Forging New Disability Rights Narratives about Heritable Genome Editing

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A roundtable conversation with Silvia Yee (Disability Rights Education and Defense Fund), Larkin Taylor-Parker (Autistic Self Advocacy Network), and Teresa Blankmeyer Burke (Gallaudet University), moderated by Rebecca Cokley (Ford Foundation). This event was co-sponsored by Center for Genetics and Society and Disability Rights Education and Defense Fund. Captions provided by AI-Live Media [minimal edits made for clarity].

KATIE HASSON: Welcome, all. Thanks for joining us today. The Center for Genetics and Society and Disability Rights Education and Defense Fund are excited to present this roundtable conversation, Forging New Disability Rights Narratives about Heritable Genome Editing, with Silvia Yee, Larkin Taylor-Parker and Teresa Blankmeyer Burke, moderated by Rebecca Cokley.

I'm Katie Hasson, the associate director of CGS. I'm a white woman in my forties with curly red hair, wearing glasses and a textured jacket with a wide lapel. A few things we'd like to make you aware of. We are recording this webinar. CART captioning is available. If you would like to view the captions, you can click on the CC button on the bottom of your screen, and we have also pasted a link to view the captions into the chat box. Many thanks to the captioner today and to our ASL interpreter, Anne Leahy.

Please use the Q & A box for any questions or comments for the panel, as well as any technical issues you may have. You can upvote, discuss, and respond to other attendees' questions as well. And we will occasionally use the chat box to share links and other resources with everyone, and we can make those links available after the event. Finally, before we begin, we 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.

Today's discussion focuses on heritable human genome editing, that is the potential use of techniques like CRISPR in reproduction to alter the genes and traits of future children and generations, sometimes also called germline editing or modification. Heritable genome editing carries a broad range of grave safety, ethical, and societal risks that make it very different from somatic gene editing, or gene therapies, which use gene editing to treat a condition in an existing patient. For example, treatments currently being tested for sickle cell disease and beta thalassemia.

This conversation will pay particular attention to the social context and social justice dimensions of heritable genome editing from a disability rights perspective. Disability communities and disability rights advocates have been at the forefront of anticipating and working to prevent the potential harms of heritable genome editing. But people with disabilities, especially those who don't desire cures, and disability rights advocates, have often

been excluded from consequential discussions of heritable genome editing. Disabled people and communities should not only be included but be primary participants. Calls to use genome editing to prevent the births of people with particular genes or traits are often based on a simplistic model of disability that conflates disability and disease, assumes a life defined by suffering, and identifies "bad genes" as the cause. The focus then turns to editing out bad genes and therefore the individuals or communities who carry them. Heritable genome editing could both increase stigmatization of people with disabilities and diminish necessary social supports.

Focusing our conversation today on narratives helps us highlight the false assumptions, ableism, and eugenic legacies underlying many arguments in favor of using heritable genome editing to eliminate some forms of genetic variation. It's clear that we need new narratives, generated from within disability communities, that value disabled people's lives and rich cultures, and that will give us new ways of thinking and talking about the prospect of heritable genome editing. There are also challenges to forging these new narratives, which our panelists today will explore.

Given the current situation, these conversations are more urgent than ever. Rapid scientific developments are fueling dubious claims that heritable genome editing could soon be safe and effective, while a small group of vocal advocates are attempting to challenge near-global consensus that heritable genome editing should not be pursued, which we see embodied in the policies of more than [70] countries that prohibit it.

Consequential decisions about whether to permit and pursue heritable genome editing may be made in the very near future. But to date, the conversations have been dominated by scientists and bioethicists focused mainly on technical challenges and individualized notions of risk and benefit. Centering the voices and perspectives that are seriously engaging with concerns about disability rights, reproductive rights and justice, racial justice, health equity, and Indigenous sovereignty would fundamentally change the conversation. We urgently need dialogue that addresses the social context of pervasive ableism, eugenic legacies, and reproductive oppression in which this technology – with the power to alter humanity – would be developed and deployed.

