**Belonging: On Disability, Technology, and Community.mp4**

**Erik Parens:** Thank you all so much for coming. Thank you for joining this first in our series of six events called *The Art of Flourishing: Conversations about Disability and Technology*. My name is Erik Parens. I'm a senior research scholar at the Hastings Center, which is a bioethics research institute in Garrison, New York. The primary funder of this series is the National Endowment for the Humanities. But this series would not have come into being without the generous in-kind support offered by the Hastings Center's President, Millie Solomon. Nor would this series have come into being without the tireless work and invaluable insights of Joel Michael Reynolds and Rosemarie Garland-Thomson. Joel is a philosopher, bioethicist and disability studies scholar. Alas, our dear colleague and friend is the one of the six of us who couldn't make it here due to the storm. It's somewhat miraculous that Haben made it from Miami, and Rachel made it from Atlanta, and Teresa made it from Albuquerque, and Roseberry made it from San Francisco. But Joel is snowed in in Lowell, Mass. Anyway, we miss him, but he has been an absolutely essential part and, indeed, co-director of this whole enterprise. Rosemarie is a professor of English, a bioethicist, and a pioneer in disability studies. This series has two overarching aims. The first is to broadcast a basic but profound point, which is that people can flourish in all sorts of bodies. That is, the flourishing of persons does not depend on their having any one particular sort of body. Rather, it depends on their having the opportunities to exercise the capacities of the body that they were born with.

When people can freely exercise their capacities in pursuit of their goals, they can be said to flourish. People don't need different bodies to flourish. They need different, more supportive environments. Our second aim is to explore a basic but profound question. What can all of us learn from how people with disabilities are in their efforts to flourish, using or resisting the use of emerging technologies? Indeed, on the one hand, people with disabilities are often on the leading edge of creating and using new technologies to promote their own flourishing.

Our first speaker tonight, Haben Girma, is a DeafBlind lawyer who advocates for equal opportunities for people with disabilities, and Haben will describe how technologies have been a crucial element in her efforts to flourish.

Our second speaker, Rachel Kolb, is a deaf scholar of English literature and disability studies, who, in addition to using ASL, uses a cochlear implant. Rachel will explain how using American Sign Language and a cochlear implant allows her to be a member of the deaf and hearing communities.

On the other hand, people with disabilities have been among the most outspoken critics of some emerging technologies, notably genetic technologies that aim to influence the sorts of bodies that babies are born with. Our third speaker, Teresa Blankmeyer Burke, is a deaf professor of philosophy at Gallaudet, who will invite us to think about new gene editing technologies that in principle could be used to select against or to select for traits like deafness. Teresa will invite us to ask whether an environment in which parents can choose what sorts of bodies their children will have would, in fact, be a better environment for those children.

All three of our speakers tonight share an unshakable commitment to creating a society where we use technologies in ways that support many very different ways of flourishing. The question surely is not, “Are we in general for or against technology?” I don't think that's a very helpful question. The question is, “How can we wisely use technologies in ways that enable all of us to flourish?” After our three speakers shared their remarks, Rosemarie Garland-Thomson will moderate a brief conversation among our speakers, and then I will facilitate a conversation between all of you and all of the folks on the stage. Sadly, Joel is not here to do that. That was to be his role. He'll be here for the next event, I'm sure. So it is now my pleasure to turn the microphone over to Haben Girma. Thank you very much for coming tonight.

**Haben Girma:** Good evening, everyone. Thank you for the welcome. So my name is Haben Girma, and I work as an advocate for people with disabilities. I'm also the author of a new book called *Haben: The DeafBlind Woman Who Conquered Harvard Law*. Harvard has not been the same since.

Before I got there, I had to understand. What does DeafBlindness mean? DeafBlindness is a spectrum of vision and hearing loss. And we in the deaf blind community use lots of different techniques and strategies for communication. Some sign visually. Some sign through tactile, through touch. Others use print on palm, where they write letters on palms and me, I had to figure out what can I do to best access information. When I was growing up with DeafBlindness, I was excluded from a lot of information. The schools I attended were sighted, hearing schools in a sighted, hearing society, and I missed out on a lot of information, even within my family. I experienced isolation and it's frustrating to feel that. And I wondered, “Do DeafBlind people just tolerate this? Is this just part of being disabled, accepting inferior experiences, less access?” Then I asked myself, “What are my strengths?”

One of my strengths is my sense of touch. In first grade, I learned Braille, and I've been using Braille all my life. Then in 2010, a new Braille device came out. Humanware produced the first real Braille note with Bluetooth support. I'm holding up the device. There's Braille on the bottom. I ran my fingers over the dots to feel the letters. And I found that if I connected this device with a keyboard, I can hand people the keyboard and they can type and I'll read their words. Most people in my family and community don't know Braille, don't know how to sign. But most of them can type, especially millennials.

So throughout this presentation, this is the system I'm going to be using. There are typists in the front row, typing on a keyboard, and I'm reading the words in Braille. I want to stay connected with the audience. Everyone needs connection. All humans need to find a way to form friendships, connect with family. And now I have a way to connect with the audience. So they're letting me know when people smile, laugh, fall asleep. They're watching you.

The name Haben comes from Eritrea. It's a small African country. Ethiopia borders to the south and to the north is the Red Sea. My mother grew up during the war between Eritrea and Ethiopia. There was a lot of violence and a lot of fear. Schools were places for students to come together and hear stories from around the world. Stories are powerful. Stories influence the organizations we design, the products we build, and the futures we imagine for ourselves.

My mother heard stories that America is the land of opportunities. America is the land of civil rights and stories inspired her to take the dangerous journey, walking from Eritrea to Sudan, and took about three weeks to do that walk. She was in Sudan for about 10 months, then a refugee organization helped her come to the United States. Several years later, older, wiser, my mother realized it's not geography that creates justice. It's people that create justice. Communities create justice. All of us face the choice to accept unfairness or advocate for justice. As the daughter of refugees, a black woman, disabled, lots of stories say my life doesn't matter. I choose to resist those stories. My parents heard from the Ethiopian Eritrean community, “Poor thing she won't get a job, she won't go to school,” and they had to learn to resist those stories. So, we found, and we can define disability as an opportunity for innovation. If you can't do something one way, come up with a new, innovative way to do that thing.

People with disabilities have been doing this all throughout history. These are hidden stories. Many people in the mainstream don't know these stories, so we have to get these stories out there, so the public realizes that disability has an opportunity for innovation. We have challenges, but we also have talents.

Technology plays a tremendous role in increasing opportunities for people with disabilities, but only if it's designed to be accessible. My computer will allow me to connect with people, if people choose to meet me halfway. I've had people say, “No, that's strange. That's weird,” and walk away. And that creates the barrier. We've also had people develop technologies that are not accessible. For most of my life, I could enter an elevator, read the button in Braille, select the button and step out when I get to my floor. Now I'm encountering elevators that are all touch screens and not accessible to blind individuals. So a freedom I used to have, to freely move around a building, has been taken away by technology.

People who develop tech should design with access in mind so they can reach the largest number of people. There are over a billion people with disabilities around the world. When you design tech to be accessible, you get more customers, people with disabilities, their families, their communities. So I'm hopeful that more people in tech will design with access in mind, or risk litigation.

