# TRANSCRIPT

# Reproductive and Genetic Justice: Bridging the Resource and Knowledge Gap May 23, 2024

Hosted by Rebecca Cokley, Ford Foundation US Disability Rights Program Officer with Black Women for Wellness (BWW), Center for Genetics and Society (CGS), Disability Rights Education and Defense Fund (DREDF), & National Center for Lesbian Rights (NCLR)

Moderated by Kavita N. Ramdas, Independent Feminist Advocate and Philanthropic Advisor, and Founder, KNR Sisters

# Speakers:

Katie Hasson, Associate Director, CGS Nesta N. Johnson, Family Law Staff Attorney, NCLR Onyemma Obiekea, Policy Director, BWW Silvia Yee, Public Policy Director, DREDF

# REBECCA COKLEY:

Good morning and good afternoon everyone. My name is Rebecca Cokley, I am the U.S. Disability Rights program officer at the Ford Foundation. My pronouns are she/her. I am coming to you from Piscataway land, here in Washington DC. But in this exact moment I am sitting in the Acela lounge at the Amtrak station here at Union Station which is not where I was planning on being, but you know, we work from where we work from.

I have shoulder length red hair, a glorious abundance of freckles and I'm wearing a cobalt blue suit today. I would like to take a moment to welcome all of the people with disabilities and chronic illnesses who have joined us today. Whether or not it is safe for you to identify publicly or professionally, it matters that you are here. Our community is infinitely strengthened by your presence and we see you and meet you where you are.

It is a pleasure to be here with all of you today, for this conversation on reproductive and genetic justice. The moment for this work really and truly is now, and today has actually been formally dedicated as Disability Reproductive Equity day.

When talking about reproductive and genetic justice, I reflect on the values that our CEO Darren Walker talks about whenever the subject of eugenics comes up. That we have a need to embrace risk and reflect honesty. And this is particularly important for the Ford Foundation as, frankly, one of the principal funders of the eugenics movement.

And let's be real, the movement itself will not be defeated by one voice or one organization, but by a collective of multiple organizations and communities coming together to push back on antiquated ideas, grounded in values that do not support today's multiracial-cross-disability democracy.

That's why it's so exciting to see the Center for Genetics and Society, Black Women for Wellness, the Disability Rights in Education and Defense Fund, and the National Center for

Lesbian Rights, working together on this issue, and why Ford is thrilled to be a funder of this work.

And now, I know you after you hear from the various speakers today, you will no doubt find yourself excited and compelled to join us. And with that, I am going to turn this over to one of my absolute favorite people, who I've got to spend time with over the last three weeks, and we may or may not be going on a road show together, so cross your fingers on that, the amazing Kavita. Kavita, take us away.

## **KAVITA RAMDAS:**

Salaam, namaste, and thank-you, my dear Rebecca, I'm so delighted to be here. On behalf of all of the organizations here, I want to express huge appreciation to you and my former boss, Darren Walker, for co-sponsoring this one-of-a-kind event. We are so grateful for your efforts to bring concerns about the social justice impacts of genetic and reproductive technologies to the public and to the funding world.

I'm Kavita N. Ramdas. I use she/her pronouns. I'm coming to you from Lenape land in Inwood, popularly known as upstate Manhattan. I have silvery mid-length hair, gold hoop earrings and I'm wearing a red-and-black patterned blouse and I have a bit of a pointy chin and my background is blurred. I work as an independent consultant, a philanthropic advisor, and I've been a feminist advocate for many years now, focused on issues of advancing gender justice, disability rights access, reproductive justice and equity for all.

This conversation is especially important to me because it ties together issues that are often considered by funders in separate silos! But in fact, it requires all of us to be able to consider and support this work by transcending those silos.

Let me tell you little bit about how today is going to work. I'm going to start the conversation by posing a question to each of our extraordinary speakers, I'm going to name them: Nesta, Silvia, Onyemma, and Katie for a brief response. We will follow that with a moderated discussion among the panelists, leaving the audience with plenty of time to ask questions at the end. I'm gonna ask each of you to acknowledge that we are recording this webinar, and that we will share the recording with everyone who is registered and is on the call with us.

Captioning is available. Please click the "CC" button at the bottom of your screen or view the transcript externally using the link in the chat. Many thanks to our captioners and to our ASL interpreters, Holly and Sharon, who are with us.

Please use the chat for any questions or comments for the panel and we will also use the chat to share links to other resources and make those resources available after the event.