Today's conversation is the second in a series of webinars that aims to show what that conversation could and should look like. It is organized by CGS's Missing Voices Initiative, which works to bring social justice and human rights perspectives to consequential public and policy discussions about heritable genome editing. The first event focused on equity, sovereignty, and racial justice, and I encourage you to check out the video of that conversation with Krystal Tsosie, Milton Reynolds, and Dorothy Roberts, if you haven't already.

And I'm delighted at this point to turn things over to Rebecca Cokley, who will moderate today's discussion. Thank you, Rebecca.

REBECCA COKLEY: Thank you so much, Katie. Hi, everyone. My name is Rebecca Cokley. I have achondroplastic dwarfism, A-C-H-O-N-D-R-O-P-L-A-S-T-I-C, which is the most common form of

dwarfism. And I have red hair that's a little bit — I guess it's almost at my chin level — a glorious abundance of freckles that, thanks to genetics, have made it through three generations in my family. I'm wearing a black blazer and a black shirt. And an orange lanyard that says Ford Foundation, which is actually where I work as the US Disability Rights Program Officer. The Foundation itself is seated on unceded Lenape territory here in New York.

As we move through introductions, I do really think it's important to also acknowledge the very real history that the Ford Foundation has had in promoting eugenics in the US and abroad. [It's also important to acknowledge] the dedication that our current CEO, Darren Walker, feels when it comes to the importance of conversations like this and the foundation's participation in conversations like this. [He holds] the strong notion that we have a responsibility to embrace risk and reflect honesty when talking about issues like heritable gene editing, and the very real history that the organization where I'm sitting today has had in helping fund and promote the eradication of people like me.

I'm also the mom of three children, two of whom also had achondroplasia. And I'm the daughter of two parents, both of whom had achondroplasia. They've both passed away now. I think it's important to acknowledge all those various things as we go into this conversation, because this is one of those cases, as tends to be the history in the disability space, where the professional work that we do and our personal lives is so deeply blended and rooted together that it's very hard to separate. With that, I am going to turn over introductions to our speakers, starting with Silvia, then Larkin, and then Teresa. So we are asking our speakers, please introduce yourself, provide your visual description, and your initial substantive comments as it relates to heritable gene editing. Silvia?

SYLVIA YEE: Hi. Thank you, Rebecca. My name is Silvia Yee. I use she/her pronouns. I am a senior staff attorney with Disability Rights Education and Defense Fund, which is a national disability rights organization that is mostly located in Berkeley. The land we are on is the same historical land as CGS, introduced at the beginning. I am a Chinese-Canadian woman in her fifties with short, black hair, glasses, and a tasteful set of earrings. Behind me is a red chair, and the rest of the background is blurred, which is better for all of us, believe me.

I am primarily going to be providing a level set on disability and ableism in the health care field. I'm providing facts, but I really want all of us to set this in a context of the societal stereotypes and prejudices that make these facts possible. I'll be looking briefly at eugenics, education, healthcare access, and reproductive rights. With these four issues, I'll be trying to look at the persistent belief that the human race as a whole can better itself through selective genetics, and assumptions about who is worthy of passing on their genes. I'll be looking at assumptions about who is educable, assumptions about who is worthy of medically saving, and assumptions about who has sex and is worthy of control over their bodies – including the decision to have or not have children.

Beginning with eugenics, we have had laws in the United States for many years now, or had them historically. Laws permitting sterilization of "the feeble-minded" and those considered

incapable of caring for children, as well as those who had undesirable traits that shouldn't be passed on, have been on the books in 32 states, a majority of the US. The laws by design and by practice primarily affected people with disabilities as well as people of color, especially people of color that could be noticeably seen with larger families.

So one way of doing it — one thing that happened is that women who had many children were suddenly characterized as having a disability, especially a mental health disability, or sexually precocious in some way, and were placed into state mental hospitals where these laws would then take effect and allow people to be sterilized without consent.

