stable person from a marginalized group rather than a community that is fully representative of the diversity of the entire community.

I think that really impacts things. A lot of these struggles are shared struggles. If we look at sterilization, if we look at forced abortions or coerced abortions, if we look at things from a justice perspective these are all incredibly connected, and I think that is something we need to be mindful of. I really like what Milton said about that about making sure it is not just the right faces at the table but making sure everyone is really meaningfully there.

KATIE HASSON:

Thanks, Maria. There is a question from the Q&A about how coalition building between disabled activist groups and reproductive rights and justice can be strengthened. I wonder if you want to comment on that briefly?

MARIA NÍ FLATHARTA:

Yes. It is a really, really hard one. I do think that one, it is hard for disability rights organizations and disability movements to focus a lot on reproductive justice because they tend to be overstretched organizations.

There is not a single issue in the world that is not a disability rights issue. Basically, you can find a disability rights angle on pretty much everything because disability is everywhere.

No matter how hard they try, they will not actually eradicate us because they will probably create more of us. Anyway, the point is, it's really hard for disability rights movements to always be engaging.

What seems to need to happen for reproductive rights to do it? It seems to require a disability rights movement, which is happy to constantly be effectively annoying themselves onto that table, constantly putting up their hands, constantly raising their issues, sometimes in really uncomfortable spaces.

And I think where you have disability rights organizations, like the one I am from, that do focus a lot on reproductive justice issues, it is an uncomfortable space for people to have to work in.

I've seen a few examples of people from the reproductive rights movement who truly, really engaged and have done the work on disability while being non-disabled. I have yet to figure out a way to get the broader reproductive rights movement to really do that work. And I'm not necessarily sure we are there yet.

I think the pressure to feel like you are saying the right things and have the right faces at the table sometimes does help, but it is not sufficient to actually get people to do the work and I think we are going to struggle with that.

So basically, more feminist reproductive rights focused disabled people, but that is the only thing I found that has worked.

KATIE HASSON:

Thanks, Maria. Unfortunately we have hit the end of our discussion time already. I'm sorry to say that. I want to thank this panel. Especially Isabelle, Milton, and Maria for this great forward-looking discussion that also helps people watching today find ways to engage on these issues and to see some promising paths forward, as well as challenges that will come up along the way.

But we hope that those of you watching today will join in, just to recap some of the specifically international summit-focused events that are coming up at the coalitions that are ongoing and getting off the ground now. We heard about an international declaration against legalization of heritable genetic modification that is open for signatures.

There are also several other upcoming events that you can participate in next weekend. There is an in-person heritable genome editing and equality conference if you will be in London. And the group Stop

Designer Babies is organizing a hybrid teach-in, also this weekend. We are putting links about these events in the chat for you.

Next Tuesday evening, the Global Observatory on Genome Editing is hosting another hybrid convening. If you do not catch it in the chat, all of that information is available on the information page for this symposium, and that is also where you'll find the videos and transcripts for this symposium, when it goes up later this week.

In addition to participating in these events, this is something that we at CGS are so excited about, to see this convergence of multiple events coming from groups with multiple perspectives, converging around the summit.

This has not happened before and we hope that you will jump in and add to this momentum and let that carry you over into taking the perspectives, the challenging questions that you have encountered in our event and these others with you to participate virtually or in person at the International Summit next week, March 6 through March 8.

Registration for online participation in that is still open. You can also follow CGS on our social media channels where we will be keeping you up to date on what is going on during these events.

And finally, I just want to let you know about a third webinar in our Missing Voices series coming up on March 28. This will be "Feminist Intersections: Heritable Genome Editing at a Crossroads." Registration for that is open.

As we close, I want to thank our fantastic roster of speakers today, as well as yesterday. I want to give special thanks to the CGS crew, especially Emma McDonald, who has been getting the word out about this event and keeping the Zoom tech running smoothly behind the scenes.

And also to Emily Galpern for her work in organizing as well as moderating today.

Thank you to our ASL interpreters and our captioners. And thank you to all of you for watching, for commenting, connecting, engaging, submitting questions. We think you have really made this a great event. We hope you will all keep in touch and keep these conversations going. Thank you so much, goodbye.