Navigating: On Disability, Technology, & Experiencing the World
Tuesday, 29 September 2020
3:00pm - 5:00pm ET

**Liz Bowen:** Okay.Welcome, everyone. Good afternoon. This is “Navigating: On Disability Technology and Experiencing the World.” My name’s Liz Bowen, I am the Rice Family Post-doctoral Fellow at the Hastings Center, and the moderator for this event. A few things before we get started. Access note, we do have ASL and captioning provided. In a few moments I will paste a link in the chat for a full live transcript. If you want to type the URL into the browser yourself, it’s www.thehastingscenter.org/captioning.

We will be recording this event. It will be available after the event ends on the Hastings Center website. Although as audience members you are not able to be audible or visible, you can enter questions into the Q & A function of zoom at any time. We will be monitoring questions throughout the event and offering some of them up to the speakers in the second half.

Again, you can submit questions at any time and we will be watching those. Without further adieu, I will get off of your screens and introduce mu colleague, Erik Parens, who is the Director of Bioethics and Humanities at the Hastings Center. Take it away, Erik!

**Erik Parens:** Thanks very much, Liz, for all of your contributions to making this event happening and thanks to all of you for joining for this second in our series of six events funded by our endowment for the humanities. The purpose of our series is to broadcast and to explore one fundamental theme, which is that people can flourish in all sorts of bodies.

To flourish, on our understanding, means to exercise the capacities we were born with in pursuit of the goals we find meaningful. None of us needs a different body to flourish. We need different, more supportive environments.

I should say that no one has articulated our theme more powerfully than Rosemarie Garland-Thomson, who is a co-organizer of this event, a senior advisor to the Hastings Center, and, as many of you know, a pioneering disabilities scholar. I should also mention that we at the Hastings Center view this series as an important part of our 50th anniversary celebration.

Because the term bioethics has many connotations, I want to say something about what is meant here at Hastings Center. Since its inception, many of us have thought critically about the meanings of many familiar medical technologies, like, for example, those monitors that are above patients’ hospital beds. The concern is that in drawing doctors’ attention to a single feature of how a patient’s body is functioning, such technologies can take doctors’ attention away from the patient as a whole person. Bioethicists at Hastings have been concerned that reproductive technologies like prenatal genetic testing are being used to ensure that only people with certain sorts of bodies will be welcome into the human community. And we’ve been concerned that medical professionals sometimes foist onto people with atypical bodies some very old fashioned technologies, like leg braces, with a view to fixing those people who don’t need any fixing at all.

So we at Hastings have often emphasized that such technologies have been integral parts of systems that can thwart the flourishing of many people, in particular, disabled people. In developing that line of critique, we have not always given equal attention to the myriad ways that people in general and people with disabilities in particular use technologies to promote their flourishing. When we conceived this series, we said we wanted to explore the simple fact that technologies can be used to thwart and to promote flourishing. We were trying to use the term “technology” as a hook to getting to our fundamental theme, that people can flourish in all sorts of bodies. Now, frankly, today, it's not crystal clear to me today that the term “technology” is all that great of a hook for getting at our theme, but a beautiful thing about being in conversation, as we are today, is that we have an option of revising our thinking.

Indeed, the question of the usefulness of the term "technology" might come up today in the panel discussion that Rosemarie Garland-Thomson might moderate with our speakers, or it might come up in the conversation between all of you in the audience and our speakers that Joel Michael Reynolds will moderate. Joel was the inaugural Rice Family Post-doctoral Fellow at the Hastings Center, and he is the co-director of this series. He’s also a philosopher, bioethicist, and disability studies scholar who is now at Georgetown.

The term "Activity" is another hook we have used to get at our fundamental theme. Each of our six events is linked to an activity that can be crucial for functioning for flourishing, and each of our speakers today will consider the activity of navigating.

Our first speaker is Yomi S. Wrong. Yomi is a healthcare professional, a freelance journalist, and disability justice activist who will explain the fundamental importance of being able to choose technology that fits with one’s sense of oneself and allows one the ability to navigate freely. Before I turn it over to Yomi, please remember that if you’d like to ask questions, you can use the Q & A function. Now it's my very great pleasure to turn the screen over to our first speaker, Yomi. Yomi Wrong. Yomi, over to you!

**Yomi Wrong:** Thank you, Erik, and hi everyone, I'm Yomi Wrong joining from the land of smoke and fire, otherwise known as northern California. I am an African American woman with dark, curly, shoulder length hair and glasses. I am a little person. I’m sitting in a power wheelchair with a bookcase behind me. I’m excited to be here and appreciate the Hastings Center for inviting me into this conversation on navigating.

The story I chose today is very tender to me. I’ve not spoken about it much, and feel nervous to share it, but here it is.

I was my best self at 9 years old. Happy, witty, and confident, I truly liked who I was. I had hit a stride in the 4th grade. I was mastering long division, reading and writing above 8th grade level, had beautiful penmanship and performing at the top of my class. Adding to my confidence, I was cute and popular! There is a picture of me on the bookshelf over my left shoulder. That's me at nine years old, in the 4th grade. It's black and white, I have pigtails and bangs, I'm smiling and wearing a velour shirt because this was, I don’t know, 1981 or so and that was the fashion.

So at that age, kids gravitated to me. I was outgoing and a natural leader who tried to always make others feel included. At school, I was often paired with shy kids, my task being to help draw them out, or I was paired as a study buddy with someone needing extra help in a subject where I excelled. This latter gift is how I straddled two different realities at my elementary school, and this lead to an unfortunate incident, that would shape so much of my disability identity.

My 4th grade teacher thought I needed some more intellectual rigor and arranged for me to quasi-mainstream into a 6th grade science and math class. Mainstreaming, if you’re unfamiliar with the term, is a process of transitioning disabled kids into a segregated educational settings, into public schools with able-bodied kids. Now, I very much liked my school, my classmates, and especially my teacher. But to be honest, the experience of being bussed 20 minutes away while my friends on my block got to walk together to the neighborhood school built up in me a longing.

I wanted to be with them. Going to a different school excluded me from a huge part of their world and the divide was becoming harder to overlook. For instance, when they laughed about the antics in Mrs. So-and-so’s homeroom, I couldn't follow the joke. After school when a gaggle of kids charged into the bodega for ice cream or candy or to the local pizzeria to play video games, I was never included because I wasn’t with them. I knew nothing of the games they invented at recess. I knew nothing of team sports or how to navigate a cafeteria. I’m sorry. What exactly happens in a lunchroom? You see, in my special education school, we took our meals in the classroom. Except for physical therapy or our trips to the bathroom, we rarely left our classroom, or each other. I guess we were too precious for recess, too fragile to jockey in hallways, too fussed over to rip and run after school.

Being in special education for me meant being segregated, virtually invisible to anyone outside our walls. So this chance my teacher was giving me to leave my cloistered environment and dwell in a rarefied space with able bodied children felt like a golden ticket.

The school I attended was on the first floor of a multi-story building. The upper floors was occupied by a public elementary school with hundreds of kids we never interacted with. So each week, I left my campus on the first floor and rode an elevator up to the public school. And of course, I was a freak at first. Kids often giggled, but over time, we all got used to me being in the space. Soon, I was paired with a boy who needed support with math and we became great friends. I don’t remember his name, but I remember his kindness and smile, the happiness I felt when the elevator doors would open and he would be waiting there to escort me to class. We had so much fun together.