As we get started, could all of you who joined us, please introduce yourselves in the chat with your affiliation, the areas you focus on, and the location from where you are joining us. Our speakers will then briefly introduce themselves as they speak, when they first speak, and we will drop links with their very impressive bios in the chat.

To begin with, I'm going to ask each of them to talk from the perspective of their own organizations and from the movements that they are representing here. I'm going to ask each of you, what are the pressing issues, as you see them, related to this critical question of reproductive and genetic justice? What feels really urgent about this moment? And can you

speak to it from both your assessment of this work professionally, but also anything personal you'd like to add at this moment?

And we're going to start with you, Nesta. Each person will have five minutes and I will waive an imaginary flower at you. Please go ahead.

#### **NESTA JOHNSON:**

Thank you. Hi y'all. My name is Nesta Johnson. I use she/her pronouns and I'm a LGBTQ+ family law attorney with the National Center for Lesbian Rights.

I live and work on unceded land of the Susquehannock and Lenni Lenape peoples in Pennsylvania. I am a medium-sized fem-presenting person with short curly black hair and brown eyes, wearing an aquamarine blouse, fuchsia shawl, and cameo necklace. I have a pretty cool pride flag virtual background. Thank you so much for inviting me to answer this question and I'm so grateful to have this opportunity to speak with all of you today.

I want to share a little about my own background in answering this question. I've been with NCLR since 2020. Before that, I represented children and youth in family courts and appellate courts, mostly in so-called "child welfare cases," often termed "family regulation cases" by lived experience advocates.

The themes that we are discussing today are woven into the structure of that system. Controlling people's bodies and relationships, targeting people who are poor, queer, black, brown, disabled or pregnant, and disguising harm and exploitation as help.

I left that work because I could no longer play a part in a system that diverted resources away from families, although the vast majority of cases did not involve abuse, but rather so-called neglect, essentially poverty, and could have been resolved by providing resources directly to those families — without red tape, judgment, surveillance and trauma.

I witnessed firsthand the sorry results of so-called "better safe than sorry" approaches which function to create a presumption of guilt, despite the simple and obvious truth that most parents love their children and want the best for them. It may seem as though I am straying from the topic that brings us all here today, but that simple and obvious truth, that most parents love their children and want the best for them, is the reason why it is so crucial, while this brief window of opportunity remains open to us, to coordinate resistance to the surge in efforts to control and criminalize pregnant people through fetal personhood legislation and restrictions on access to healthcare; to engage with the implications of pro-natalist policies that recognize a government interest in reproduction; and to prevent the development and deployment of eugenic technologies.

Parents love their children and want what's best for them. We live in a society which is deeply ableist, racist, sexist, and queerphobic. No parent dreams of a future of discrimination, stigmatization or criminalization for their child. If parents have access to technologies that would allow them to manipulate their embryo's genomes, to convey an advantage or to remove a perceived disadvantage, then many parents will use those technologies—in the name of love. And in the aggregate, those choices will replicate and exacerbate the hate and inequity that plague our society.

The narrative that people should change to fit society and not the reverse cannot go unchallenged. And that is why it is so crucial to have a coalition representing marginalized voices, with the capacity and resources to ensure that whenever and wherever academics, policymakers, and professionals gather, to discuss the "promise and peril" of technologies which mostly promise profit for the privileged and peril for the rest, our communities are spoken for and not just spoken of or exploited as potential consumers of these technologies.

We dream of a future in which no parent need fear that their child will be disadvantaged by the body or the identity that they inhabit. We dream of a society in which loving and wanting the best for your child means letting them be exactly who they are.

We dream of a world that sees the beauty and worth in every individual. Because every one of us is born perfect. Ase. And back to you, thanks so much.

#### **KAVITA RAMDAS:**

Àṣẹ, Nesta. Silvia, I am so grateful that you have volunteered to be the next in our amazing lineup. So, over to you.

## SILVIA YEE:

Thank you, Kavita and thank you so much Nesta. My name is Silvia Yee, I use she/her pronouns and I work with Disability Rights Education and Defense Fund. I also live and work on ancestral lands that were usually protected by the confederated villages of the Xučyun and on the territory of Huichun, the original landscape of the Chochenyo-speaking Ohlone people whose successors are the sovereign Verona Band of Alameda County.

I have short black hair, I am wearing glasses and earrings. I have on a denim dress and my background is blurred. My skin is tanned. And I believe that's it.

I wanted to begin by emphasizing something that is not always recognized, and that's that the disability community's work on this subject, on this area of reproductive justice and genetic justice, has never been about legally, economically or even socially, constraining abortion or a person's right to choose whether or not to give birth or have children.