The world's first sterilization law was passed in Indiana in 1907. You should note that the US Supreme Court decision *Buck v. Bell*, from which comes the infamous quotation, “three generation of imbeciles is enough,” is from 1927, two decades after Indiana’s law was passed. The Supreme Court justices were only reflecting prevailing social and scientific opinion, not necessarily leading it. Please note I'm not excusing lawyers, because I'm one of them; I just want us to be sharply aware of where and how the flawed assumptions that underlie policies come from. We look back on them with distaste, but they come from all of us.

The Indiana law and California's law were the model for the Nazis’ 1933 Law for the Prevention of Offspring with Hereditary Diseases. Over 60,000 people were sterilized without consent in the US under these state laws, and one third of these was in California, which didn't repeal its law until 1979.

On November 29, 1975 – interesting overlap – there came the first federal special education law, the Education for All Handicapped Children Act. Before that, as of 1970, for example, states were educating only one in five children with disabilities, which pretty well seals their future as an individual. Some states had laws that specifically excluded from public education kids who were blind or kids who were deaf or who had intellectual disabilities. And even if there wasn't a specific special exclusion, a wheelchair user, for example, simply couldn't physically get into many classrooms and then simply were de facto excluded.

Turning to healthcare, we have a history of people with disabilities being denied medical treatment *or* having treatment forced upon them. An example, one of the first being denied medical treatment is people with developmental disabilities who would not be placed on organ transplant lists, even though they had the medical need, because they were deemed incapable of being able to follow postoperative care instructions. Then on the other hand, we had people with disabilities having medical treatment imposed upon them.

One of the most recent examples of this was a 12-year-old who underwent a medically unnecessary hysterectomy and removal of her breast buds so she would remain prepubescent and small and therefore easier for her parents to transport and care for; that’s the case of Ashley, the so-called “pillow angel.” In a bioethics journal, there was an article which opined that Ashley, this young girl, who was subjected to involuntary surgery to prevent her growth,

was “not deprived of anything that she values because she does not have the capacity to value her own existence let alone to miss anything taken from her."

We've also had well-regarded ethics professors like Peter Singer, who has advocated in the past for actively killing infants with severe disabilities, in the belief that they will not lead good lives and will burden their parents and society. His opinion is that these justifications for death equally apply to older children or adults whose mental age is that of an infant.

Turning to healthcare treatment, a little more recently, in 2020: the emergence of crisis standards of care as applied to people with disabilities. People with disabilities feared they would go to the hospital with COVID-19 and be automatically deprioritized for treatment or care; and that even if they had to go to the hospital for any other reason, and they actually had a personal ventilator, that that personal ventilator would be taken away from them and repurposed for another person deemed more worthy of medical treatment. This is something that seemed to be allowed in New York State, for example, under their laws.

This fear of deprioritization occurred again when vaccines were new and scarce, and again, with new COVID-19 treatments such as Paxlovid and preventive treatments such as Evusheld. These fears of being left behind untreated have similarly been experienced among communities of color who have also faced a history of exclusion in the healthcare arena. Of course, they apply to those who fall in both communities; and both communities — all these communities — also have reason to fear medical experimentation and treatment without consent.

These fears of being left behind without access to health care occur whenever health care personnel have discretion over who gets care, because there is clear evidence of ableism and implicit bias among physicians, including an abiding belief that people with significant disabilities have a lower quality of life. This last bias is both entirely subjective and is consistently contradicted by people with disabilities themselves when they are asked for their own assessment of their quality of life. They're not responding, "I have no quality of life, things are terrible." Yet that contradiction in what people with disabilities say for themselves and what others say about them doesn't seem to go away. I'll check on my time. I can continue, but I also can stop.

REBECCA COKLEY: Silvia, why don't we kick it over to Larkin.

SILVIA YEE: Happy to do that.