A few months into the schoolyear this perfect boy asked if I wanted to go to a movie over school break. Calm down, was not a date. We were 9 years old. But it was a big deal. Meeting up for activities outside of school was a social and developmental milestone I was missing out on. Now some of the details of the movie caper are fuzzy, but this is what I remember. It was somehow worked out that his big brother and my big brother would escort us to a matinee. And I feel like these teenagers must have hijacked the encounter because they each ended up inviting an extra friend, but whatever. Movie day arrived, and my mom left money for tickets, snacks, and cab fare. This last detail is critical. You see, had we taken the bus, I wouldn't be able to go to the movies in my wheelchair. My wheelchair was clunky and rigid and impossible to haul onto a bus or subway. This was 1981, in the Bronx, New York, a full decade before the Americans with Disabilities Act made public transportation accessible. But with cab fare there was no need to leave my chair behind. With a little muscle, my wheelchair could be folded up into the trunk of the car.

For reasons still mysterious to me, someone made the decision not to take my wheelchair. It was decided I would go to the movies in a stroller.

Now would be a good time to mention that for most of my early childhood I had two modes of mobility. The wheelchair, which I used primarily at school and around my neighborhood, and a lightweight toddler-sized stroller.

Navigating NYC, and, really, anywhere as a pedestrian was much easier to do with me in a stroller. Unlike with my wheelchair, one person could pick me up and collapse the stroller in seconds. We could run up subway steps or get on a bus or even hail a cab very quickly. The stroller weighed next to nothing.

In the NY of my childhood, a toddler stroller was the most convenient piece of adaptive piece of adaptive technology because it allowed for greater access and movement around the city, but the stroller also changed how I showed up in the world. Tucked down low to the ground as I was in a stroller, everything about me became obscured. My age, what grade I was in, even the fact of my disability. Unless I opened my mouth to speak, strangers could easily take me for a toddler or a little kid or maybe three to five years old.

Let me say, this worked brilliantly at amusement parks that let toddlers and little kids in for free, but I don't think this was the motivating factor for the person taking me to the movies that day. It was the carrying me down the stairs to the cab, the breaking my wheelchair apart, the putting it together at the movie theater, and then repeating the whole rigamarole for the return trip home. I acknowledge this was a hassle. Again, I blocked out some details of what occurred next and no one in my family remembers it quite this way, but it didn't happen to them. Emotion imprints memory and here’s the way I experienced it.

Someone said, “We’re just going to take your stroller, okay?” Um, no. No, I will not go to the movies in a baby stroller. "But you've done it before!" That was before. This is today. Different stakes. I threw an epic fit My mother was called at work to mediate. I wanted her to force these people to bring my bloody wheelchair! Someone said, "If he's really your friend, Yomi, it won't matter how you show up!" They were right, technically, and I had no counter argument. Again, I was nine and having a tantrum. I do remember not wanting to go anymore but being forced to, anyway. I remember feeling so sick in the cab. I remember hot tears running down my face. I remember praying we would crash. Dramatic, I know, but for me, seeing a school friend out in the real world for the very first time was a big deal. Must we make it awkward?

I feared my friend’s reaction, seeing his smart school chum, stripped of independence and infantilized, seeing me so out of context. Would it be too much? Indeed it was.

I recall this next sequence in slow motion. That sweet boy dancing nervously in front of the ticket booth, rushing to greet the cab when we pulled up to the curb. My sister emerges, pretty and smiling. She whips out the stroller. My friend looks confused. Then she lifts me from the backseat, plops me from the stroller, and straps me in. My friend looks horrified. The older boys with him look befuddled, unsure who has shown up, certainly not the vibrant girl he's been talking about.

The moment turns rancid with my mortification. My sister, ever my champion and my shield, breaks the spell by striding confidently to the ticket counter. She did her best to lighten the air. But my friend looked away, and I did too. We did not talk the rest of the day. Back at school, things shifted. We stopped studying together. We stopped looking at each other. We stopped being friends.

Like I said earlier, I've hardly spoken of this to anyone, but it has stayed with me and I have spent 40-some years trying to get over it, to make sense of it. My wheelchair, more than any piece of assistive technology, is the thing I will fight for. Because there are real and unforgiving consequences for disabled folks when we are denied technology of our own choosing. The wrong technology can cause physical pain, or secondary impairments, or deep emotional scars. When I choose for myself, I source technology that is as much about maximizing my function as about making the right statement of who I am.

My chair is how I first get read when I show up in any space. I fill in the rest, of course, but my chair gives much important information at the start. Thank you.

**Liz:** Hey, everyone, we're going to pause for a moment. Two things. First, our ASL interpreter needs to switch, and second, we know there are some problems with the closed captioning. We’ve been trying to figure out what the source of the problem is, and so far we have not had any luck. I will reiterate. For the time being, there is a link to the full transcript in the chat but we understand that's not adequate for everyone here, and so we're doing our best to resolve the problem with the closed captioning. I think it may be an issue with the Zoom webinar format, because it seems like the toggle closed caption option is not showing up for people. But we’re really not sure what’s going on with that. If anyone has any wisdom to what the problem might be, we appreciate you letting us know.

Okay, I'm going to let the interpreters switch now. Thank you.

**Erik:** And while our interpreters are switching I will thank Yomi for such a wonderful talk and introduce Rod Michalko. Rod is a sociologist, memoirist, and disability studies theorist who lives in Toronto and teaches at the University of Toronto. As soon as Liz says we're ready, Rod, it’s over to you.

**Liz:** Okay, apparently the closed captioning has just showed up for most people now. Thank goodness, and again, we really apologize for that lapse in accessibility here. Thank you for bearing with us, for all your patience, and take it away, Rod.

**Rod Michalko:** Thank you. First of all, I’d like to say just a correction on the introduction from Erik, although thanks for that. I am mostly retired from the University of Toronto right now. That’s number one. Number two is it’s, Yomi, that was a beautiful talk and I’m going have to remind myself never to follow her again in the future. It’s a tough act to follow!

I'm a blind white guy and I’m, I think, about average build. I’m not sure about that. I think I have long, kind of wavy hair and I'm wearing dark glasses that are blue and hopefully matches my purple t- shirt. If not, I’m going to blame my partner Tanya for that, in case it doesn’t match. I’m sitting at home. There’s a bookcase behind me. I'm going do my talk on a piece of technology that’s so dated that I’m sure many of you don’t even know the term. It’s called a Dictaphone, and on this Dictaphone is a tape of what I’m about to say. And I’m going to repeat it with this ear thing in. So I’m going to start that, and please indulge me for your time. Thank you, and by the way, welcome. Everybody, I'm glad you're all here.

All right. Here we go. The freedom of movement is something many people take for granted. Some have the freedom to move from one country to another, from one region to another. Some move freely between careers and jobs and many have the freedom of bodily movement, the freedom to sit, to stand, to walk, and to run. The freedom to move freely in a city such as New York or Toronto, where I’m from. The freedom to negotiate a flight of stairs, escalators, elevators, the freedom to drive cars, take public transit, and the freedom to negotiate the rest of the environment, built especially for those who take the freedom for movement for granted.