If that were not the case, our community would arguably be pleased with some of the decisions that have come down from the US Supreme Court and other federal and state courts over the past few years. Decisions like Dobbs have directly constrained the right to choose whether or not to carry a pregnancy to term and they have done so without workable exceptions, pregnancy, disability-rooted or otherwise.

This has created a patchwork of laws across the country when it comes to receiving full reproductive and abortion services. The decisions have created fear and anxiety for everyone who wants to have a baby and faces the reality of term and birth complications that implicate their health, their ability to carry future children to term and the capacity to plan for a family. And often, it is people with disabilities who may have birth complications that implicate their health and their ability to carry future children to term and so forth.

Instead, every disability advocate I know has supported and worked with reproductive justice organizations and advocates here in California and across the country to ensure that reproductive services are fully accessible to people with disabilities, including both abortion services and assisted reproductive services.

Given how much ableism parents with disabilities, including people with disabilities of color and who are LGBTQ+, face when it comes to their ability to become parents and to form families, there is a natural alliance here.

I wanted to just highlight a recent amicus brief that DREDF, my organization, has brought, supporting the appeal of a young father who may or may not have a specific diagnosis but who has a genetic medical condition that results in clearly visible physical difference. He is small, about 60 pounds, and like many people with physical disabilities, he has supports. He has supports in place that allow him to live a full life in this community. He lives with a family member in his household.

He changed that community, moving more than halfway across the country to establish a household in California because he learned that his son was involved in dependency proceedings, his son had been living with his son's mother. The father works. He has the current financial means to take care of his son. His evaluations from the LA Department of Children and Family Services showed that he demonstrated appropriate care for his son. But the court nevertheless ordered termination of the father's reunification services and scheduled a hearing to terminate his parental rights.

My organization came in at the point of an appeal and wrote an amicus brief. The court had assumed that the father had cognitive disabilities despite the lack of any testing on that point. The testing showed otherwise, and the court had elevated concerns about the father not driving and being outpaced in size as his son grew and the son also has disabilities.

It seems that the original court decided that a 60-pound man with a genetic condition would be unable to be an effective father—he looks weak, his child will grow larger than him, his child is disabled and needs more control, not less. In other words, he can't be the father that society expects, and these are the same accusations that have been leveled for years at LGBTQ+ parents and tossed at black parents and other parents of color.

So, the disability community has never wanted to force a certain choice but has wanted to emphasize that real choice involves freedom from feeling like one has no choice. What DREDF wants is to ensure that people who can give birth and their families have relevant and full information about what it means to have a child with a disability. About what it means for your family. About what it's like to raise a child with a disability, given the current state of the US healthcare system. We want parents to understand what genetic testing about a fetus's chances of having a disability actually means for the potential future family. And we want this knowledge to be readily available and stripped of stereotypes about the capacity and future of people with disabilities.

And we know there are many concerns that unite us in our work and our causes. There are millions of children, for example, that have been disenrolled from Medicaid upon the reinstatement of re-determining Medicaid eligibility after the pandemic stopped the procedure for about four years. For example, there are eight states that have disenrolled so many children from Medicaid in 2023 that they have fewer children enrolled than they did prior to the pandemic.

KAVITA RAMDAS: Time to wrap up soon.

#### SILVIA YEE:

OK, thank you. Thank you very much. We also have in common great concerns about genetic engineering and the unknown risks to people carrying the fetus, to the fetus, and the social implications of a scientifically and socially engineered society. Who has access to the technology, who controls it? What does the perfect human being look like? We think it will not look like us.

The disability community knows that we live in societies that have long sought to control the bodies and minds of people with disabilities, the bodies of people who can become pregnant and the transgressive bodies of people who don't look and act typical. Fighting this unjust control is what unites all of us here. Thank you, Kavita, back to you.

# **KAVITA RAMDAS:**

Think you so much, Silvia, and thank you everybody for joining us. If you're joining us just recently, please put your name, your pronouns and the organization and location that you're calling from, into the chat. I am now going to turn to our third speaker, Onyemma. Onyemma, over to you.

#### ONYEMMA OBIEKEA:

Thank you, Kavita. Good morning everyone, my name is Onyemma Obiekea. I use she/her pronouns, and I'm a policy director at Black Women for Wellness. Forgive me, of course the moment I start speaking, construction in the background takes off, so forgive me. I'm currently on the unceded territory of Tongva land, also known as Los Angeles, California. I'm a black woman with two flat twists in her hair. I'm wearing a powder blue top with pleats and thick framed glasses in what the brand calls marzipan tortoise, so do with that what you will. I'll note that I get my compliments on them, so I'm always pleased when functionality has a style moment as well.