Now I'm going to share a story from my book. When I decided to become an advocate, it was a slow process, and it started when I was in college. I went to Lewis and Clark College in Portland, Oregon, and at Lewis and Clark, they love their pioneers. Everything is called pioneers. The football team is the pioneers. Their bus is the Pioneer Express, and the bus takes you to Pioneer Square. I thought maybe this would be a place that celebrates difference, a place where I can pioneer my way through the unknown. The college did a great job providing me all my course books in Braille. The exams were in Braille. The even worked with the Outdoor Club so I can have access to rock climbing and kayaking.

There was just one problem. The college cafeteria was a place for students to go in, eat, relax between classes. It's in a large room and as you enter along three of the walls were panoramic windows showcasing Portland's rain. And on the fourth wall were food stations. Sighted students would walk in, browse the print menu, then go to their station of choice. I couldn't read the menu, not because of blindness, but because of the format of the menu. So I went to the cafeteria manager and explained, “I can't read print, but I can read. Can you provide the menu in Braille or posted online or email it to me? I have assistive technology that allows me to read e-mail and websites.”

The manager said, “We're very busy. We have over a thousand students. We don't have time to do special things for students with special needs.” Just to be clear. Eating is not a special need. Everyone needs to eat.

There's this myth that there are two kinds of people, independent and dependent. It's not true. We're all interdependent. Many of you like drinking coffee. I bet very few of you grow your own coffee beans. You depend on other people to grow your food and build your technology. That's OK, as long as we're honest about the fact that we're all interdependent. Everyone at some point needs to depend on other people.

The manager of the cafeteria didn't understand this. I was a vegetarian back then, and it was hard to eat vegetarian when you don't know what the food choices are. There were about six different stations. I’d go to one at random, get food, find a table, try the food and discover an unpleasant surprise. It was really frustrating, but I told myself, “At least I had food. Many people around the world struggled for food. Why should I complain?”

My mother, when she was my age, was a refugee in Sudan. At least I was outside of the war. At least I was getting an education at a college here. Maybe I should just be grateful. We engage in the oppression Olympics, where we compare struggles, point to someone and say, “Their struggles are worse. Therefore, I need to stop complaining and just be grateful.” That's not helpful.

When you do that, you accommodate institutions. You allow problems to persist. So I talked to friends, did research. Then I went back to the cafeteria manager and explained, “The Americans with Disabilities Act prohibits discrimination and if you don't provide access to the menu, I'm taking legal action.” I had no idea how to do that. And I was just 19. I couldn't afford a lawyer. Now I know there are nonprofit legal centers that help students with disabilities. But back then, I didn't know that. All I knew was I had to try, had to do something.

The next day, the manager apologized and promised to make the menus accessible. He did. He kept his word. They started emailing me the menus. Life became delicious. The next year, a new blind student came to the college and he had immediate access to the menus. That taught me that when I advocate, I help everyone who comes after me.

There are many barriers in our community, lots of small barriers, and sometimes we tell ourselves, “Just tolerate it. Don't complain.” But that's not helpful. All of you face the choice to accept unfairness or advocate for justice. When you take the time to address the small barriers, you build up the skills to master the larger obstacles. Tech has helped me throughout my life, but more than tech, it's people doing the work to dismantle barriers that truly creates access and allows the disabled to flourish. My name, Haben, means pride in the language Tigrinya. A lot of people are ashamed of difference, shamed of disability. I want to create a culture where everyone celebrates difference, where we have disability pride. The stories we tell ourselves about disability, shape our culture and shape our access. Let's work to create a world where everyone has access to the tools that allow them to flourish. And now I'm going to pass it on to an amazing speaker and scholar. Let's hear it for Rachel.

**Rachel Kolb: (spoken)** OK, thank you all. Hearing people. Can you hear me? Thumbs up. Good. I can't rely on myself with that. OK, thank you for having me here today. I remember pretty distinctively the first day I started thinking about getting a cochlear implant. It was almost exactly 10 years ago, October of 2009. I'm a sophomore in college. I trust God, in whom after I learned was really there. It was the kind of day that other hard of hearing people in this room will immediately recognize. It was the kind of day when all my hearing friends talk too fast, interrupting each other, switch conversation topics, then suddenly all burst into laughter. When I asked what was going on, they said, “Oh, everything's fine. We’ll tell you later.”

I go home and wondered, “What was I even doing? How is I'm going to live in this hearing world with the rest of my life?”

This feeling was not new, but I had always go down new ways to navigate it. Later I would figure out even more new strategies, including picking more friends who can sign. But that day I'm still young, and I would also see how profoundly the world was not made for deaf people like me. I knew communication was my right, but how was I supposed to access communication if most people spoke and heard? So that day in 2009, the thought up into my mind for the first time. What if I got a cochlear implant? Could that be a way to make some things easier? Sometimes, right away, the very idea felt like a betrayal. It felt like a betrayal of the larger deaf community, too, and for the sake of the conversation we're going to have tonight, I want to explain why.

We sometimes frame conversations that we had about ourselves and our communities, but also the technology we all use too simply and absolutely. Culturally deaf people have, sometimes with good reason, viewed cochlear implants as technology that involves deeply problematic able-bodied ideas of medical care and social restoration. A cochlear implant could be a powerful tool for assimilation, or it bore me with specific sets of behavioral norms, like hearing and speaking to have a conversation.

Now, the problem arises with those cultural norms that turn to the many other equally rich and valuable ways to be in the world, such as communicating primarily through sign language.

So if I got a cochlear implant, I already knew I wasn’t lucky to be fixed. I didn't need to be fixed. I had grown up deaf, with a wonderful family who gave me access to sign language. I was fine with the way I was. I knew a cochlear implant would not make me hearing. Like many other deaf people, I already felt whole. So here’s what I wondered in 2009. I wondered if this piece of technology could still be a valuable tool for some situations. I wondered if it would be possible to get a cochlear implant and still be deaf. Now, fast forward to 2019, I never thought I would be here talking about this. I’ve had a cochlear implant for 10 years now. And I have some new feelings.

**(via sign)** Yes, I’m still deaf. In some ways, I’m more deaf than I used to be. I haven’t betrayed myself or my community. There are many different ways to be deaf in the world. Having a cochlear implant introduced me to the strange, overwhelming but also wondrous world of sounds. Many people are curious about this journey and what it was like. They want to know how much can I hear now? How do I like it? I enjoy discussing the oddities of sound and hearing with other people. I really do. But here's another thing which is often less recognized in the hearing world. I also like being able to not hear. To take my cochlear implant off, to communicate this way with ASL. I like the attention to eye contact, space in the body. I gain that through being deaf. I still see myself as a fundamentally deaf person, even though I happen to hear and speak sometimes. To some extent, in some situations.