There are some, however, perhaps even many, whose freedom of movement is restricted beyond any typical limitation and for whom free movement is not taken for granted. I am speaking here of disabled people. We negotiate, one that is not built for us, and we do so daily. I want to talk about the unique world my blindness gives me and how my guide dog Smokey and I moved freely with my blindness in this world.

First thing I want to say about this blind gig, is that, while it does impose some limits, it is sight and the way it organizes the environment that hits my freedom to move, and hits it hard. The material and the virtual worlds are built by and for those who see. This is the world I negotiate, and have negotiated all my blind life.

Sorry. Movement in the world, free or not, is almost always accompanied by technology. Whether walking with the technology of footwear, traveling in airplanes or trains, whether moving in wheelchairs, with white canes or with guide dogs, whether negotiating the virtual world with nimble fingers on a keyboard, and quick eyes on a screen, or with software that imitates such movements, poorly as they do, in whatever way we move, with technology by our side.

For many years I moved with, literally by my side, my guide dog Smokey. He didn’t so much move me through the world, and in blindness, as he accompanied me in my movement. Although he did guide me through the world, I experienced it more as a liberation, as free to move. This was my experience with Smokey in the beginning of our life together. Soon though, I began to realize it wasn't only that Smokey accompanied me. We accompanied one another, blind man and dog moving together, negotiating a world not strictly ours. The world in which Smokey and I moved was a sighted world, one where people looked and saw. It was a human world where people moved so many and so freely on two legs and in a world they typically experienced from a point much higher than the place from which Smokey viewed the world.

It was a sighted world, a human world. There were blind people and dogs in that world of course, but it wasn't the blind world nor a dog world. And it was in this world that Smokey and I moved.

We were not completely strangers to the world, however. We had experience with the world, strange as we were from it. Smokey was a dog, an animal. At the same time though, he was a guide dog, a highly trained and intelligent service animal. Moreover, like other dogs in our culture, Smokey was domesticated. The world of humans was his home, even though Smokey himself wasn't human. But with his high level of training, he was not only accepted in the world of human, he was understood as a useful and valuable member of society, in a world fashioned for and by sight.

I, in contrast, and not in the way Smokey was an animal. And yet there was something unnatural about my humanness. It is natural for humans to see, I don't. And therein lies my unnatural human status. Whereas Smokey represents domesticated nature, I represent the unnatural nature of the human, with eyes gone wrong. The estranged familiarity that Smokey and I were, was the fertile grounds for experiencing the world stripped of its taken-for-granted character. Our life together presented us with the unusual opportunity to see some of the ways our world is put together.

Ways that are as invisible as sight itself. Smokey not only showed me ways of negotiating the world, he gave me a glimpse of that world from a different viewpoint, a viewpoint that revealed some of the invisible features of the sighted world. The most crucial thing he gave me was a further reach into the world. He also firmed up my contact with it, a contact that permitted further reach. Until then, I had three points of contact, my two feet and the artificial contact of my white cane. Smokey gave me six. My two feet and his four paws, none of which were artificial.

My reach into the world was now extended by the length of his body, by the speed and grace of his movements. I didn’t so much follow Smokey, as I moved with him through the world, negotiating it with a habitual rhythm that came eerily close to moving confidently and with, most surprisingly, joy.

There were of course many close calls Smokey and I had as we moved, such as the time that he suddenly cut across my body and moved me away from a speeding car running a red light. There were also many fun times, such as a time we visited a summer fair in rural Nova Scotia. He loved animals and walking through one of the barns housing farm animals proved to be Smokey’s favorite time. It wasn't easy to encourage him out of there, and when I was finally successful we continued our tour of the fairgrounds. Smokey’s intricate movements around the unfamiliar grounds soon were too much for me and I allowed Smokey to show me the fairgrounds in the way that he chose. I got caught up in Smokey’s flow, clearly his intention, since, in a few moments, we were back at the barn.

Smokey did free my blindness in the world even in the midst of the stereotypes and bizarre media representations of blindness our culture offered as we moved. But as Smokey and I moved, it released yet another freedom. The freedom to belong in that world and to belong on our terms. Smokey did help me negotiate this world and he made it clear the world we were moving in and through was our world. We belonged there. And we belonged as blind and sighted, moving and living together as human and animal, forming the basis of this strange yet familiar movement and life.

My left hand on Smokey’s harness and a simple, "Forward, Smokey," we entered the places and spaces, the sounds, the touches and the smells, that were our world. A world we released into our world. We were one of those places and spaces, one of those sounds, touches, and smells. We were not, though, merely one more of "them," seeing with the banal gaze of difference. Instead, we were distinct. We were the sight of blindness, not as the banality of difference, but as the richness of distinction and never before had I moved through the world where sight did not have the right of way.

Before I met Smokey, and then movement, speed, grace, the world opened before us and Smokey and I elegantly entered it.

Thank you.

**Erik:** I'm sorry, Liz, I thought you were going to give a chance to switch interpreters but I think no. I believe we're going to turn it over to Kim. Rod, thank you so much for another just spectacular talk. Kim Q. Hall, our third speaker is a philosophy professor and scholar of Gender, Women’s, and Sexuality studies at Appalachian State University in Boone, North Carolina, and she is currently teaching there full time. Rod, I’m sorry for that mistake earlier. Over to you, Kim!

**Kim Q. Hall:** Thanks, Erik. Thanks, everyone, for being here and thanks again Yomi and Rod for these wonderful talks.

My walk has always been a problem, or, should I say my walk has always made me a problem. I was born with what, in my life, has often been referred to as a malformed hip joint. More specifically, I was born with a shortened acetabulum, which mean that my hip socket did not completely curl around my femoral hip on my left side. It was a case, one might say, of arrested hip development. Not enough hip, not hip enough. My so-called birth defect for such anomaly was diagnosed during a routine pediatric exam meant to check for such anomalies. When the pediatrician bent my knees toward my chest and then rolled them outward, he heard the telltale sound of my left femur popping out of joint, and when my mother changed my diapers, my leg would fly off at an awkward angle. I have no memory of what my left hip popping out of joint felt like. However, I do have memories of treatment, of being wheeled into surgery, being casted and braced, having my cast changed when I outgrew it, regular follow-up appointments with the orthopedic surgeon, and the dreaded trip to the shoe store that was I never allowed to get the shoes I wanted for orthopedic and gendered reasons.

I was nearly two when I had surgery on my left hip. This was followed by three months in a body cast, coupled with a brace that consisted of a metal bar between two shoes that kept my feet fixed in position, pointing outwards. All of this meant that my walking was delayed. One of my uncles attached four wheels to a piece of plywood so that I could roll around the house. My earliest ambulation in the world was headfirst, on my stomach. My mom says I was hard to catch. By first grade, I was no longer braced at night but still had to go to the orthopedic clinic where I was X-rayed and I was required to walk up and down the hallway in front of the diagnostic gaze of the orthopedist and my mother. The result? The orthopedic conclusion is that I was fixed, cured, if you will. The result from my perspective: I walk, but with a difference. In my remarks today, I want to reflect on why and how this difference matters.

My focus is not on whether technological intervention is good or bad. Technology can be informed by an ableist commitment to disability elimination and it can be used in creative, resistant ways for disability flourishing. But the effects of technology can also exceed these aims, creating zones of embodied being in the world at the edges of ability and disability.