As I mentioned, I work with an organization called Black Women for Wellness and we are a reproductive justice organization committed to the empowerment, health and well-being of black women and girls. So I will be sharing from that perspective. I generally like to grant everyone in the definition and tenets of reproductive justice, to make clear that it is a framework and has a meaning, a perspective.

And also, as this year marks its 30th anniversary, I steal every opportunity to share a little bit about what it means. So as I noted, it is important to note that it is a framework established by black women in the 90s and there exists a significant amount of scholarship, writing, and just work to develop it. So the framework has a particular definition when we say reproductive justice, or RJ, we mean a particular thing.

An evolutionary theory, RJ is inherently intersectional, meaning that it recognizes the identities that we occupy and works to address unique oppressions that work together to adversely impact our lives. The tenets of RJ are the right to have a child, the right to not have a child, and in the event that you do have a child, that you have the resources and living conditions necessary to raise or parent that child safely and with dignity. Then there's also the right to bodily autonomy and sexual pleasure.

We situate our conversation, concerns, and questions around assisted reproductive technology within this right to have a child or the right to parent. We think about the social

and societal constraints that prevent a person from making informed decisions about their reproduction, in this case, having a child.

As we think about the impact of race and the right to have a child or create families by engaging technological means, is important to note that black women are nearly twice as likely to suffer from infertility as white women. Yet, black women are half as likely to seek assistance with infertility. Those most likely to use IVF are not those most likely to suffer infertility, you know, which tend to be black, low income, folks with low socioeconomic status. This cannot be understood without acknowledging the history of reproductive oppression and control of black bodies, particularly of black women's bodies dating back to slavery when black women were bred to have as many children as possible.

So, when they were no longer needed to supply free labor, and then there became a shift to sort of tempering notions around our hypersexuality and reducing our so-called "burden on society" leading to an era of state-sanctioned sterilization of black women and Native American women, and disabled folks—which came to be known as the Mississippi appendectomies.

All of this has impacts on our relationship to and interaction with reproductive technologies. Thinking about these intersections, I will focus on barriers to access, although I know that there are many concerns as it impacts assistive reproductive technology and race. So, when thinking about barriers, we have the accessibility barriers, right, those look like economic barriers, assisted reproductive technology generally is cost prohibitive. It is so expensive, right?

So, with the expenses of these procedures and low success rates, this means that many patients undergo several procedures, multiple times, before having a baby or giving up entirely, right? So, there has to be ... you have to be able to make a certain amount and considering the disparities in pay, in wages, oh goodness ... OK, I've got one minute left and I'm just talking. So, we've got economic barriers, patchwork or lack of insurance coverage, and lack of Medicaid coverage which then uplifts or determines who has access to these technologies.

There's the issue of racial steering, there is evidence of fertility doctors and clinics sort of deliberately steering patients away from reproductive technologies. Racism, biases, and ideologies are very present and don't stop at the door of the clinical setting. And that impacts whether appropriate fertility treatment is offered to black birthing people or BIPOC birthing people; it informs notions of whether a mom is capable of giving birth and that informs certain diagnoses, treatments, referrals and recommendations.

There are self-imposed sort-of barriers where based on the shame and stigma around infertility, from internalized stereotypes or tropes of black women being hyper-fertile. That impacts whether or not we are ready to admit or seek care for infertility, right, we don't want to admit that.

There's also a skepticism and a healthy and founded distrust of the medical system that prevents us from, or that makes us reticent to use or seek out assisted reproductive technologies.

**KAVITA RAMDAS:** 

Oyeema, I'm going to come back to you and we will expand on some of these as we move ahead.

I'm going to let Katie do her opening comments, and we are going to come back to make sure that we get... There is so much that each of you have to be able to offer that I'm really looking forward to it but I will make sure we get these opening comments out and then I will come back and dig into this meat a little bit more.

Sorry to interrupt you there.

Katie, may I turn it over to you from CGS?

# KATIE HASSON:

Yes. Thank you. And thank you to all of the speakers who have made such great points already.

I am Katie Hasson, I use she/her pronouns, I am the Associate Director of the Center for Genetics and Society. I'm a woman in my 40s with pale skin, curly red hair to my shoulders, wearing clear framed glasses and a gray blazer.

I am speaking today from San Francisco, on the unceded land of the Ramaytush Ohlone.