I want to give you some examples of what I mean. First of all, my cochlear implant has helped me to see how much I enjoyed silence. The first day I got my implant, I was thrilled that I could take it off. My deafness was still in there. I would plunge into the chaotic world of sound for a few hours, and I'd feel odd and sometimes annoyed by the new spoken words that I heard and the sounds of birds singing or dogs panting. But I also feel deep relief from knowing that I could still return to silence at the end of the day. I was especially grateful I could get a good night's sleep without being interrupted by some siren or a clap of thunder. How do you hearing people sleep at night, especially in a place like New York City? It's so loud. I really don't know how you do it.

My cochlear implant also helped me to see how spoken and auditory modes of communication can be useful tools, but not always and not for everyone. We can all benefit from embracing more communicative flexibility. When I got my implant, I suddenly realized just how noisy most restaurants and public social spaces are. Huh? I couldn't hear myself think. My voice grew sore from shouting over other people. I started to observe how those other people didn't always hear each other and they wouldn't admit it. Struggling through futile noise and sound felt like a waste.

My deafness gave me a valuable distance from these social norms. I already had other options to communicate. I could sign. I could gesture. I could write. I already knew how to use these tools. I saw how much of a gift that flexibility was. And I started wishing that more people could have access to it. Finally, I realized that even if my cochlear implant was a useful tool, in some situations, other technologies were equally useful for ensuring my right to communication. My implant helps for talking with other people in a quiet environment. It helps to alert me of many different beeps and buzzes and whistles in my world. But it's also shown me where my strengths already lie, writing, seeing other people's faces, typing and using my body to communicate.

Instead of trying to conform to auditory and verbal norms all the time, I've become more deliberate about embracing my strengths. The implant has given me fresh appreciation for other technologies like online messaging, Skype, Facetime captions, subtitles. None of these technologies cure deafness or actually cure much of anything at all, but they're valuable tools for empowering many people. Sound or sight, or any other sensory channel shouldn't be prerequisites for social inclusion. Rather, we can work towards integrating more of these different options into the world we live in.

Once upon a time, 10 years ago, I worried that getting a cochlear implant would betray or erase my deafness. Let me tell you, it hasn’t. It's still possible to be deaf in the 21st century and have an implant. However, it's possible only when we think of deaf people's experiences as fluid, accessible, nuanced, even in messy things. The fact that I have a cochlear implant still sometimes reinforces other people’s ideas about a binary about hearingness or deafness. It is in this in those spaces that the risk be arranged. I have conversations with new acquaintances where it becomes tricky to explain how I can be deaf and still hear. Or how I can still hear some things, and still need accommodations, or how I can be speaking like I am right now and still not understand what they’re saying. They become so confused about how I can supposedly hear them with my implant, without any attention to how they can’t sign like me.

**(via sign)** Sometimes I've had conversations with some deaf people who worry that I seem to hearing. I listen and speak. I have a cochlear implant. How deaf am I, really? I tell those people I love my hearing friends and family, but I need deafness too. I need deaf people to continue to exist in the world in all their different forms. I need to react, and I needed to recognize the very real privilege associated with sound and speech and also work to empower more deaf leadership and create more signing accessible spaces.

**(spoken)** My cochlear implant hasn’t fixed my deafness. It's given me a new tool for navigating different communities and situations. The tragedy that I had been assuming without realizing it, or that I must really be cured by now both fail to recognize the complexity of my experience. I would like for us to see that this, like nearly all other technologies, cochlear implants can be used by some people, sometimes to attach their own history in different ways. We look at technologies as tools, not barriers, we can consider multiple options for communication. We can also pay more attention to the existing resourcefulness of deafness and disability. I enjoy this about that, but also hears something sometimes and sometimes not at all. I contain multitudes, as we all do. I'm looking forward to our conversation about all of the ways we use technologies to take joy in each other’s multiple different ways of communicating. Thank you.

Now?

**(signed)** And now over to Teresa.

**Teresa Blankmeyer Burke:** Hello. Hello, and good evening, it's so nice to see you all here tonight and to follow two wonderful presenters. Thank you both. My title of my presentation is called, “The Best for All of Us.” And there's three parts, which each have its own point or topic. I begin with, “The Best of You.”

I'd like to start with asking a question of the audience. How many of you are now or hope to become parents, please raise your hands. Anyone? About a third to a half of the audience. So how many of you want the best for your child? You want them to have a good life, a flourishing life. Raise your hands again. How do we fit technology into this discussion? We've seen these two presenters both talk about how technology can shape and support, as well as help our lives. But I'd like to shift a little bit to talk about how technology can impact our lives before people are even born and how technology itself shapes our world and potential future.

The movie, some of you might be familiar with the science fiction film called *Gattaca*, is now part of the classic bioethics movie canon, and this movie has one scene with the genetic counselor talking with two potential parents and the counselors telling them that they can pick height, they can pick intelligence, they can choose how fast the child might run. They can pick a whole bunch of features about their potential child. And the mother was thinking, “Well, I don't know. I think I want to avoid illnesses, but I'm not sure how tall I might want the child to be.” And the counselor says to the mother, “Your child will still be you. But the best of you.”

So I guess most people would who are themselves parents would like to pass along your genetic traits and characteristics that might benefit your child's life and give joy, but perhaps avoid passing along things that you would struggle with, things that you found frustrating. So my question then is if you could use genetic technology to remove those negative, or traits that you perceive as negative, would you do so? If we think about the best of you, that depends on the context, the environment, right? Sometimes you have a genetic trait that expresses itself one way that perfectly fits a particular environment. But there's another time when that could be a mismatch or a struggle or the other way around. So the environment, the context is really both shaped by our technologies as well as we making choices that space and that shape the technology. So that's an important thing to consider when we're deciding to use technology that influences our next generations. And if this is open or closed to diversity in the world.

So that brings me to point two about CRISPR technology. A year ago, there was an announcement about the first use of this CRISPR technology with two girls before they were born. A Chinese scientist named He Jiankui used CRISPR genome editing technology to manipulate the genomes of two children prior to their birth in attempt to make them immune to HIV infection. This was very controversial for many reasons, and I won't go into all of the details here, but I'd like to point out two things in particular that we need to know for our discussion.

First, it's very easy as well as powerful technology, easy by saying, well, suppose you have a phone, you know, and you're typing the word cat, C-A-T, but you really wanted to type the word cot, C-O-T, so you're able to do a quick, easy cut and paste. So CRISPR is similar, and that might be a very oversimplification, but that's generally how the technology works. CRISPR is not only for the person themselves who's using it. They can change all where the genetic material will be changed for that individual, but also for all of their descendants. So we see this possibility for the threat and the elimination of our humanity, of our elements of our human community.

Earlier this year, in July, a Russian scientist announced that he identified several deaf couples who were willing to consider the use of CRISPR gene editing technology to ensure the birth of children who would be hearing not deaf. My guess is that most hearing people would see this as being very positive, but it's not that easy or that simple of a decision. In philosophy, we also talk about two different divisions. What is necessary and what is sufficient?

Necessary and sufficient. A necessary condition is something that is required. Is hearing necessary, but obviously there's people here on the stage who are deaf, who have disabilities, who have flourishing lives, as all of us here do. And we also have this idea that hearing is not enough for a full flourishing life. And so we can think about one characteristic, but this one characteristic itself is not sufficient. So maybe now we think, well, yes, but. Right? Philosophers always have this sort of objection. Yes, but. A few things I'd like to throw out in terms of the yes but category. Well, yes, these people are exceptional or yes, but their lives would be even better. They would flourish more if they could hear or see or what have you. Yes, but they miss out on a key human experience. Well, yes, but look at the struggles they've had to deal with.