Within ableist context, what is either abled or disabled? A technological intervention like surgery moves one from abnormal to normal, from disability to ability. How might we understand navigation at the edges of these categories? In an effort to think about some of the issues raised by this question, I focus on two points. First, how my gait troubles ableist assumptions about the distinction between ability, and disability, and second, how we might think about flourishing between ability and disability.

First, gait. I have what many characterize as a limp, though it is a limp that also embodies a swagger. I have walked under the diagnostic gaze of doctors, and I have been periodically chastised for walking like my father and like a truck driver. These accusations signal that my gait defies both abled and gendered expectations. I have a limping swagger, or a swaggering limp. Either way, my gait exceeds the balance of the normal. From an ableist perspective, the surgery, bracing, et cetera were successful because it fixed an impairment that would have prevented walking. That said, from a perspective that I call queer and Crip, these technological interventions did not completely erase my body's difference. My gait bears the trace of disability experience, situating me between ability and disability, in ways that call into question ordinary assumptions about those categories and their relationship.

In an ableist society, the aim of curative technologies is disability elimination. The orthopedic technological innovations I experienced aimed to normalize my body to make it possible for me to navigate the world by walking. Still, my limping, swaggering gait violates gendered, heteronormative, and ableist expectations of how a body like mine is supposed to move through the world. While my gait might not count within narrow legal and medicalized understandings of disability, it is shaped by disability experience. Walking does not make me anonymous, for reasons to do with gender and disability. It's not uncommon to encounter a stranger’s stare that first goes to my foot and leg and then takes in the rest of me. Sometimes the starer just stares. In limping, staggering along, I confess that it's difficult, if not impossible, for me to know whether the stare is initially directed at my limp, or my gender non-conforming swagger. But both converge to shape how I navigate the world between ability and disability.

Second, flourishing between disability and ability. I use the phrase queer Crip to describe this way of navigating the world, drawing on Nancy Meyer’s explanation of why she prefers to identify as crippled rather than disabled. She writes, “As a cripple, I swagger.” Like the word “queer,” cripple has a history of being weaponized against a marginalized group singled out by the term. And like queer, Crip, a shortened form of cripple, has been reclaimed by many to describe experiences that aren’t typically associated with disability, and to name a politics of proud, spectacular defiance of pressures to assimilate to exclusionary norms. Queer and Crip call for a more expansive understanding of gender, sexuality, ability, and disability, attuned to experiences that defy conventional assumptions about who is included in or excluded from a category like disability. An experience of being disabled at birth and then subjected to medical interventions aimed at normalizing the body by erasing disability is not what most people have in mind when they think about disability experience. Within conventional understandings of disability, my experience might be categorized as an experience of cure.

Nonetheless, in limping one stands out, and one’s navigation is often interrupted by questions like "What's wrong?" and “What happened?” and “What did you do to yourself?” Such questions communicate that one doesn’t belong. To limp is to fail to meet expectations of fluid motion, a monstrous occupation of space. When one has been categorized as cured, the limping gait defies expectations of how abled, normal bodies move. “But you had surgery and you were able to play sports? Why are you limping?” To swagger is also to defiantly move through space. A swagger is an embodied assertion of self, that is unconcerned with what others might think.

When it's part of one’s gender nonconforming ways in the world, a swagger flaunts gendered expectations, asserting one’s presence in the world, predicated on one’s shame, misery, or nonexistence. And so, in characterizing my gait as queer Crip navigation, I aim to reframe disability and ability beyond the framework of diagnosis and cure and understand how heteronormativity, ableism, and other forms of oppression work together to normalize bodies and minds. As queer crips know in our bones and joints, orientations toward the normal won't cure what ails us or create possibilities for flourishing.

Following the concept of deaf gain in deaf studies, the term disability gain has been used to describe disability as a source of knowledge about and creative being in the world. Disability gain defies ableist assumptions of disability as a lack of ability, or a disabled people as objects rather than subjects with knowledge. Perhaps what I am thinking about here might be called Crip gain, a perspective between ability and disability that troubles the boundaries of both. What can be gained from understanding experiences of childhood medical interventions not as eliminating, but curing disability, but instead as situating one between disability and ability, in ways that don’t make one disabled in a legal or medical sense but nonetheless positioned as queer Crip. I suggest that such queer Crip navigations offer a perspective of how various forms of oppression work together to impede or enable navigation in the world and forge paths of aspirational solidarity for others who, for various reasons are denied free movement in the world. Rather than aim for a fixed destination, queer Crip navigations open possibilities for flourishing at the edges of normalizing conceptions of identity and belonging, thus suggesting another way to be.

**Liz:** Thanks so much, Kim. We are going to pause now for another interpreter switch and before we do that, I just want to thank all of the attendees again for your coaching us through our captioning difficulties and thank you for your patience. It seems to be working now but if you have any more problems accessing the caption, please do let us know and we'll do our best to troubleshoot. It seems like it was some kind of Zoom related issue. But yes, thank you for bearing with us as we learn to use this webinar format.

Okay, now I’ll take a moment to switch.

**Erik:** Thank you so much, Kim.

**Liz:** Just a second, Erik. We haven't finished switching yet. Okay. We should be good now.

**Erik:** Thank you so much, Kim, for a terrific talk. Thank you so much, Liz, for shouldering these logistical matters. It's time now to begin the conversation among the speakers. Rosemarie Garland- Thomson will moderate that, and I want to assure everyone that we will be getting soon to an opportunity to you in the audience to put questions to the speakers. Over to you, Rosemarie.

**Rosemarie Garland-Thomson:** Good afternoon, I'm really honored to be here. Thank you very much to everyone who contributed to this really terrific event: NEH, the Hastings Center, Joe, Erik, Liz, the support team, and most of all my fellow panelists, my colleagues, my friends, my fellow travelers who have spoken. I am joining you today from my home office in San Francisco and I wanted to tell you a little bit more about who I am. I am a senior woman educator with silver hair that's a lot longer than it used to be and pale skin that's a lot paler than usual. The technologies I'm using here today are my glasses and the machines and applications that I need to use to be with you here today and to participate because I don't type.

I have three questions I want to present to our team of speakers, and these questions recapitulate or recap in some ways what the speakers have thematized in their work and what they’ve said. I'll begin with question one. We’ll take a few minutes for the speakers to respond. If you don't get a chance, our speakers to answer or respond to my three questions as fully as you would like, I think there will be ample opportunity for us for the question and answer period from the attendees. And I do want to also say thank you very much to our audience for being here today with us.

So question one: each of you has offered a story about an event that shaped your disability identity. Those are the words that Yomi Wrong uses in talking about our stories. Each of your stories shows the ways that you get around in the world, how technology, and how you use that technology, and how that technology, and I’m quoting Yomi again here, makes a statement of who we are. Technology such as wheelchairs, guide dogs, braces and canes, are often understood as aides that compensate for what we can't do, or for some inadequacy the world seems to think we have. Your stories today show us, as Rod tells us. We use technology to move from a segregated world that separates us from those without disabilities to one where we can access opportunities such as education, employment, economic security, housing to enter into a world where we have what Rod calls, “freedom of movement.”

I'd like to ask the three panelists to give us a few more examples of how you intentionally use the technology you need to access the kind of resources that enable you to flourish as people with disabilities. As people with disabilities rather than people who are trying to become non-disabled.

Ready?