For more than 20 years, CGS has been working to bring social justice and human rights into public and policy conversations about genetic and reproductive technologies. And that's because of the kinds of concerns that you've just heard. That LGBTQ communities will not have access to technologies to form families, or that genetic and reproductive technologies will lead to further control and restriction of women of color's reproductive autonomy. Or that existing and future reproductive technologies would be used to deselect or edit out people with disabilities.

Addressing these concerns is key to making sure that these technologies are used in ways that support, rather than undermine, our prospects for an equitable and inclusive future. But when it comes time to make decisions about whether, how or by whom genetic technologies will be used in reproduction, it is scientists, bioethicists, even startup founders, the fertility industry, who get called to the table to shape the conversation with policymakers. And that means that people who would be most impacted by these technologies are rarely there to raise these concerns.

So, we make the case that it's not just science and ethics at stake here, but social justice. And as you've heard, when we talk about reproductive and genetic justice, we're talking about the ways reproduction and bodies have been stigmatized and controlled, talking about eugenics and reproductive oppression, talking about biological and genetic determinism, and these are core issues of racial, reproductive, LGBTQ, and disability rights and justice.

And we are in a moment where we are seeing intensified attacks on reproductive rights and LGBTQ people and communities. And we're seeing resurgences of blatant eugenics, talk of good genes or poisoning the blood or pro-natalism for some, as a remedy for fear of population decline. Genetic and reproductive technologies are another arena where we are going to see this play out, in determining whose lives are values, whose reproduction is encouraged or curtailed, and whose families are recognized and supported.

And the recent Alabama Supreme Court ruling on IVF has made very clear how reproductive technologies are tied up in these fights and it has revealed some of the difficult political terrain. We are increasingly heading toward a world where basic reproductive and bodily autonomy is being denied to many women and birthing people, while a select few are sold technologies that promise ever more control of reproduction and even enhancement of future offspring.

So, we need to be able to advocate for abortion rights and access without using ableist arguments that devalue the lives of people with disabilities. We need to maintain and expand access to IVF and abortion, not carve IVF out as an exception in ways that further stigmatize abortion.

And new technologies that are coming down the road make this even more essential. For example, well-funded startups are currently working to create human eggs and sperm in the lab, starting from just a skin cell. They are selling the enticing promise that it will allow LGBTQ couples to have fully genetically related children. But they're also downplaying the significant health and safety risks it would entail, as well as the ways it would vastly increase the ability to genetically test and select embryos, or even modify the DNA of future children.

So, we urgently need the perspectives you're hearing here in this conversation. CGS works to bring together advocates and scholars across fields and sectors to build the relationships, the knowledge, and the capacity that enables social justice advocates to join and to lead these conversations.

A few really quick examples, our most recent collaboration, the Gender Justice and Disability Rights Coalition of our Missing Voices Initiative, which DREDF is a member of, has drafted a groundbreaking set of social justice and human rights principles for governing the potential use of gene editing and reproduction. This is the first document to spell out the foundational social justice concerns about this technology. We've also previously collaborated with Black Women for Wellness to produce an info sheet on genetic editing as a reproductive justice issue and with NCLR to map the complicated patchwork of surrogacy laws in the US.

So, building on this work to meet the current challenges and those that are coming means our organizations need the resources to forge new collaborations, to build capacity among groups in our movements and to organize and be ready to take on these issues collaboratively in ways that don't undermine each other's goals.

## **KAVITA RAMDAS:**

Thank you so much, Katie, and thank you everybody else. We are, as always, a little bit short of time, but I wanted to say a few words and ask if each of you might reflect upon this.

At the time that I was a funder at the Open Society Foundations Women's Rights program, our support of the work that an organization like CGS did was seen as being very distinct and a bit avant-garde, and, well, what we really have to do right now is focus on winning the vote, for whatever the particular issue, whatever particular date it was. I'd love for each of you to talk to the fact that we are in an election year, funders are feeling often very pushed and driven to feel like what we actually have to do is preserve the right to abortion or we can only focus on this one issue. Rebecca began by explaining the core concepts of intersectionality

that she as a disability rights activist at the Ford Foundation has been using and why she supports this kind of work.

But I think we also heard from Onyemma who talked to us about what the fundamental principles of reproductive justice are. What are each of you seeing, in your own experiences, as you try to seek the kind of sustained long-term and operational support that your organizations need, not only to do your own work but really to be able to do this work, as you said, collaboratively, and building these important coalitions? Take a few minutes to speak to that because I think often funders' responses might be "Oh, this sounds very sci-fi, why should we be doing research on CRISPR technology? That doesn't sound as urgent as funding Planned Parenthood to get out the vote in 2024," for example. So maybe I will start back to front here and Onyemma maybe I will ask you to go first and then come to Nesta to speak a little bit to the issues that we just heard and then I will end with Silvia and Katie again.