LARKIN TAYLOR-PARKER: Hi, I'm Larkin Taylor-Parker. I use they/them pronouns. I am the legal director of the Autistic Self-Advocacy Network. I am a younger white person in a dark suit jacket and a button-down shirt in front of a wall of art and books, including a quilt that was made for me. I live and work on the unceded ancestral lands of the Tuscarora people, predominantly, though there have been many Indigenous communities with roots and rich traditions of stewardship of this part of the country.

Silvia covered a good deal of what I have to say, but I wanted to highlight a frustration that I have with conversations about genome editing. It is that these conversations really do center on what kinds of life are worthwhile, what kinds of human experience are worthy of perpetuation and are beneficial parts of the rich tapestry of human life and human diversity. Often when disabled people such as myself end up in these conversations, we struggle to get past the threshold question of whether our lives are worthwhile, whether it's a good thing that they occur in the world in the first place. Often it is so difficult for us to convince people outside of our communities that there is something that we offer to the world, that our lives have quality and meaning and value, that we can never clear that threshold question and delve into the risks of heritable genome editing and the reasons there might be for the widespread consensus that it's simply too dangerous.

To have meaningful conversations about things like heritable genome editing, we need to get past that threshold question and recognize that many kinds of human life are worthwhile, including disabled lives. Treating disability as an inherently bad thing, something that wouldn't exist in an ideal world, can make it hard to have sensible conversations about germline editing, because if we view disability as this thing that's so horrible that it should be prevented at almost any cost, we may miss what it adds to the human experience, and also fail to properly weigh the risks that this technology carries.

I come to you from North Carolina, which had one of the most aggressive eugenics programs in the country that brutally targeted disabled families and families of color. I would posit that trying to stamp out certain kinds of people, certain forms of diversity, has very well-known risks that the human community has already seen play out horrifically. This is not an experiment that needs to be done ever again. Thank you.

REBECCA COKLEY: Thank you so much, Larkin. And now we're going to turn to Teresa.

TERESA BLANKMEYER BURKE: Hello, everyone. I apologize. Zoom is asking me if I want to unmute, which I do not. Again, ableism at play of Zoom. Am I right? OK. My name is Teresa Blankmeyer Burke. I am professor of philosophy and a bioethicist at Gallaudet University. I'm also the director of the School of Arts and Humanities. At the moment, I stand in my home located in what we know as Albuquerque, New Mexico, which is situated on the Tewa homelands, unceded though they may be. I present as a female in her fifties, Arab American and European American. Behind me you will see my adobe interior walls with books and some pictures and a little table with a Guatemalan Tipico-type fabric covering.

I'd like to start off with four points in my opening remarks. The first of which being that we often frame this kind of discussion about what we've been talking about, quality of life, which remains hugely important, and I did want to push our vision even further to what it means to have more than just a quality of life but flourishing, a flourishing life. What do we envision for ourselves in our own lives? And I should add – you know what, I should have added – I'm a deaf person and I'm using American Sign Language with my interpreter, as well, providing the voice.

What does it then mean for us as deaf people and people with disabilities, disabled people, to have a flourishing life? I want to really call attention to that question, first and foremost.

My second point would be how to talk about heritable genome editing in a more nuanced way. This conversation is ideal for such a vision. When we have conversations outside of this setting and we look at external perspectives to this, of course we know very well that disability is what I call multivocal.

There are many perspectives which are baked in and included and overlapping in our identities. For example, I am a deaf woman, of Arab American heritage. My experiences have been shaped by that identity, [by] my experiences of discrimination, opportunity, privilege, et cetera. So we can't divorce ourselves from those perspectives, and it is certainly just a real 360 view of many perspectives that comes to this conversation.

Also, there is a challenge in the topic of chronic pain. In that particular condition, I think most people would tend to agree that chronic pain is something that we would like to minimize, yes. And we can minimize that through genetics, through medical interventions, treatments of that kind. But we don't always use the disability lens writ large to look at that overlap. There might be some real subtle points that we miss in teasing that out, so I did want to get at those subtle perspectives.