**Yomi:** Sure. The last part of your question about flourishing and being present as a person with a disability versus trying to not being disabled, I would say that right around maybe a few years after that period in the story that I told, I stopped participating in physical therapy. I stopped trying to use crutches and walkers, I was using those to both gain strength and mobility. It seemed important to people and to the medical community and to my family that I learn to walk. But the truth is, my disability, which is osteogenesis imperfecta, I have brittle bones and I’m a very small person and it was quite unsafe for me to be walking, to go to school with a walker or crutches because I broke so easily. I could be walking or trying to exercise or riding on a tricycle. I could be doing nothing. I could sneeze, and break a bone. In fact, my wheelchair became protective. I use my wheelchair as an exoskeleton to move through the world and I have just given up on some of those other types of devices and aides because I don't aspire to walk, ever. It is not safe for me to be a walking person in this world, I don't care to do it and so I don't know that that gets to all of your question but it did resonate when you talked about showing up as disabled which for me is a personal identity. It is also political identity and a point of pride. And trying to approximate able bodiedness, which I have no interest in.

**Rosemarie:** Thanks. Kim, or Rod, did you want to say something about this question, follow up what Yomi has said? Yeah, please.

**Kim:** Yeah, just in terms of thinking about that question, for me, I’m not somebody who has disability as an identity at present but who was born disabled. And it’s interesting to me in terms of conversations about disability where folks often think about how disability is in the future, and that is, of course, always a possibility and yet it is part of my past and has shaped my habituation and embodied way of being in the world and how I think about myself and how I think about my relationships with others. So I think about myself as situated between, which is one of the things I was trying to underscore, in what I said.

But in terms of technology, I think about the square piece of plywood my uncle made with wheels on it. That's something I loved throughout my childhood, it enabled me to get around quickly and to run away from people by rolling really fast out of the reach of adults but much faster than if I crawled or something like that, which I couldn’t do. But, in terms of thinking about limping, swaggering and technology that has been really important, I think shoes are incredibly important. Shoes for gendered reasons. Shoes for supportive reasons, not being able to choose the shoes I wanted was part of my gender identity as well that was rendered invisible in that moment, which was also about disability, but for me, part of walking or navigating in the world is also about doing so in ways that defy gendered and abled expectations of embodiment.

**Rosemarie:** That’s great, Rod did you want to address this particular question?

**Rod Michalko:** Sure, thank you. I think one small point I'd like to make. While I think it's true that all of us who understand ourselves as disabled do use certain kinds of technology as a way to gain access to the world of economics and housing, and that’s hugely important, but as Yomi said, I view my blindness as political. That kind of identity. Technology for me is also how do I bring blindness into the world in a way that’s different from the typical, sighted way of understanding it, not as a deficit of eyesight but merely as a difference? Rather than that, I find ways - and I have done this all my blind life and continue to rebound, in ways, yes, that I am not satisfied yet, bringing blindness as a distinct way of being, bringing that into the world. And I view technology as a way not to access your world, but to bring my world into your world, in a way different than how you have it.

Thanks.

**Rosemarie:** Thank you, Rod. I always love . . . Rod and I have been friends a long time and I love the way you talk about having a blind life. My blind life. I find that very poetic. I'm an English teacher and I love poetry and literature, so it's particularly important for me to be able to be involved in and hear your stories today, so thank you.

I’m going to go on to the third question, which I think actually might be more powerful of these. So in your stories, the three of you today that you shared with us, about flourishing as people with disabilities, all three of you have used words that describe your lives and yourselves, which might be surprising words to people may not know too many disabled people very well.

Yomi spoke of having power. Rod spoke of experiencing grace and joy as a blind man. Kim spoke of her swagger not as a defect, but as gain.

Can you tell us more fully about the benefits you've experienced in your life by living in a way of being which many people, really society in general, often understands not as power or gain or joy, but as deficit or defect?

Okay. Hard questions.

**Rod:** I'll start.

**Rosemarie:** Thank you, Rod.

**Rod:** Yeah. This is difficult. While I think Kim is right, there's a certain gain with disability – in some sense, there’s a kind of a gain with most ways of being in the world. I think rather than benefits or gain, one way I like to think of it often with my blindness is while the world generally and typically give me some sense of blindness as clearly something others don't want to be, where it’s clearly living a life where nobody wants it, and that’s sometimes, depending on my mood and during COVID-19 times, that's not really that great.

I think that’s not exactly something I like to think in terms of not being a possible gain or benefit. I think though, in terms of not being trapped, really, with understanding in conventional ways, I think, for instance, of understanding the visual or sight. Those are typically understood as something natural, as something you look and see, and that's all there is to it. Really, in some sense, eyesight is something that, as a blind person, my blindness has given me the opportunity. Now, whether I take it or not is in many ways . . . But it's given me the opportunity to realize that eyesight is the furthest thing from natural as possible.

You need to get a sense somehow, show one another that you can see. In a sense, it's beautiful to "watch" from a blind point of view. Because sighted people are so busy demonstrating to one another that they can see that sometimes it's humorous. Other times, it's a little sad.

Nonetheless, it's really, really interesting and a lot of fun and joy to move in a world, particularly with my late guide dog Smokey, and talk to him as I move about see and sight, and pretending that he actually answers.

It's fascinating. One little example that I have is looking toward people when you are talking, something I can really imitate well. It's interesting how well I can imitate seeing, and sight. Sometimes when I'm sitting where nobody knows me, I’m taken for sighted, and I just love how the perceived accuracy of sight can be that tricky. I love tricking sighted people. Thank you.

**Rosemarie:** That’s great. Yomi, Kim? Did you want to comment on joy, gain, power? Complicated as we say, in the way that Rod . . .

**Kim:** I can comment on joy, I think. It's no fun, in some ways, not to be anonymous, having to be stopped and having your gait commented upon by whomever one might encounter while you're trying to go from one place to another sometimes. At the same time, I think the joy has to do with a sense of living in ways that create new ways to be.

I think there's a navigation that's a forging of a path of new ways living and relating to others that I've found that incredibly joyful as a queer person.

**Rosemarie:** Yomi, did you want to get the last word or shall we go on to the audience?

**Yomi:** No. I'm good.

**Rosemarie:** Of course you are.

**Yomi:** I'm still thinking about it, so I'm not quite ready to take it on.

**Rosemarie:** Of course you are. That’s what this format will give you the opportunity to do.

So Erik, why don't we and Joel move to audience questions? Obviously all three of us, or maybe all four of us can participate in these questions, which I think that will be very productive. So thank you all for this part of the program.

**Liz:** Once again, we're going to pause for an interpreter switch.

Okay. I think we're ready.

**Erik:** Well, I'll add just my thanks to Rosemarie and the wonderful speakers, and turn it over to Joel. Joel Michael Reynolds.

**Joel:** Hello, everyone. This is Joel Reynolds speaking. I would like to encourage people who are watching to submit their questions or comments in the Q&A. We've been watching that very carefully the entire time. We've already got a number of questions written down that we'll look through, but whatever comes to mind, please go ahead and submit it.

We're also going to take a look at Twitter and Facebook, but the Q&A inside of Zoom is a bit easier to manage at the moment. I’d like to start with the following question. Each of the three speakers' presentations take up in different ways the problem of ableism. Although ableism is a concept increasingly discussed in international media and other public spaces, it is not as well understood as related terms like sexism and racism. Can you talk about what ableism means to you and why combatting it matters?