## ONYEMMA OBIEKEA:

Thank you, Kavita. I deeply appreciate what everyone has said and I appreciate the question. You know, it is an election year, and these are very stark times. So, there is a focus on getting out the vote. There is a focus, a narrow focus on, you know, we understand that reproductive rights are on the ballot, but there is a narrow focus as to what those rights are and I think that we have to think expansively and intersectionally around what that means and what that can look like and who that stands to impact, right, so that we don't make certain mistakes that we made in the past by leaving out a justice analysis in thinking about reproductive rights.

When we talk about abortion rights, for instance, we talk about Roe as being the floor and not the ceiling simply because it didn't contemplate the lives of all those, right, who would be accessing abortion care, and there was sort of this "Wait hold on, let's just address this issue, and then we'll come back to it," and what instead happened was a 50-year strategic erosion of these particular rights. I think learning from lessons past, we have to be intentional around how we're thinking about reproduction and be intentional about injecting a justice lens, and a justice frame towards ensuring access for all communities.

My thought is we can't just in the name of moving and garnering some kind of movement leave folks behind. We did that with voting rights, for instance, right, we know the suffragette movement allowed for only white women to vote, black women and women of color didn't really have access to voting until 1964. How do we take lessons from different movements that have so often left folks behind, and do something different to ensure that equitable outcomes and reproductive autonomy and the ability to realize or self-determine is available for all of our communities.

And so, that's what I urge folks to think about when we are thinking about funding, repro rights or repro healthcare for instance, who does it impact. I know that sounds really vague but I'm hoping that kind of offers some thoughts.

Oh, Kavita you're on mute.

## **KAVITA RAMDAS:**

Thank you, sorry. And I think that's very important also, I'd like to be able to get some others' thoughts on that, but I think the important takeaway that I'm hearing you say is that we do

tend in the funding world, to be driven, as in many other sectors, by the urgency of now, and yet I think what you are reminding us with in terms of looking back at history, is that if we go only with the urgency of now, I think we are failing to see what actually all four of your organizations have so wonderfully manifested here which is that if you with your limited budgets and resources are finding time to take the effort to build coalition and to do this work in partnership, then we in the funding world must do better also to be able to think about how we build those bridges and how we support organizations, not one against the other or one as a priority and others not. Nesta, let me go to you and see if you want to add something to this conversation.

#### **NESTA JOHNSON:**

Sure. I think in a way, this broad topic area is very familiar to NCLR's funders because relationships and families are and always have been at the heart of our work since our founding in the 70s. And we've done a lot of work around ART and access. I'm proud to say that we've always prioritized the needs and interests, not just of intended parents, but of everybody including gamete donors and people acting as surrogates.

That said, I do think that it is easy to get caught up in addressing specific harms, particularly at a time of an attack on our community, and I like to garden, you know, bad roots grow strange fruits, and I think the temptation is very much to sort of weed whack and to not get in and to address the narratives and the values that are really at the heart of all of these efforts that pop up and spoil our garden.

## **KAVITA RAMDAS:**

Thank you for that. Very beautifully put and I think an analogy that also, I think one of the things Silvia began with was by disabusing us of the notion that the disability rights community is somehow in opposition to the reproductive justice and reproductive rights community. So, Silvia, is there something you might want to add? Sometimes we are accused of saying "to focus on these technologies is too sci-fi, it's too technical, why should social justice organizations or rights organizations be focusing on these issues?" Would you like to add anything to this conversation, before I ask Katie to weigh in as well?

#### SILVIA YEE:

I have just been thinking about how long that, pardon the pun, the gestation period of climate justice has been.

KAVITA RAMDAS: That's a great analogy.

# SILVIA YEE:

And other areas that have been really urgent, or AI: 10 years ago, were we all thinking about "Hmm, what's going to happen with artificial intelligence?" Maybe we thought about it, but it was in reading our fiction, it wasn't really thinking about how it might impact on our actual work and how it will deeply affect relationships — not just between our organizations but in our own lives with our families, with our coworkers, with our government, and so forth. And yet, it's truly sort of a huge issue out there.