Another issue at hand about heritable human genome editing – I hate these signs we have to use for editing, because I don't know the right synonym. I'll spell it. I don't want to use the sign for fix anymore, which was the sign I was using: to fix or repair. I will spell it from now on because I don't like that choice I'm making.

So the process of heritable human genome editing, if it does take place, gain footing, you might say that it's based on maybe groups of people, such as we've said, with disabilities. That will impact our understanding of the need for a critical mass within a community for the purposes of, say, advocacy on disability rights, crafting disability policy, and other sort of salient parts of disability work. If indeed this technology takes hold, then we have to ask what will happen to these communities and sub-communities that we are advocating for, what kind of support will they have.

My last point is to really ask a question whether or not genome editing is neutral. Quite often people in the scientific community label this technology as neutral, and I have to push back and say, is it, though? Is it? If it's technology-neutral, then could we apply, say, if you had a deaf person who wanted to engineer the next generation to be deaf, would that capability exist to allow deaf people to have deaf children purposefully? So neutrality is, well – maybe I'm not sure that is the right way to characterize this. But when we do talk about the kinds of children that we want to see in the world, it also depends heavily upon context.

One example being: we had a few years ago a Russian scientist talk through his approach, which is going to several deaf couples wanting to use this technology, this CRISPR technology, to

ensure that they had hearing children. Now, it seems from the media reports that I can access, most people were willing to have hearing children. These were deaf people in Russia who were in a sign language–using community. What kinds of privilege would that afford deaf people in that community? Maybe they would be opposite from the kinds of contexts that exist in the United States. You see that we could talk about people in the United States who are deaf, if they wanted to use this technology, as I said they have, for the opposite reason. There is a context of policy and resources that are available that really doesn't have anything to do with the technology and the kinds of priorities that exist in our society.

Gosh, thank you for the opportunity to have me here. Back to you, Rebecca.

REBECCA COKLEY: Thank you so much, Teresa. You ended us at a really phenomenal question. I remember when I had my third child and we were going in for sonograms, and my older two children both have dwarfism. My youngest is boringly average, is what we say in the dwarfism community. I remember looking at the sonographer during the sonogram, and my OB and I were laughing back and forth because I was like, "Why are his legs so long? What's up with those arms?" My OB is like, "I don't know. What kind of life is he going to have?" And I said, "I guess he can live at home with me and his dad, and he could get a job dusting, or he could be my own really big light bulb changer."

I was watching the sonographer be so perplexed and completely confused, who was like, "He's normal, not like you and not like your other kids." My OB and I were just laughing at him for a good ten minutes. I said, "You have to understand our definitions of normal are completely polar opposites."

Teresa, when I read your blog on "hearsplaining" I related to it so much. Let's dig into that. Do any of you want to delve into each other's comments a bit? I want to give you space to do so before we move on to the next formal question. But I think there's a lot here to talk about.

SILVIA YEE: I will jump in a bit. Teresa, thank you for your remarks, and Larkin as well. I do think about that. I think about that in the context of race as well. I have a daughter. My husband is Asian. So my daughter is Asian, Asian American. She's Chinese. If that option was there, if I thought, "There is so much API hatred in the world right now, there are assaults on people who are visibly Asian, I don't want her to have to deal with that. What if it inhibits her education in some way? What if she wilts under the heavy stereotype of having to be good at math? There are lots of stereotypes that will be imposed upon her just because of the way she looks." If I had the choice of altering that, would that be seen as ridiculous, extreme, out of the ordinary, out of the normal, the extreme of normal? She had a school picture taken not long ago, and for some reason I guess everyone appeared quite washed out. Everyone was very white-looking, I'll put it that way. I remember my parents looking at it and going like, "What's wrong with that picture? Why does she look white?"

It's such an interesting thing, what we consider as being within the realm of normal, the choices we make that are considered normal and OK, and the choices we make that are considered not

OK; and how we're talking about inheritable genomic editing that changes the germlines for all time, for the future, as something that just falls within the realm of what we kind of make personal decisions about, like the clothes we wear. I think what we find out about genes is only going to grow over time. So in theory, the realm of our choice, if we consider just our choice, grows as well.