So at the same time that we have some of these objections, I also have some more questions. How many of you would be willing to use a technology like CRISPR to have a child with a life that seems to fit your vision of the best flourishing life possible? Context is crucial. So I'd like to change the frame. So now imagine a deaf couple. And their lives are flourishing and very gratifying and rich as being a part of a beloved community and using a very powerful language. And they want their child to have the same thing, but they want a deaf child. Can they use CRISPR to get the deaf child that they desire? My sense, I might be incorrect, but my sense is that this topic when I present to a hearing audience seems very unsettling, the idea of making a child deaf on purpose seems very controversial. But that sense of uneasiness is what many deaf people experience when people talk about eliminating us from the world.

CRISPR is a very powerful technology and how we decide to use it and if and when we decide to use it, all of these questions are very important discussion topics. Lastly, the best of us. One option is to use CRISPR for many people, they think they think that perhaps it could be used to eliminate deafness and disability. And those people can then have good flourishing lives. Another view is maybe we see deaf people who want to have their community legacy continue and that we don't want to use CRISPR for all situations because if we use CRISPR, then we lose some of the people within our own community and our own world.

Or perhaps we think about people with genetic disabilities and their experiences and their lives in the world with their genes and how they decide they don't want their children to experience the same kind of life, and they want to use CRISPR technology to change the type of life that their child might have. If we block CRISPR, if we stop that technology from developing, there could be serious repercussions. Some communities don't have the opportunity to have children. The deaf couple that wanted deaf children, they had a desire to use perhaps CRISPR to ensure they had a deaf child like themselves, which supports their way of being in the world of flourishing. And it's a way to see the deaf community survive.

So I recognize that these options are all fraught with controversy. And at the same time, I'd like to add one last comment and perspective from a disabled bioethicist, Adrian Ash. And she wrote about the idea about mentality, some selective mentality. And the idea is if we focus too much on one characteristic, one trait deafness, for example, or sightedness or blindness, that we can then lose our sense of humanity for the future. That we're creating a world that's not ultimately the best for all of us. And so now we have this tension. We have the tension of acceptance. And the embryos as we get them and the tension with a sense of control. And I invite us all to start this conversation about the sense of acceptance and the sense of control and the balance for using technology and accepting or rejecting technologies and figuring out how we can together create a world and an environment that supports all of us. Thank you. And just imagine. Thank you, Rosemarie?

**Rosemarie Garland-Thomson:** Thank you, Haben. Rachel and Teresa, thank you. Thank you, Haben, Rachel. Teresa, Erik, the NEH, the Hastings Center and all of you for coming. I'm delighted to be here on the podium with my three colleagues and good friends. And in the next 15 minutes or so, I've prepared several questions that I'm going to direct to the panelists, the three presenters, for us to talk about together for maybe five or six minutes for each question, and then we'll take some time together for audience questions.

So the first question is this: so one question that people with disabilities often get asked goes something like this would you rather be deaf or would you rather be hearing? People often ask me some version of this question, like whether I'd like to have typical hands and arms instead of the unusual hands and arms that I actually have. My blind friend tells me that people frequently ask her if she'd rather be sighted or blind. Now, this kind of hypothetical cure offer has always seemed really nonsensical to me, especially for those of us who have had our disabilities from birth or early on. Our disabilities can't simply be pried off of us. They are who we are. Perhaps the three of you would like to reflect a little bit on how questions or propositions such as this sit with you.

**Haben:** I've had that question many, many times. People ask, “Would you rather be blind or deaf?” Like anyone had that choice. Honestly, they’re all cool. I’ve had an amazing life. I do love developing tools, developing my skills and talents. If someone offered me the ability to fly, if I could just spread my wings and go toCalifornia tomorrow, I’d love that skill. I’d take it. That would be an amazing gift. Until then, I’ll take an airplane. So it’s not helpful. You can flourish and thrive without flying.

**Rachel:** I can speak to that as well, and say, I’ve been asked questions like that before. This is Rachel speaking. And when somebody asked me that question like would I rather be hearing? I would say I'd rather be myself. I don't have any other experience growing up with my relationships with friends and families. My experience is what made me who I am. And so that's why if they asked me something like that, it's like them asking, “Would you rather be someone else other than yourself?” Because I can't separate who I am, from my disability. It's the experience of living in my body. We all have experiences living in our bodies, in the world, and they're all unique. They make you who you are, your interactions with people and your environments are what make you who you are. And going through the world as a deaf person isn't something I would give up just to fit in with a normative sense of what hearing people think is the way to go about in the world.

**Teresa:** This is Teresa. And what I'm thinking about is how having so many different identities shapes my response to that question. For example, I'm deaf. Yes, and I grew up hard of hearing and I'm a woman. I'm straight and cisgendered. And I'm also Arab American, and so it's all of those elements that become who I am and I can't unplug one component just pulling out the deaf part or pulling out the female part. All of these are interconnected and intersectional for my sense of identity. And they're all valuable parts of my life.

**Rosemarie:** Thank you. So all three presenters this evening have told us how they use the designed and the built world in order to flourish. Rachel and Haben have explained the communication tools that they used to extend their bodies out into the world in order to connect with other people. Both deaf people and hearing people. In this sense, people with disabilities are what Elizabeth Jackson calls lifehackers. We take the given tools and the ways of doing things of the non-disabled majority, and we make them anew for ourselves. Now, all three of you have suggested that this opportunity for innovation and resourcefulness has benefited you in adapting to living in a world that's not built for us. I'd like to invite you each of you if you'd like to give us a few more examples of how this capacity for resourcefulness and adaptability has benefited you or other people from our shared disability community.

**Rachel:** This is Rachel, I'll start and respond to that. I would say my answer is probably familiar to a lot of the deaf signing people in this audience, oftentimes in the hearing world, people think that speaking and hearing is the only way to communicate. But when I travel internationally, I travel around the world, and I meet strangers who will of course at first try to talk with me. And even if we don't know the same sign language, somehow we find a way of communicating, whether it's with gesture, physicality or facial expression. I'm able to connect with new people. And it's surprising. It's surprising to many of my hearing friends sometimes.

I remember a while ago I was traveling with a friend internationally, abroad, overseas, and we did not speak the local language and we went into a shop to buy some sunscreen because it was a really hot, sunny day outside and we hadn't packed any. So we went into the store and my hearing friend, in her hearing way, went to the woman who worked there and started to say, “Sunscreen, we need sunscreen.” She tried writing it down in English. But again, mind you, this woman did not speak English. We were overseas. So their language for two hearing people was a barrier. I went up to the woman and did this. I gestured, rubbing sunscreen on my face. I gesture to the sun above and showed that it was very hot, and my hearing friend was floored by how I had been able to traverse that barrier. It was a new option for communication she hadn't considered. That's something that many people would call deaf gain, that ability to use our deafness to find new ways of overcoming obstacles and new ways of interacting in a visual, tactile way to communicate. Do you want to add anything, Teresa?