I will use the same method that Rosemarie used. I'll rely on you raising your hand or saying something. Whoever wants to jump in, you're more than welcome to.

Yes. Kim?

**Kim:** It's hard to know how to jump in here. That's a really important question. Ableism is systematic and institutionalized normalization and naturalization of abled-bodied mindedness, of the sense that being abled-bodied, having a certain appearance and way of moving through the world is something that is natural.

And there’s somewhat of a question, I mean, lots of people have written about this in disability studies, like Robert McGruwer, in terms of my own thinking about ableism, I'm interested in how it is that it both informs and is informed by other systems of oppression. One thing Robert McGruwer talks about is compulsory able bodiedness, and compulsory able-mindedness, that there's an imperative to fit into these norms of embodiment and movement in the world.

And I think what's so important about that is, first of all, that no one really does. Most of us in some sense fail to embody that norm. But also its exclusionary force is quite harmful. It informs all kinds of efforts to normalize the body, whether through medical interventions or surgical "corrections." It also informs violence that people can encounter in the world. So I think understanding how the institutionalized pressures to be normal basically are part of what it means to inform ableism.

**Joel:** Rod or Yomi? Would you like to jump in on this particular question?

**Yomi:** I feel like Kim said it very succinctly.

**Joel:** Okay. And Rod, I think we accidentally have you muted. Oh, now you’re unmuted.

**Rod:** I think Kim was really good with her comments. Also, one of the things is that's it’s a systemic problem, really, that doesn't belong to disabled people, incidentally. It's related of course, as Erik said, to racism and sexism and various systemic kinds of systemic discrimination and exclusion. It does often lead to violence.

I think when people speak of various oppressions like ableism, sexism, and racism, it’s often as I understood it, a systemic, “but not me." "It's the system, not me,” is sometimes one of the issues. It's interesting with disability, or in my case blindness, how an ableist perspective is a sighted community acting as though, speaking as though, and thinking as though they understand blindness in some kind of a complete way. First that it's an absence of sight, i.e., an absence of who they are, and secondly that the person living with blindness would rather have what they have. There’s that sense of "you'd rather be me, but you're not."

Then there’s that ableist version of gain, which we spoke on that concept. That we have somehow rather naturally compensated for our loss. In my case, loss of sight. So I hear better, smell better. You know what I mean. Even some comments begin with that.

Often, in a group people will say things like "you will appreciate this, having better hearing." Then I'll say, "Pardon?" and often they'll either get it or they don't. So often there is ableist stuff that is informed by, to use Kim’s terms, a more systemically ableist oppression.

**Joel:** That’s really powerful. And one of the things that I hear in both of your comments is the way in which one effect of ableism is to create what you could call ableist common sense. Right? The idea of, "Of course I'd like to be able to see and not be blind."

This kind of fundamental, default assumption that it's easy for able-bodied people to have, that being able-bodied in x, y, or z ways, is certainly better, is certainly desired, is certainly . . . and this ties back directly with Kim's citation of Robert McGruwer’s notion of compulsory able bodiedness, this imperative, I think you used the word, Kim. An almost command that operates often, not necessarily on a reflective level but operates in the background of people's assumptions about the world and how it should be.

All right. I'm talking too much. Let me ask another question. I'm sorry if it looks like I'm not paying attention. I'm trying to track and compile questions as well as listen. Apologies for multi tasking.

Here is a question that I think is very much worth talking about that comes from the audience. How do you think the medical field should change in order to have a better response and relationship with people with disability and disability communities?

And the person who wrote this then further specified, how you think your specific interaction with it could have been better? And if you want to speak to that specific point, that’s entirely up to you.

**Yomi:** I’ll go first, and I work in healthcare and have the opportunity to see the field from another view, working in healthcare but also being a subject and participant my whole life within the medical model.

For me, when it comes to disability and impairment, I think speaking globally about the medical field and if we speak about children, we need to be preparing people and addressing function. Like it would have been much better to prepare me to be an adult and function in the world as it is rather than try to fix me to try to make these minor in-roads in an ableist society. Ableism exists, the world is not built on a scale for me, and how can we maximize function and independence, and autonomy, and agency? So rather than looking at fixing my bones and straightening my legs – and some of that was beneficial since some interventions allowed me to physically thrive in certain ways.

But so much of energy, and just wasted time, and money was wasted in trying to make me fit into and blend into an ableist world. And I just feel like, for me and so many people I know, it's really about function and how I can live on my own terms. How can I make decisions about my care and well-being? What does it mean to me to thrive? Not to my doctor or social worker or the other people who will look at it through an ableist lens. What does it mean to me to flourish? Then we get through that together and have a care partnership for it.

I think that's the direction a lot of the medical field in addressing patients with disabilities should go.

**Joel:** Yeah, Kim?

**Kim:** That's really great and important. To add from my experience, too, is that not to assume when thinking about flourishing on one's own terms, as one thinks about what that means, not to assume heterosexuality, not to assume gender conformity. Because so much of the notion of what it means to “walk” is the style of walking, is what it means to have a "normal" walk, just moving somewhere, putting one foot in front of the other, but also doing so in a certain way in terms of one’s body comportment. And the two are fused in my experience of having my walk commented on. I think flourishing has to be . . . that we’re not separating disability also from gender and sexuality. We should think of people as whole beings, and allow for diverse modes of flourishing.

And also that I was an infant, so I don’t . . . I know this as a story told to me, but my parents were upset I might not ever walk. I think there's a lot that can be done to make it so people who are making decisions have access to communities and people who can communicate that it's possible to flourish in all kinds of ways of being in the world. I think that's important, too.

**Joel:** Yeah, Rod?

**Rod:** I have a comment. I think Kim and Yomi addressed it beautifully. I think in my experience with the medical community, and as others have told me about their experiences in the medical community, the medical community, it seems to me that individual practitioners are committed to something that Rosemarie talked about way back in 1997, a norm-made version of the body, of the mind, of the senses, et cetera. They come to their interaction with us generally with that notion of the normates, and that they would, as Kim and Yomi said, like us to be anyone other than who we are.

There is that assumption, as Kim said, our sexuality and gender notions. Medicine, it sometimes appears to me as the quintessential protector of the normate. It's as if, somehow I'm an enemy that invaded that. I remember, one thing I think about ophthalmology, and I’ve seen a ton of these people, other than one, I'd love at least a little bit of sense of humor from a practitioner. I remember once in graduate school at the University of Columbia, I had an ophthalmologist look at my eyes. Something was up. So the ophthalmologist looked at my eyes really close, that kind of thing. And I remember he, just one ophthalmologist, he pushed away and said, "it's really messy in there." I said he should see it from this side. And not a word. There needs to be a bit more humanness, a bit more letting go a little bit of the normate, letting go of some of the assumptions of what the human, in a moral sense, ought to be. Should be.

**Joel:** That's really powerful. And this opens quite naturally to another question we’ve got.

**Liz:** I’m just going to stop you for a second. We need to give the interpreters a chance to switch. Also, this is the 90-minute mark of the event. There are about 500 people in the audience. We have a ton of questions. We're planning to stay here until 5:00. You're welcome to stay with us. We hope many of you will. Again, thank you for all of your patience. Okay. Go ahead and switch. Okay.