REBECCA COKLEY: Definitely. Larkin, did you want to jump in or should we move to the next question?

LARKIN TAYLOR-PARKER: We can move on to the next question.

REBECCA COKLEY: Wonderful. I want to ask: What does it mean for disabled voices to be erased or spoken over in this conversation? I think one of the things as pointed out by Katie early on that's so unique about this conversation is that it's a group of folks with disabilities having this conversation. So often, we are not in those rooms, or if we are in those rooms, we are intentionally silenced, we are denied accessibility in order to be able to participate. Obviously, that's extremely problematic. Why are these voices missing, and what would having voices like ours, people with disabilities, people with chronic illnesses and, to Silvia's point, people living with chronic pain even, at the table, help contribute to this conversation? Teresa, your blog, I referenced it a moment ago, or your essay, "Hearsplaining," touched on this. I was hoping you could start, followed by Silvia and Larkin.

TERESA BLANKMEYER BURKE: Yes, Rebecca. I'd be glad to do that. I might want to preface this with one example. For several years now, I've been developing and teaching a course here at Gallaudet University called "Deaf Bioethics." One of our units is on genetic technology. My students have been trained to recognize these issues when they come through the mainstream media and they catch their attention.

One of the first international Summits which was held on the human heritable genome editing possibility was live-streamed, and everyone could tune in — if you had access to the internet. So were it not for reliance on captions, mm-hmm… And the organization who put on the Summit of course did not have captions available. So one of my students contacted me and said, "Dr. Burke, we can't watch this. What are we going to do?" So in my far-reaching network, it just so happened that I knew one of the conference organizers and I could reach out. This person I knew had been very responsive in support of captioning requests in the past. But were it not for my network, the raw fact that they had no recognition of making something like that accessible — when you have an audience of people with disabilities — livestreamed, there was no thought to make it accessible for people like us.

So one huge issue, I think, for the Deaf community, and maybe I think for honestly any community, disabled communities, is opportunities to get in the room, so to speak, right? The internet room, as it is, doesn't necessarily need a ramp. But whatever the room would look like in this context for my purposes would be captions.

REBECCA COKLEY: Wonderful. Thank you for kicking us off. If we could go next to Silvia.

SILVIA YEE: Thanks, Rebecca. The missing voices, I think first of all you would get… When you don't have the actual voices of people with disabilities, it isn't like it disappears. You just have the imagined voices of people with disabilities. You have scientists and doctors and a whole profession and an industry that is not very familiar with people with disabilities, doesn't actually interact with them very much, sort of assuming what people with disabilities want.

I think it's hard. I absolutely agree, as Teresa said, that the tables in which these scientific conversations are happening need to be fully accessible. I also think that people at those tables need to be placed in a different context. Because when people with disabilities are brought to the science tables and they're kind of made to be the… they have to exemplify everyone, all people with disabilities. They're made to be the model in the room and you have to sort of justify your existence, why your life is good and why you don't need to be fixed. That's a hard position to be in.

Also, you're judged on things like how credible you are, what's your affect, are you communicating well? Someone who may have great things to say and uses communication devices, there will be a time lapse, and there will be all kinds of judgments attached to that. To fill in the missing voice is a heavy, heavy burden. I worry about that burden being placed on the individuals with disabilities who show up.

But I also am a little worried about a scientist or a doctor who says, "Well, I read a book by a Black woman and have gone to a conference where there are people with disabilities, and I feel pretty expert now. I can fill in the missing voice." That would be completely wrong, too. I think there has to be a constant effort to sort of meet in the middle on these two sides; the two tables have to set up a bridge.

REBECCA COKLEY: Definitely. Larkin, would you like to add?

LARKIN TAYLOR-PARKER: I would. I wish Teresa's experience surprised me. Unfortunately, I've heard about all too many of those situations. I have seen what Silvia discussed as well, and I want to expand on her comments a little. Part of the problem with people with disabilities and many other marginalized people not being at the table where decisions are made is under-representation among the decision makers. Discrimination in educational opportunities and employment disproportionately keeps marginalized people, including people with disabilities, out of these important decision-making roles.