**Teresa:** Yes, I would like to add a similar point about deaf gain. So ASL is not my first language. I have many of you who are signers might probably recognize. And when I arrived at Gallaudet University, and which is a signing university, everyone signs to varying extents and I was trying to figure out how I can teach philosophy in sign language. And it occurred to me that what I need to figure out is how we do philosophy in ASL. Maybe I'm not starting borrowing from English per se. But how can I address my students and invite my colleagues into discussions about how we can do a deaf philosophy. And then we may be able to see what we can contribute to philosophical discussions in general, because it's not just about what we can figure out in terms of how to we can accommodate the greater society, your hearing world, but how hearing society can also accommodate the deaf community and what we have to contribute to one another.

**Rosemarie:** Since we have a minute or two, I'll add something, of course, to my own question. Rachel and I work together. And one of the really interesting, I guess, resourcefulness experiences that have come out of working together is that we have, even though we both identify as people with disabilities, we have complementary and yet contrasting preferred modes of communication. I don't type and well, I kind of can type. But my preferred mode of communication, of course, is talking. Rachel's preferred mode of communication is typing, and in working together, we have used technology in really interesting ways to discover delightful new languages, a kind of poetics that comes from my dictating, talking to my machine and her inputting in her machine with her fingers. And it's been really, I think, interesting for us to learn or to develop this new poetics really in our communication together.

**Rachel:** So jumping on from there. This is Rachel again, learning how we think in a way that we don't normally think is another thing that's been instrumental for me. I don't talk to my phone. I don't dictate messages, but then I stop and think about talking to my phone and dictating, how would that work? I mean, obviously for you, you don't type emails. So maybe we should be thinking about . . . In doing this, we're entering into each other's worlds and getting insight into what the other things and getting a look at each other's experiences is truly wonderful.

**Teresa:** And this is Teresa also adding a comment. I think it's really interesting to think about how our very recent conversation of the four of us having and figuring out, OK, you know, Haben gave me the keyboard and then Rachel was speaking and I'm looking up at her speaking and I'm also looking down and I'm typing, and I was just thinking, how, you know, it's one big benefit, I think, of the disability community is having this flexibility to see that we have a situation come up and we need to figure out how best to accommodate everyone. And we try something. And maybe if that doesn't work, we have and we'll try something else. And then one more person joins in the conversation and we're incorporating them, is something that I really cherish and admire about our disability community is that flexibility. And I do wish that more people had this flexibility, this innate flexibility in our mainstream society. And I think that's something that's really challenging is how to figure out how to share this attitude of having this flexibility in terms of communication, as well as open mindedness in terms of being able to accommodate a range of experiences and ways of expression.

**Rosemarie:** Thank you. So the last question. So in modern liberal societies, parents have an obligation to provide their children with the sustenance and support that they need to flourish. As Teresa has suggested, modern medical science offers parents ways to shape their children. So they . . . I'm sorry, to shape their children so that according to the preferences that the parents have determined to be the most advantageous traits. Now what all three of you have suggested in your presentations is that what a typical parent might consider an advantage or a disadvantage has not determined your own flourishing. And I'd like to ask you to reflect a bit on this dilemma that modern parents face in the form of advice, maybe that you might have for parents as they make decisions about what they think will be their children's futures and their children's opportunities?

**Teresa:** Well, as a parent myself, I'm very hesitant to give advice, but I'm thinking about one kind of experience that I think is pretty common for most parents. When my first child was born, I remember having this dream as I stared into my child's eyes that they would do all of these kinds of things in the world that I loved things that I appreciated. And then my child decides to love other things, and I'm trying to figure out then how to be supportive of those interests, learn from my child. And at the same time, give them what they want and need with my sense of reasonable limits, with support and love. And now my children have grown. And I think about something that I value the most about becoming a parent are those unexpected experiences, what I learned from my children and what I learned about myself, from being a parent and how the relationship has really shaped both of us and how our environment has shaped those relationships. So if I were to have advice, I would say it would be to be open to what life presents you with in terms of your experience of being a parent because you never know what you get.

**Rosemarie:** I know what you. I do have one of those, so. Rachel, or Haben?

**Haben:** Haben speaking. My biggest advice for parents is to learn alongside your kids. My parents thought, “Learning sign language is beautiful. We should learn sign language.” They never got around to learning sign language. The same thing with Braille. I’ve seen this in other families, too, where a disabled child is in a non-disabled family, and have completely different experiences. It would really be cool if a family could learn alongside a child. So if a child uses a wheelchair, understand wheelchairs. Become an expert in wheelchair use, alongside your child. If your child is deaf, learn sign language with them. Make it part of the whole family. Same thing with Braille, other tools and devices. Learn to use them together. By doing that, you can combat isolation and exclusion.

**Rachel:** This is Rachel again. One quick thing I'd add, I think there's a difference between the perception of learning new things and the burden, and being a burden. Maybe think about it as an opportunity. Think about this as a positive advantage for the whole family that will really enrich the family's relationship. I think Teresa put it well when she talked about flexibility and open mindedness and different ways of learning and different ways of interacting with one another, if parents want to be supportive of their children, they'll do that because it'll have a ripple effect. And if you start doing it with your family, it'll ripple out to the whole community. It won't just stay in that little nuclear family structure. It'll bleed throughout the community and it will benefit everyone because we all are interdependent and have to support each other in our everyday life.

**Rosemarie:** Thank you very much. Now we're going to have questions from the audience that Erik will moderate and the presenters will respond to.

**Erik:** Does anyone hear that now? Before we open it up to your questions, let's just say thank you to our team.

So this is an NEH grant. It comes under the rubric of promoting public conversations, and we are exceedingly eager for all of you to engage in a conversation with our wonderful speakers and our simple plan or request is that either you come to this microphone and ask a question or go to that microphone and ask a question, or indicate to Susan or Bethany that you would like to ask a question from where you are sitting. But whatever you do, please make sure that you have a microphone in front of you. Or if you're signing, please make sure that there is someone with a microphone who can interpret your signing. So. Questions?

**Amber Martin:** Where do I stand? Where should I stand? It's OK for me to stand right here? Hi, I'm Amber Martin, and I have a question that comes with a little bit of a comment before it. So my comment is that I'm seeing a lot from your stories and other people with disabilities noting their stories with a theme throughout them is that we know our own value and our own worth. But part of our job, then, is to teach other people that we have this value and what our worth is because most people don't see it. And so sometimes what I feel like is that I feel like people who don't have disabilities, hearing people, often they're missing something. And that part of my work is that I can see things and I know things about the world that they don't know. And so that's my preliminary comment. My actual question is, how do we address that? How do we address this issue about instructing people and demonstrating our word? Because I think this is a relevant discussion in terms of technology? And does technology have a role to play in this process? And this is for any of you to answer.