**Joel:** Another question would be about each of your talks were in relationship to technology, technologies of multiple sorts, technological interventions, technological objects you'd use. One thing that especially stuck out to an audience member was Rod's talk, referring to, we don't typically think of with dogs as a technology. Yet it's also very natural to see why Smokey fits into this conversation and serves an instrumental function in your life, but is much more than merely a technology. You see where the question is going. I am wondering if you all could talk more about, and Rod, you could especially think about this in relationship to Smokey, but if you could all talk a bit more about what the concept of technology means to you and how you think about the relationship between your particular way of being disabled and particularly way of being in the world and these objects and practices referred to as "technologies."

**Rod:** Sure, Joel, thanks. And thanks for the question. First thing I’d like to say is my blindness and disability in general emerges or becomes a sort of entity or phenomenon because of the way we relate to it. If I relate to blindness as a technical issue, requiring such technical intervention or solution, then my blindness as technical thing.

And of course all of us who are disabled don’t necessarily see us in that way. We can see eating food is a technical matter. A lot of the world doesn't have food to eat. But we all have to use techniques that tend to overpower who we are and to overpower a disability identity. One thing non-disabled people harbor is a notion of, "How can they do the stuff I do?"

"How can a blind person read?" "How can a wheelchair person get into that building with those stairs?" You have all these notions of how we're going to do this stuff. How can do the stuff you can’t do, that normates usually do. It's a fair question. I think Smokey was a piece of technology in so far that he and I had an instrumental relationship. I relied on him to get around. My life was in his hand, really, in some sense. But what Smokey did, more than that, first of all, as the trainers say, he loved to work. He loved to guide. When he heard the harness, he was jumping. He wanted to go to work. He just wanted that. That gave me a sense of joy I was speaking of. My blindness gave Smokey a chance to do something he loved to do. It was evident. My blindness became a little bit of a source of joy, for both him and me. It was the little bit of blindness Smokey allowed me to bring into the world. It was never this sense of, “Oh, here’s a drag, how to get from here to there, and how am I going to do it? How am I going to stay safe?” And no, “How am I going to get there?” I enjoyed the trip. Thanks.

**Joel:** Kim or Yomi? Are you interested in responding?

**Kim:** It's a great question and very thought provoking. What Rod said was really amazing. We think of technology as something that we use or is applied to bodies in order to make it so bodies can move through conventional kinds of spaces.

There are all kinds of technologies in my experience as well, but I think about the one example of surgery I think of, and bracing, and so on. There are also effects that aren't anticipated in terms of interactions with technologies. In those spaces that are opened up, I think there's a different possibility of being. It's not necessarily applying technology to a body in some way and using it in some way. It also makes something else that wasn't anticipated possible that also calls into question the more normalizing mode of thinking about technology. That's what is really powerful in terms of having a critical disability critique of technology and what that means.

**Joel:** Yomi, did you want to jump in here, or did you want to wait for the next question?

This leads us in some ways back to this concept of Crip gain. Kim talked about it. It was at play in each of your talks. We got multiple questions about this idea. Some people seemed skeptical. Others seemed confused. Some loved it. All over the board. I would like to return us to this concept and maybe tease it out in a little more detail, what does this idea of Crip gain means, and pros and cons of it? you add all the talks, there's something about the concept that gets things right, but maybe others that are problematic. Ideally, can we do this in a way that ties back to the whole theme of not just this event, but the series as a whole, which is the relationship between disability, technology, and flourishing, this idea that one is living the sort of life that one actually wants to and is able to carry out that sort of life relative to how society is structured. I think I explained that in a far more complicated and less elegant way that Erik did earlier. My apologies. What he said. Anyway, Crip gain? Somebody want to take at talking about this. Yomi?

**Yomi:** I would love to hear Kim say a bit more and then jump on it. I’d like to hear Kim talk about it because I love to hear Kim talk about this.

**Kim:** When I wrote it, I thought maybe not. Maybe. That’s sort of what I said. Maybe one might not or one would call this something like a Crip gain. I have my own questions about the term. I'm not necessarily comfortable with it. I wasn't trying to say something like, “Oh, just look at all the positive things.” I was more trying to think of flourishing and using it as another word for flourishing and how it is that defying normalization, existing between disability and ability - that this isn't just a scene of loss, but a scene also of flourishing. And so how to talk about that in ways that rework an ableist distinction between ability and disability? It's not necessarily the sense of gaining a new skill or something like that. It's about creating possibilities for flourishing is more what I had in mind. And so perhaps it isn't the best phrase. I'd be very open and willing to learn from others about that, too.

**Yomi:** Oh, no. I'm going to use it. From today, going forward, we will be talking about Crip gain, just like in disability justice spaces where we talk about abolition, resilience, resistance, and freedom, and joy, and flourishing, and all of that. I really like the concept. You have given me something today, and I’m just going to keep thinking about it.

And I mentioned something earlier about the protective quality of my wheelchair. I also think about how I've experienced things in this life that I absolutely would not have experienced had I not been born with a disability or acquired a disability or anything. I would not be in this conversation but-for my specific Crip experience.

There are millions of other middle aged black women with whom I share very similar universal experiences with, and they're not invited into these conversations. What's interesting about me or perhaps what differentiates me is the way I move through the world, is this positioning of me as outside the normal way of things. Right? I see that as a gain.

I just like this concept of all the ways my disability has provided entrée into spaces and experiences I wouldn't otherwise have. But also, I see my experience as who I am as Yomi as deeply spiritual. I feel it's an exercise of spirituality that I am on. I'm working out a lot of things in this lifetime, on this plane, at this moment right now.

And so I feel like this is the body and experience I was meant to have. I like this concept of Crip gain because when I review all of the things I have been to and through, all of the things I’ve experienced, and the way my mind and heart have been sharpened and smoothed over and over again by these experiences I have, I see that as gain. It's something I've been endowed and blessed with.

**Joel:** Yeah, Rod?

**Rod:** That's beautiful, Yomi. I have some of Kim's and Yomi's understanding and feel about gain. I think what's interesting to me is that is that the gain I get from blindness isn't what people usually think. It's not better hearing or touch. I think the gain I got was the understanding that being on the margins of life, as Yomi hinted at, is, as bell hooks used to say, not such a bad thing. It's just not too bad of a position to be in. You can see a lot of stuff in the margins that you can't see from the centers, using that metaphor.

As Yomi says, I would not be here at all if not for my blindness and who I am, in that sense. It’s just a part of who I am, and that's not "what" I am. It's not something that attached itself to me. It's me and part of who I am. It has also given me a sense of having to look at the center in a way that being smack dab in the middle of it doesn't really give you. It’s kind of an old-fashioned thing to say, that a fish has no idea he’s in water. It gave me a chance to ask a question and revisit a question my partner and disability studies colleague Tinya Titchkosky once asked. "Once we, as disabled people, are in, what are we in for?"

That kind of question that centers this visceral need to include us. Now "inclusion" has gone from an act to a thing. It's amazing how badly they want us in. Thinking about another blind scholar, Devon Healey yesterday, about inclusion, to get in is one thing. To stay in is another. It's almost as if we were saying once we're included, if we want to stick around, we need to bring our own glue. It's given me a chance to take a look at that stuff as well. That's some version of a gain. Plus I love how Yomi said it.