That's something I certainly saw in a previous role working on medical rationing, first in the organ transplantation and then in the COVID context. Looking at biases in medicine and the under-representation of certain groups, including people with disabilities in the sciences, in medicine, it was not hard to see why there was a lot of room for assumptions. And the way in which anyone who was brought into conversations about the ethics of those sorts of decisions as a representative for marginalized communities was often brought in kind of ad hoc, after the

fact, just to represent marginalized communities in a way that can easily result in tokenization and that person being there to check a demographic box rather than to be taken seriously.

It would be easier for these decisions to be made in a way that is respectful of the lives of people with disabilities, as well as other marginalized people, if marginalized people were more included among the scientists, the doctors, the ethicists who are making these judgment calls, rather than a sort of after-the-fact addition that's easily brushed off.

REBECCA COKLEY: Larkin, thank you for making that point. I think — Teresa wants to jump in. I was going to say that is the reason why this year at Ford we funded the creation of a national organization of disabled and chronically ill healthcare professionals, because we know how important it is to have our people at the table across the board when important… well, when *any* topic is brought up that centers people with disabilities. Teresa, I want to turn it over to you.

TERESA BLANKMEYER BURKE: Yes, Rebecca. Thank you. I do want to thank both Silvia and Larkin as well for their comments about this topic. I'm compelled to add also something that's often overlooked because I think, well, most of the time these conversations take place in very specific academic and scientific circles at that register of language. This is a high register. This is an academic language. The impact is that they're not going along the gradient of registers of language. There's not the effort toward plain language, for example, that would be more accessible. There's no opportunity to support people with, say, developmental disabilities who use a different register of language. That's another absent voice.

I feel strongly that we need to make more effort to include those kinds of voices as well and provide descriptions and information in plain language. Not dumbing it down: In my experience, in the academic setting and in the scientific and medical communities, quite often when we change to a more plain-language-type layman's terms, there is a perception that we're pandering to people, but it's not the case. We don't want to be patronizing in any way. But this is being inclusive, not patronizing. I think there is a stark difference there.

REBECCA COKLEY: Absolutely. I had one more question, and it sort of ties into one of the questions in the chat, that I want to pose to all of you. It's really grounded in some things we've touched a little bit on already, but noting that we're in a space with folks from the Deaf community, the Autistic community, and the dwarfism community.

I think something that is particularly unique and beautiful about this conversation is the fact that in the Deaf community and in the dwarfism community there's often celebrations about having multiple generations in the family. As we're starting to see in the Autistic community, as more folks are finding diagnoses or are able to come and find community and starting to self-identify across multiple generations. I know as a person in the dwarfism space, I get really excited when I hear about multiple generational autistic families.

To me, it is a tangible recognition of the fact that we still exist and that our cultures exist and are thriving and are flourishing, to use the term that I know somebody else used a minute ago. I want to delve into that a bit. How does the conversation shift when we focus on the flourishing, on the pride and value that Deaf, disabled, and Autistic communities place on multi-generational families? And how can that help shift some of that really nasty, negative connotation to our communities' preservation and existence? Larkin, can I kick it to you first, since the Autistic community is, I would say, the newest to the table in this space? I think this is such a cool and, frankly, not typical angle on this conversation that we're really privileged to be able to have.

LARKIN TAYLOR-PARKER: Sure. Over the last decade or so, a lot of people have had a child diagnosed, looked at the reasons that the child was diagnosed, and recognized that the kid came by it honestly, that it shows up in one or both parents, maybe some aunts or uncles or grandparents. There is a significant amount of autism, dyslexia, and ADHD in my own family – the gene pool just doesn't produce many neurotypicals. I think there are more families out there along those lines than have recognized it yet.