I think the tyranny of urgency really does take our minds off these very important things, growing things. I'm very grateful to CGS for working in the area it works, because for my organization, our capacity to have kept focus on it for the last 15 years is very limited but because we can work with CGS, it has helped us to, sort of, just keep one eye, knowing that

things are happening. And the relationship between funders and organizations working on social justice, it's a little like creeping forward, one will learn something and then they will put maybe a little money towards it, and then another organization will be like, "Yes, we should put... Maybe our fellow could be looking at this a little bit," but it takes a long time to sort of flower. That creeping is so important because when the problems or the issues finally bloom upon all of us, the work that we've done, even if it hasn't been the main part of our focus, is critical to build on. At least we've made a beginning.

## **KAVITA RAMDAS:**

Thank you for that. Katie, is there something you'd like to add before — I know we are opening up the space for questions. Time flies when you're having fun. It's that time.

# KATIE HASSON:

It does! I'll say two quick things, one, to the urgency of now and the political moment that we are in. The quotes I referenced earlier about good genes and poisoning the blood, I mean that was Trump. It doesn't get more in-your-face election-year than that, and we can see direct links there to policy and anti-immigration, great replacement theory. These all have their roots in eugenics and are part of the resurgence of blatant eugenics in our politics today.

So, these issues are here. They are urgent now but also to the sci-fi, the seeming sci-fi nature of these issues, it is so great, Silvia that you brought up AI because I was thinking about the same thing. It's becoming a lot more common to talk about AI as a social justice issue, right, with advocates highlighting how these technologies have been developed and put into use in ways that reflect existing biases and inequities, and to reinforce and multiply them. Right, but even before AI was everywhere like it is right now, it was already working its way into systems. It was determining sentencing and criminal justice, and it was, you know, making unequal current car insurance rates and things like that, before we really recognized how it was working.

And I think there are parallels to that with genetic and reproductive technologies.

# **KAVITA RAMDAS:**

Let's look at that for a second.

Rebecca also opened with reminding us about the conversation that Darren and John Palfrey of the MacArthur Foundation had on the issue of eugenics, the critical ways in which these technologies intersect with concerns about eugenics. And for any of you haven't seen the movie "Origin" by Ava DuVernay based on the book "Caste" by Isabel Wilkinson, and then right after that, I suggest you watch the movie called "Zone of Interest" where you watch a nation, Germany, that actually used eugenics, that in fact it had learned how to do that and how to structure that from the United States and the experience of black people in the United States.

Talk to me a little bit about how you see your own organizations, the way you are, the spaces that you see these technologies interacting with your concerns about the kind of comment that Trump made, for example, and whether you are feeling that you are getting the acknowledgement and support that you need from your partners in the funding space, to actually ensure that we don't find ourselves unprepared to respond. I don't know who would like to go first.

Silvia, would you like to take that and then I can come to Nesta? You are on mute.

#### SILVIA YEE:

I thought I had just unmuted myself. I do think that one of things we are always thinking about is the degree to which ableist assumptions underlie so much of our policy and the way in which we do things. Of course, you want to get rid of disability, it is just the disability just inhibits what people can really be. And when you have that in your mind and your heart, you're making all kinds of decisions about social policy that you don't question.

So, I think that underlies so much. Directly taking it on is really challenging. But when you don't take it on at all, then you do just get people nodding along, they hear things that former President Trump says or that other right-wing authoritarian figures say and part of them thinks, "Maybe there is something to that, that sounds right, that's the problem."

It's always this red-herring finger-pointing, whether it's disability or other so-called "bad" things in society, and I think if we don't address that in some explicit way, it will always come back to haunt us.

#### **KAVITA RAMDAS:**

Nesta, is there anything you want to add to that?

# **NESTA JOHNSON:**

I am so glad that Silvia mentioned assumptions because I had a similar thought which is really that I think often, there aren't the resources to really investigate and interrogate the assumptions that underlie development of technologies like IVG, mentioned before, that could allow same-sex couples to have children genetically related to both partners, for example. Those assumptions privileged genetic relationships and assume that genetic parents are real parents and the best kind of parents when everybody here knows that parent is a verb and not just a noun.

## **KAVITA RAMDAS:**

Thank you. That is so well said. I can see Onyemma from her nodding that she wants to add something there.

#### ONYEMMA OBIEKEA:

Goodness, I don't know that I have much to add. I'm nodding because you are all taking me to church today. So, you know, it is like a service.

## **KAVITA RAMDAS:**

Onyemma, maybe something about, you are emphasizing this whole business of the cross-movement work and, are you finding that movement is also getting the kind of support and funding movements? Because, I think this is such a rich discussion but it is transgressive in the sense that is transgressing all of the normal boundaries of where you're supposed to fit, you don't fit in the disability rights portfolio, or in the racial justice portfolio, or the LGBTQ portfolio, or in the reproductive health portfolio. So, I'm curious as to what, do you have any advice for us on the whole question of how you promote this cross-movement work?