**Joel:** Yeah, Yomi?

**Yomi:** Thinking more about gains, there's some perception that people with my disability have these super brains. That a lot of people with OI are super intelligent and articulate, great communicators. And of course I was told this growing up. "Hey, this is a positive!" That's fine, and I believed it was true because I was reading at a very young age. I started memorizing books at 2. I could recite them back. I started reading very early. I was very conversant. I was a good and clear communicator. I met a lot of other children with OI who were the same way. It just seemed we had these super brains, and that it was something we gained as having a congenital disability. Later on, my orthopedic specialist at Stamford, Dr. James Gamble and I were talking about this. He would ask what I do, where I go to school, and what my job was. He would want to know people's position and trajectory and whether the smart gene carried. He told me something fascinating and that I believe is true. It's not that we have super brains. Because our bodies are fragile - I was born with several broken bones. It's not unusual to for people with my disability to break hundreds of bones in our lifetime. Because of always being in peril physically, we had to develop language early in order to communicate danger, pain, fear, how to handle us, how and where to move us, it's an adaptation. I believe it probably caries through a lot of other disabilities. People develop early verbal skills. I see it as Crip gain. It's not because of big brains, but due to the adaptation, of needing to be able to communicate to anyone touching or handling us the right way to do it so that we were not repeatedly injured. I see that as a gain.

**Joel:** Before I ask another question or provide a comment on this one, we've got about 11 minutes left. I want each of you to have an opportunity to add something you may have wanted to say earlier. I want to make sure you have an opportunity to throw something else in the ring, as it were, before time runs out.

**Yomi:** I have to say I'm not mad at my siblings. The very few people who have heard this story ask how they could have done this to me. I have no animosity or ill feelings toward anyone in that movie incident. I get it. Everyone was doing their best. I need to say that in case any of my family members get a hold of this recording.

**Joel:** Duly noted.

**Kim:** I was very much loved and cared for. I think people do their best. That doesn't mean there are not effects that are not intended, but yes, I don't blame my parents or anybody for things that I experienced.

**Rod:** I feel the same as Yomi and Kim. When I mentioned the joy and gain of blindness, I wasn't suggesting that the "sighted world" as I’m calling it is exactly the most joyful and pleasurable place to live if you're blind. There are many assumptions blind people aren't happy to live with. Another thing I wanted to say, that there are people I’m extremely grateful to. My partner, Tonya, students I’ve had. There are two artists, writers, one blind and one not, Lynn Manning and Austin Clark, who was a Caribbean author and writer, novelist. They were both great friends. About 8 or 9 years ago, Austin was an award-winning novelist and poet, said one evening to me at his place, he said, "you'll have to bring blindness out in fiction, my friend." I started writing fiction with his tutelage. The experience of being blind in the world, or as it seems like as a marginal way of being, has given me a lot of opportunity to do a lot of things.

**Joel:** Thank you, Rod. Thanks to each of you. I am having trouble to figure out how to end this. I don't want this to end. It's been such a fantastic set of talks and a fantastic set of conversations. Oh boy. There are a lot of good questions left. The audience has been active and fantastic.

How about this? A number of people asked about the relationship between gender and disability. There were also a number on race and ethnicity, and it seemed a number of audience members were eager to hear thoughts on how to think these things together or perhaps how to think about them separately while keeping the focus on disability, and what a truly intersectional understanding of disability looks like. That might be a way to phrase a set of questions from the audience. It's a tall order.

**Liz:** I'm going ask you to hang on a second to let the interpreters switch.

**Joel:** Okay. Think about that while we do that. Would someone like to go first?

Kim?

**Kim:** In terms of gender and disability, let’s start there, but thinking more broadly about class and race and disability as well, when we think about what body norms are, they're always already gendered. There's a way to move. There's a way to be embodied and to gesture. Those are always gendered modes. Disability places one outside of those gender norms as well. As does being gender non-conforming and being queer. That places us outside of what's expected in terms of the body that one has, where you expect a heterosexuality, gender conformity. The experience of that in one's navigation of the world is also a performance ability. I think that’s what Robert McGruwer talks about compulsory able bodiedness and compulsory heterosexually and how they rely on each other. They're normalization and naturalization depend on each other. In terms of walking, that's one way they come together in terms of how I move and navigate the world, and how my modes and navigation are responded to, whether that's by a stare or comment. One is always aware you're not quite what people expect you to be.

It's important to think about those. I didn't talk about race or class, but when thinking about access to technologies and class, how important that is. Also, thinking about race and how there are ways in which, in a white supremacist context, as a white person, I have more fluid movement in the world. We're in those spaces between moving through the world in an unobstructed way and then being perceived as not belonging in it. That environment needs to be navigated as well. It’s part of what is navigated.

**Joel:** That's wonderful, Kim. It brings me back to this theme that I heard in each of the talks of the betweenness, the not necessarily being on one side or the other of a phenomenon or norm or expectation or even how one relates to oneself. And that one of the aspects of many sorts of disability experience involves feeling in the margins – we can use the center metaphor Rod used earlier, or this kind of inside-outside metaphor. Thank you, Kim.

**Yomi:** The way I think about all this and apply certain practices is by being a student of and learning more about how to embody a disability justice framework, which is intersectional and centers the most impacted and picks up where the disability rights movement left off, where we're explicitly naming racism, sexism, and gender violence, all of these things, as identities and experiences we shouldn't have to rank or check at the door in order to have rights or to be free. There are 10 principles to disability justice in that framework that I think really illuminate what you and Kim were just talking about. It's where my political heart and home are these days, in really understanding my place in the world, and where I see the work being. The work is toward liberation. The work is anti-capitalist and abolitionist, to tear down white supremacy and ableist. That work is led by people of color and queer people and people who are neurodiverse. It is led by people who haven't been the standard bearers of the disability rights movement.

**Joel:** That might be the most perfect place to end. I want to add one thing to what you said so wonderfully, Yomi. When we talked about ableism earlier, I should have said the best understanding of that term is from TL Lewis. They worked with also Dustin Gibson and a collective of people to come up with a version of ableism that takes colonialism and capitalism seriously. It's really a genius understanding of the term. If you're interested more in that, I recommend TL Lewis' and Gibson’s' work. Each are involved with disability justice, et cetera.

**Yomi:** Those are our luminary thinkers. Stacey Moore, Patti Byrne, Leon Mingus. These are the people who gave us this gift of the disability justice framework. Then we have so many others, as you’ve named, who are carrying that work forward. They are the guiding lights for us and for me.

**Joel:** Yes. And each of you are guiding lights also. I'm so pleased we got this time together. I don't know what happens right now, but I believe Liz will appear, or that we'll hear from her about what occurs at this juncture.

**Liz:** Yeah, we are going to wrap things up. Erik might have a few closing comments. Before that, I want to say there were a couple questions about the Q&A. Since there are hundreds of you, we couldn't get to all the questions. We hope you'll continue on Twitter and Facebook. We'd love to keep hearing from you after this. So Erik, did you have any final comments?

**Erik:** Liz, my video isn't activated, which is fine, because all I want to say thank you to all the people who made this terrific event possible. That includes all the people in the audience. Thank you all so much. This is a wonderful event and way to celebrate the Center's 50th. Hopefully we'll see you all at our next event. Keep a look out for that ad for the third event.

Be safe and stay well. Thank you.