**Rachel:** Well, this is Rachel speaking. I'll answer first. I have not finished my PhD in English. I go back to art and literature, and I think we need more stories because stories are what influenced the world and show nuance. There are a lot of ideas about what are norms or what's normative out there. And if we're to be received by an audience, we have to communicate with them through stories. And I think technology could play a role in that effort. I see how technology has been so useful in so many ways for the promotion of sign language in different communities. And I think we're all connected to each other more easily now as signing people, using technology and sign language like video conferencing and video phones. And so it really comes back to stories and sharing stories. Thank you for that question. Amber, I think that's just one short answer, just one idea. But the power of stories is really paramount.

**Teresa:** This is Teresa. I really liked your response, Rachel, and I think that's very similar to what I was thinking as well. Thinking about how our stories have so much power and also our stories have the ability to support connections and interconnectedness and community. And when we get these stories, when you hear these stories, you might be more willing to give some more time and attention to developing a relationship with the person. And I think sometimes people are just afraid, afraid to say or do the wrong thing. They don't want to offend someone. They don't want to maybe call someone out or call someone in. There's a sense of awkwardness and then people just distance themselves, but I think it's really sharing our knowledge, sharing our stories is really one way to emphasize how we can make these connections and have the sense of belonging together.

**Haben:** I’m thinking too that stories are incredibly powerful. We need more positive disability stories out there. One story that’s potentially harmful is the story that people with disabilities exist to teach non-disabled people to listen. And essentially that reduces our whole existence to be props to teach non-disabled people about themselves. And I wish more non-disabled people had more reflection skills, and had more self-awareness. But it just reveals that that’s a very dangerous story, to build this hierarchy. And it continues the hierarchy. So instead of buying into that story, when we see an accompanying idea, the culprit isn’t disabled people teach non-disabled people gratitude or other things. Touch it. Identify it. So we can stop the marginalization on this viewing.

**Erik:** Is that a question over there? Please don't be shy.

**Rosemarie:** And please say your name.

**Julian:** Hey, good evening, everyone. My name is Julian. And the idea of intersecting identities came up a couple of times, and I'm curious as to know to what extent in your experience did you feel more connected to different groups that are particularly marginalized? And I guess a second question would be, to what extent do you see different forms of sort of identity-based oppression, racism, patriarchy manifests itself within the community.

**Haben:** Haben speaking. Our society is way more august in disability discrimination compared to racism or sexism. I mean, I am often told we can’t compare it. We have a hog. We are often told we don’t want to hire an interpreter, we don’t want to make accommodations. And sometimes they’ll make excuses, but it’s very direct about disability. Whereas racism is not only the experience that I’ve been excluded from something because of my race, or that I’ve been excluded because of my gender. And I wish our culture were more aware about how all these identities intersect. I see a lot of disability organizations have ignored race, or ignored gender, but they’re all connected, and we need to advance disability rights, advance LGBTQ rights, racial justice, gender equality, all of that is connected. No one’s going to be free if no one’s free.

**Teresa:** This is Teresa again. You asked about a sense of solidarity. And I think for me, if I see people with experiences of inclusion, my immediate response is to be supportive. How can I be supportive of this person if there was a situation came up and they were excluded? So I think about how my experience might be different, even if it's not racially motivated, but were or ableism. But all these characteristics, all have a lot of people with these characteristics have similar experiences of not being included or being excluded. When we would like to be included, so that exclusion, unfortunately, can be solidarity building, not always, but it can be. I like Haben’s point about focusing on making sure that we recognize all of these differences and how we can really emphasize human rights and our commonalities, that we're not just disabled humans or people of color or women or lesbian or what have you, but rather having this sense that we are all here on this planet and we need to figure out how to work together. I know that seems considerably naive, but I think that it's really important to figure out how we can be supportive of each other for our future. We have to be.

**Rachel:** This is Rachel again, I would add briefly to what Teresa said, I liked your comment about supporting each other and also realizing that my experience is not necessarily directly relevant to someone else's. It's not the same. Yes, I'm a woman and yes, I'm deaf. But other people have taught me different things from their experiences, and I have my own unique view of the world. I remember . . . Any time I meet people to think about how their experiences are unique and how we all are the authority of our own experiences. Everyone is the authority of their unique experience and their unique story to tell. And so how do we work towards building a more collaborative society and more interdependent and supportive community?

**Teresa** And I would like to also add, this is Teresa, that our experience to set up this program even was very challenging. I mean, we didn't know about each other's different perspectives and needs, and we were trying to figure out how to be respectful and at the same time, learn how to best accommodate each other. So we would make some strides and then have to go back and maybe apologize to each other and not step on each other's toes. So it was both humbling and at the same time, very exciting because we were figuring out how to build this collaboration together.

**Erik:** Excuse me-

**Speaker:** I have a question for all three of you, actually. So my question is all three of you are their role models. Are you part of the deaf community? Do you go to deaf events? Do you go to book signings? Because I think a lot of deaf people would look up to the three of you. So I'm just wondering if you are willing to have events like that and what your level of participation is in the deaf community.

**Rachel:** Sure. Yeah, I mean, I love being a part of the deaf community in Atlanta and the New Mexico community, where two pieces from the interpreters and deaf folks there have a great community. And it's such a small world, the interconnectedness is amazing and people know each other from all different places. It's always six degrees of separation between us and I think that it's great because you meet so many different kinds of people, and one really cool aspect of being deaf is that you meet such a variety of people who are brought together by the fact that we're deaf. And sometimes I think I get to meet more different kinds of people from more different places and backgrounds and walks of life and professions, different races. I just two people who have different socioeconomic status, different upbringings, I get to do that more because I'm deaf and I get to stay. I wouldn't get to do that if I just lived a full life in the hearing world. I think the deaf life is so rich and I could never give that up. I could never stop participating in the deaf community.

**Teresa:** And this is Teresa. So I was just talking at dinner with a few people about my experiences, and I started my graduate school experience without thinking that I would become a professor. I wanted to get my Ph.D. in philosophy. And at the time, I was working at a deaf social service organization, and I was very involved in the deaf community in New Mexico, and I really learned a lot. This is where I started picking up learning sign language and being more involved in deaf culture. I was very involved with the hard of hearing community at the time as they age that community. I was also on the board of the hearing hard of hearing organization, and more and more parents were asking for my advice about their deaf children. They see me also as a parent and a role model, and I realized that I was interacting with these little kids at the same time.

And even with my role now teaching at Gallaudet, there are students I'm working with and I really try to be very supportive, whether they're deaf or hard of hearing or they're deaf blind students and try to be very supportive because I think it's important to be very open and honest about their frustrations and the struggles that one might experience. And at the same time, tell them that they can do anything. They have a very strong future ahead of them and they can flourish and thrive. So I think that we can be both a role model as well as figuring out this direct connection with the deaf community, not only with parents. I mean, I don't ignore the parents, and I want to be very supportive of parents who approach me with deaf children. But the role that I see is being more of an advocate for deaf children and also others in our community who perhaps don't have as much of an experience, a positive experience with education as I have.