When we recognize that these multi-generational families that are autistic or deaf or have dwarfism or some other disability have always been a part of the rich tapestry of human life, and have always been there in our communities – to the extent that we have been allowed to live in communities – and having rich, worthwhile existences. [When we recognize] that we have a history worth celebrating, that helps us get past that threshold question and recognize that these can be good kinds of lives to have.

REBECCA COKLEY: Absolutely. Teresa, did you want to jump in?

TERESA BLANKMEYER BURKE: Oh, yes. I wanted to hold back until everyone else had a chance to respond, though. I really appreciate that, Larkin, in what you responded there. It's the way I guess, for example, that parents, if we take the example of deaf parents who have deaf children, those parents have a cultural and linguistic resource to pass along that hearing parents of a deaf child would lack. So there's the ability to share, to shape, in a very real way, that flourishing life for a deaf child relative to, say, a hearing one who has hearing parents.

There's a very rich cultural history of intergenerationally deaf families that has gone largely overlooked. Intergenerationally deaf families can share experiences over time. I see the potentiality among other disabled communities in families with maybe different kinds of disabilities that are passed along, and the overlooked heritage and expression of that life experience. I think it's a very rich and unique and wholly human experience that expresses and reveals our humanity.

REBECCA COKLEY: Absolutely. Silvia, did you want to add anything?

SILVIA YEE: I did, because the idea of flourishing really caught me too, and I love that you introduced that, Teresa. I think of it especially in conjunction with families and communities.

I think of it also as something that unites people with disabilities and without disabilities. Because even if we do have germline genetic editing, disability is always going to be in the world. There are people who have accidents, there are people who age into disability. I see multi-generational families living together, and often they are Hispanic – or Latina – or Black families, and you have different generations caring for one another. A younger generation growing up with an older generation that has acquired disabilities. And they work things out. They can value one another for each other's experiences and each other's expertise in different areas.

As a community, my vision of flourishing is of a community where people with disabilities and people without disabilities are flourishing and valuing one another. I don't think we ever get there if we just edit out disability. We'll just start placing hierarchies on ourselves for other reasons, for income, for status. We always want to be ranking one another.

But this idea of flourishing as a way to be generous to one another…this is the way we improve ourselves, not through germline editing but through figuring out how to overcome the worst habits of humanity, our selfishness, our short-sightedness. Anyway, that's enough of the preaching. But I just think it's lovely; it's at the core of what we should be aspiring for.

REBECCA COKLEY: Thank you, Silvia. In the efforts of selflessness, I will say that the gingers [redheads] were actively contemplating a takeover of society and will now be holding back in order to allow all the rest of you to flourish.

Before we wrap up, I did want to acknowledge [webinar participant] Abril's comment in the Q & A because I think it's really important, that this conversation very often happens in English, and we need to take the discussion to other places and other languages. Nonacademic, non-Western ways of seeing these issues. Thank you so much for sharing that, and I don't feel like I'm out of line saying [that] I think, across myself and the panelists, it's something we would really love to see, and we think is a vital part of the conversation. With that, I'm going to turn us back over to Katie to bring us home. Thank you all for being with us today and thank you for joining us.

KATIE HASSON: Thank you so much, Rebecca, Silvia, Teresa, Larkin. This has been such a fascinating conversation and I wish we had another whole hour to cover all of these issues and the great questions in the chat. I'd like to thank each of you for your participation. I would like to thank our captioner and our ASL interpreter, Anne Leahy. Special thanks to Emma MacDonald at CGS who is running things behind the scenes, and to Emily Galpern who did a lot of organizing work in bringing together our access team. I'd like to thank all of you for coming and for participating in these events with CGS's Missing Voices Initiative, and also co-sponsored by DREDF.

Missing Voices will have a few more events coming up in early 2023: one more webinar and then an event immediately preceding the Third International Human Genome Editing Summit.

We're really excited to share details on that with you in the future. If you're new to Center for Genetics and Society, you can find out more about us at our website, geneticsandsociety.org. Or find us on Twitter and Facebook.

Thanks so much, everyone. Goodbye.