## ONYEMMA OBIEKEA:

That's interesting. I appreciate that question, Kavita. And in some of my thinking around this and hopefully, I'll come back to your question — I appreciate Katie for raising the great

replacement theory because I've been thinking about intersectionality about how all of these reproductive oppressions are interconnected.

In the RJ movement, we've been discussing the impacts of Christian nationalism and their motives for restricting abortion access, and we talk about how they are not concerned about black folks terminating their pregnancies, right, because the goal is to actually force white women to continue to give birth. It is to control their reproduction in that way, to sort of advance, or to sort of prevent this great replacement theory from coming to terms.

So, we see here in the abortion space, the anti-abortion movement is fueled by really ensuring that or increasing the population of white folks, yet here in the assisted reproductive technology space, we are seeing an effort to prevent undesired populations from having access to this technology, so as to limit their ability to procreate, right, regardless of the fact that they tend to suffer more so from infertility. But you have access to ART or reproductive technologies offered to communities that don't suffer that same disparity, and so you can even start to think expansively around reproductive health.

I guess my advice is to think expansively and think creatively around how these issues intersect with each other because I can guarantee you that they do and so, like one of the ways that you can support — like one aspect of the work is by encouraging and supporting collaborations and cross-movement collaborations and supporting the coming together of expertise, such that we can really advance the movement that goes back to again, not leaving folks behind.

#### **KAVITA RAMDAS:**

Thank you. You get the last word and I do see there is a hand up there from Nesta, so I will come back. Nesta, is it a direct follow-up as to what you just said or otherwise should I take Katie's comment or do you want to add something right now?

# **NESTA JOHNSON:**

Katie is welcome to go ahead either way.

#### **KAVITA RAMDAS:**

Why don't you go ahead. You have your hand up and then I'll go to Katie.

# **NESTA JOHNSON:**

This is sort of on how funders, really just to bake engagement of intersectional partners and lived expertise voices and sustainability into funding structure and deliverables. We are all here today because we all know each other, because we've all been trying to work together with what capacity we have to do so. The results, be comfortable with intangible results, but if you are going to structure with tangible deliverables, please provide time and resources, not only to develop or demonstrate X solution to Y problem, but to make X self-sustaining and require that Xs address and ameliorate the root causes of Ys and include lived experts in every stage and channel power and resources to those most impacted. It is hard to learn when you're hungry and that's why we need to give people fish and teach them to fish at the same time!

## **KAVITA RAMDAS:**

Amen. You were right, Onyemma, we are in church.

Katie, I'm going to let you take us home, I know people are going to have to leave in a few minutes, so I want to thank everyone who is here and appreciate my colleagues at CGS, at DREDF, at NCLR. This has been such an important collaboration for all of us.

Katie, please finish your thoughts on this and then we will wrap.

#### KATIE HASSON:

Wonderful. I can't say it better than Nesta (laughs). I can just give my version of it. I mean, CGS is here. We've been able to focus fully on these issues, right, as our issues, genetic and reproductive technologies. But we can't be the only ones out here doing this work and we have been so grateful and appreciative of our partners like the ones on this call with us, who are devoting significant time and energy to these issues without direct support or resources to do this work.

And as we continue to work together, as our collaborations are successful and we bring more organizations and more advocates into this work, we want them to have staff time and resources that they can devote to engaging in these issues as well. So, we would really love to see these issues gain greater recognition among funders, as an arena for advocacy for reproductive health rights and justice, for disability, racial, LGBTQ rights and justice so that we can collaboratively and sustainably, as Nesta said, build an intersectional movement focused on these issues in the context of other advocacy work, not as a separate or standalone issue.

#### **KAVITA RAMDAS:**

Thank you, very well said. Thanks again to our speakers, Nesta from NCLR, Silvia from DREDF, Onyemma from BWW, and Katie from CGS for sharing your inspiring and innovative work. Thank you to all our captioners, our ASL interpreters and behind the scenes Zoom hosts from DREDF, and a very special thanks to all of you funders who did make time in your busy schedules to attend. Please, share the word, put it out there and think about ways in which you can be a part of this work with Rebecca, myself and others.

We hope you've gained a deep understanding of these social justice issues and the urgency and the long-term need to do this work intersectionally and collaboratively. I know these organizations will follow up individually with you and I hope you will take time to meet with them.