**Erik:** I wonder if I could ask a question that would bring us back just a bit to some of Teresa's comments about the use of gene editing technology in particular. I'm very curious about getting a sense of the room, in particular people who are part of the deaf community regarding the promise of using gene editing technology, not to ensure that deaf children are not born, but rather to ensure that they are. I mean, that is a logical possibility with this technology. Teresa articulated some concern about the use of the technology to ensure the birth of children who cannot hear. She suggested that that might be an example of the selective mentality run amok. She suggested the possibility that if we start doing that, we are investing too much energy, among other things, in particular anatomical or bodily traits like whether you hear or not. It seemed to me like a controversial issue that Teresa raised, and I wondered if there are people in the audience with views about the prospect of using gene editing for the sake of ensuring that the deaf community endures. Is that is that an issue that arises? Is it a question that has arisen much in the wake of this new gene editing work? That's a question for people on the stage or people in the audience.

**Audience member:** So in terms of your, I guess . . . can you see me clearly? Should I? So as she was saying, she thought that CRISPR can make more deaf children, and for me, growing up as a deaf person, I never thought that I wanted deaf children. I think whatever I child I have is who I had. But for others, maybe they want to have deaf children on purpose, but I don't think that gene should be edited for that reason. If I have a deaf child, I would accept a deaf child. But if I had a child that wasn't deaf, I would be just as accepting. I think CRISPR is an amazing technology. I didn't know much about it, but I realize that, wow, that's incredible. It's something to think about, that that even exists.

**Erik:** So you have articulated what Adrian Ash would call an attitude of acceptance. You want to accept the child that you get in the genetic lottery. And I have an enormous amount of sympathy for that attitude. I wonder if there are other people in the room who embrace rather than or emphasize more than this attitude of acceptance, an attitude of creative control over the shape of our children. I think I see a response. Yes. I’m sorry. Yes.

**Audience member:** Yes. Oh, hi, yes, hi.

**Rosemarie:** And you say your name, please.

**Maria:** I'm signing, and I think the interpreter on stage is copy signing. Yes, I'm Maria and I'm deaf myself and my family is hearing and they're also Spanish speaking. My parents moved from Cuba to the United States. I was born deaf, which is very common. I was found out that I was . . . I was discovered I was deaf when I was two years old and my parents were quite shocked. They were speaking. They only spoke Spanish. And so, I don't know. I mean, I feel sort of torn. I was growing up deaf as well as hard of hearing. I didn't have exposure to deaf adults when I was when I was a child. I went to a school where they didn't use sign language and I was encouraged to speak and try to hear best I could. And especially with issues of race, being Hispanic from a Cuban family is very challenging. They're also very religious and Catholic, a background, they couldn't communicate with me. I could see how frustrated they would be, trying to figure out where to send me to school. I was sent to school at five years old and I was very isolated and I wasn't doing well.

My parents brought me to church with them. They were seeking all kinds of different solutions. I went to a different school when I was seven. My language was considerably delayed as a result. And so I didn't know all of this when I was growing up. I didn't learn ASL until I was 21 years old. And so I see through my friends who come from deaf families, I was invited once to a family event where they were all signing so fluently at the table and they got to have a meal with each other and enjoy their conversation. And they all identified as deaf. And it was overwhelming for me to be able to see this for the first time. And now I meet many deaf people, or perhaps even hearing people who have deaf children who don't seem to be bothered by it. The assumption is sign language and giving their children language. So all this debate about whether or not they should sign or talk only should just be totally forgotten. The focus should be on sign language so that their children can thrive. In my in my time when I was growing up, I didn't have that opportunity. I was just so jealous. I want my education to be able to develop. So through my friends, I acquired language and I was relentless. I went to NTID in Rochester, National Technical Institute for the deaf, was a student there, learned sign language among my peers. And I just read more. I just worked harder and it was took me 20 years to get to this point. That's my story.

**Erik:** Thank you.

**Teresa:** Thank you for sharing. I'd like to add something to that, actually. I really appreciate this story and actually, we have a lot in common. This is Teresa. Just to say again, I think that's something that's really important to note about your story. You emphasize environment and what kind of resources we have as a society, what is provided by society, and also how our gaps in society are really shown through your story. Thank you for sharing that I really appreciate, it is very touching for me to hear.

**Interpreter:** Yes, thank you so much.

**Erik:** OK. Please go ahead. The woman. Yes, please.

**Audience member:** Yes, I was going to . . .

**Erik:** I believe this woman right here was next. But you need a microphone.

**Rosemarie:** Can you just give her yours?

**Erik:** I lost my phone tonight. It happens to everybody and I want to . . .

**Joyce:** I'll get it back from her.

My name is Joyce. I'd like to make a comment and then ask for a comment. I've had a complete, single sided deafness since childhood, and my oldest and best friend has low vision and a guide dog. I became a neurologist and neuroscientist, and she became a computer programmer and artist. And we're both mothers in different states. I want to comment on the extraordinary poise, resourcefulness, self-awareness and awareness of others that I've seen on this stage. I've rarely seen that, and I would like you to address the issue of people with acquired disabilities, either the deafness, blindness, loss of motor function, who see it, who may initially see it as a loss, and how you can support them in acceptance and flourishing in their lives.

**Haben:** Haben speaking. For me, it’s absolutely important to give time to mourn the loss of that ability, It is a huge transition, not just for the person, but the whole community has to adapt. And once you have time to grieve the loss, then you can move on to seeking solutions, building those skills. And people take a different amounts of time to make that transition. For some people it’s bigger than others. There are training centers around the US, for blindness training for people who lose vision later in life and who need time to learn Braille, how to travel with a white cane, how to learn assistive technology. The programs are anywhere from three months to nine months. So it’s a significant transition. But if the community is supportive, it helps people give them space to create and supports them to build up those skills to prepare to be in life with that disability. That’s where you can be supportive.

**Erik:** Haben, may I ask you a question? It's Erik speaking.

**Haben:** Yes, you may ask me a question.

**Erik**: Thank you. It's a hard one. I think it's hard for me anyway. You are as enthusiastic about some technologies as anyone on the stage. This whole, the premise of this program is that people with disabilities are especially well-situated to think about emerging technologies because they have a lot of experience, both using new technologies and refusing to use some or resisting the use of some new technologies. So what I would invite you to do is to tell us your thinking about this emerging technology that Teresa was talking about. What do you think about the idea of using gene editing for the sake of ensuring that children are deaf or that they are not deaf? Is that a realm in which or about which you would be enthusiastic? The idea that we can use this particular technology to shape our children?

**Haben:** In a way, I’ve already answered the question. I’m a huge fan of tech and tools. Hearing, sight, are just tools. They’re not necessary. There are lots of successful blind and deaf people, who don’t want hearing, who don’t care about hearing. Some people ask me, “Oh, wouldn’t you love to hear music?” I don't care. There’s this idea that I must want to do all the things that hearing people do, or I must want to look at paintings the way sighted people look at paintings. But those are not important in my life. It’s absolutely possible to have a successful life without those tools, just like I can go to California without wings. But if you give me the option to have wings, and to skip TSA and the lines, and crowds, I’d gladly take it. Now, gene editing is more complicated than that. And I’m not as well-versed at it as Teresa or Rosemarie, but based on what I already know, in general, I’m a fan of tech, and I’d love to give people the choices to use tech.

**Erik:** So I hear you, Haben, and I’m—

**Teresa:** I actually have a comment, Erik, if I may. This is Teresa.

**Erik:** Please.

**Teresa:** So what I'm thinking about your question that you've asked us to comment, about people becoming disabled, becoming deaf or becoming mobility impaired or have a different kind of body a way of being in the world. And I think that Haben is exactly right. You're giving . . . People need the time to mourn because it is a loss. It can be a real loss for the person as well as their families and their communities, and that we're all figuring out ways to adjust. And I think that part of that challenge is sometimes we've grown up with our bodies. We've grown up as hard of hearing, deaf, DeafBlind, different kinds of hands and bodies and ways of being. And we figure out how to live as we are and we think and we overlook about how hard that change and that transition is and can be. And so maybe it's not the best idea to just take a person who's become late deafened and then have them thrown into the signing community. Maybe they need to be considered in terms of what they want and what they value, and then have time to really take in those values and reflect on how we can be supportive of what those people want. And at the same time, through conversation and through sharing of stories we can show what is possible, what their possible experiences could be. Something to consider.

**Erik:** I'm going to take just one follow up, Haben, if I may. Does it make a difference if it is you who gets the technology to fly or if you get for your fetus or embryo a technology to ensure that they can fly? Does that make a difference? Is that part of your analysis, or are you enthused as enthusiastic about learning to fly yourself as you are ensuring that a child of yours be able to fly?

**Haben:** If my child got to skip TSA and I didn’t, is that going to be fair? The other part of that though is that if I decide before that child is even born, that doesn’t give the child the opportunity to choose whether they want this extra tool or not. And in a way, it’s extra. We can live without hearing. We can live without sight. And we can live without wings and just deal with TSA.

**Erik:** Yes, exactly. Thank you. I don't know who was next. There are a lot of hands.

**Rosemarie:** And also in the front as well.

**Erik:** Can someone keep up to the . . . Help with the . . . Please listen to this person.

**Rosemarie:** Erik, we have someone in the front too.

**Erik:** Okay.

**Teresa:** Who’s going first?

**Simi Linton:** Hi, my name is Simi Linton. I'm very captivated by this conversation and the dynamics and so forth. There are two issues that I'd like to bring into it. One is that at the beginning, people were talking a lot about stories. And one of the stories that I think needs to be in this conversation is the story of disability, basically the history of disability.

**Rosemarie:** Yes. Yes.

**Simi:** And without bringing in that larger narrative than some of these personal narratives, I think, lose their valence and weight.

**Rosemarie:** Yeah.

**Simi:** And that is a concern.

**Rosemarie:** Right.

**Simi:** The second point, and I have three, the second point is that we are talking about access to technologies as if they are evenly distributed and they sure are not.

**Rosemarie:** Oh, they are not.

**Simi:** They are not. I just came from a demonstration of that in part had to do with a huge number of disabled people who are incarcerated. And I think it is critical that we talk about those people who have access and those don't and that we're not just making personal decisions.

We are making decisions in a historical context and in a political context that has to be brought into the conversation. And I had a third point, but I can't remember what it is. Maybe it was that I combined both who gets access to it . . . And, oh, and we live in an ableist culture. And I remember participating in a conversation at Gallaudet many years ago about prenatal screening and selective abortion and the counselors who were charged with talking to prospective parents who are so ableist. And they didn't hear themselves. They did not hear themselves. They were almost insistent to me, and my voice got pretty loud that they were neutral and they were supportive of parents, whatever their decision is. And we know that that is bullshit. And that's where I'm feeling a tension in this conversation because of the lack of historical context and political context and the power differentials among those who can make those choices and people who can't.

**Rosemarie:** Mm-hmm.

**Erik:** Thank you very much. I am afraid that we are out of time, so we're going to have time for one last question. So who can handle that pressure? And there are a lot of fingers that are being pointed.

**Audience member:** Right here.Hi. Hi.

**Erik:** Bethany, can you see the person who was there?

**Ryan:** Hi. Can anyone see me signing OK?

**Rosemarie:** We need a mike.

**Ryan:** Hi, I'm Ryan. Can you see me? Should I sit down? Am I too tall?

**Interpreter:** I can see you. It’s just the light. It’s hard.

**Ryan:** Should I sit down, is that easier or—

**Interpreter:** Or maybe—

**Ryan:** I’m considerably tall.

**Interpreter:** Maybe move and stand in the aisle?

**Ryan:** I’ll go to the aisle.

**Interpreter:** Yeah, that'd be helpful.

**Ryan:** Is this better?

**Interpreter:** That’s better. Thank you.

**Ryan:** Great. Great. Thank you. Thanks. No problem. So I'm Ryan, and just back up a little bit, Erik asked us in terms of being part of the deaf community about CRISPR and the technology and if parents want to make a deaf child on purpose. And as a deaf person, my response would be to that, “No, I don't like that idea, actually.” Really, I would prefer just to have the child I have that nature intended me to have, or God, have you, wanted me to have a hearing child, then so be it. If I had a deaf child, that would be also great. But I encourage parents to be able to communicate with their children if they have a deaf child. And I actually have a question for the panelists. Know the deaf community has considerable divide in terms of spoken language or being supportive of sign language. And Rachel, you commented that you go back and forth between speaking with hearing people and also signing with deaf people. And so I'm wondering if you would sign with your child or would you speak with your child? In terms of giving resources to parents, who is responsible for doing that? So there's something out of question I wanted to put out there.

**Rachel:** That's a terrific question and an a very important one. To answer your question, Ryan, I think it's really important to have complete and equal access. I think it's important to give children access to sign language growing up because it's their natural way of communicating. I think it's the only way to ensure that children don't have language deprivation and suffer from the consequences of that. Sure, give them access to speech therapy if that's what they want or what you want, but it doesn't have to be an either/or, signing or speaking. I think it's not that binary. I think children need access to language, and the most natural way to access language for deaf children is through sign language and to follow up to the other part of your question. Yeah. I mean, right now, the hierarchical system of how we identify when children are born into hearing families is incredibly complicated, and we need more deaf people on the teams advising parents and parents of deaf children so that they can make informed decisions about their children's futures because parents often don't know about the resources and options available. They don't know that learning sign language is an option to let their children flourish. So I think it's a process. I had a really supportive family and great role models growing up, and that was instrumental to my development. I think more people need that.

**Erik:** Indeed, more people need that. I am sorry to have to cut it off when I know there are still questions. And in particular, I'm sorry to the woman who was standing over there. I promise we will be up here and you can come up and talk directly with the speakers. And there are a number of people who we want to thank, and I would be grateful if the people in the booth could possibly project that long list of people we would like to thank who made this event possible.

**Interpreter:** But now we can't see the captions.

**Erik:** We are working out some kinks there. There is a lot of complicated technology at work here. And the one thing I can invite you to do is please take a look at this list of extraordinary people who have worked very, very hard to put together this first event.

**Interpreter:** People are trying to read the caption.

**Erik:** And last, what I will do is thank all of you for coming out on a very cold winter evening in New York City. Thank you very, very much for doing that. This is the first of six events. I hope that many of you will come to the next five, so if we could end by thanking once again our wonderful panel.

**Rosemarie:** And thank you, thanks to everyone here.

**Erik:** I hope everyone gets home safe and sound. And the woman who was asking a question, please come up.