Navigating: On Disability, Technology, & Experiencing the World  
Tuesday, 29 September 2020  
3:00pm - 5:00pm ET   
  
Welcome everyone. This is navigating on disability technology and experiencing the world. I am Liz, the moderator for this event. A few things before we get started. Access note, we have ASL and captioning provided. In a few moments I'll paste a link in the chat for a full live transcript.   
  
We will be recording this event, it will be available after the event ends on the Hastings Center website. As audience members you are not able to be audible or visible, you can enter questions into the chat at any time, we will be monitoring them and offering some of them up in the second half.   
  
Again, you can submit questions in the q&a box. I will introduce Erik Parens who is the director at the Hastings Center. Take it away!   
  
Erik Parens : Thank you Liz for all of your contributions and thanks to all of you for joining for this second endowment for the humanities. The purpose of this series is to explore the theme 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. She is a pioneering disabilities scholar. 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 by it here at Hastings Center. Since its inception, many of us have thought critically about many medical technologies, like monitors about patient 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. Bioethics at Hastings have been concerned that prenatal testing are more concerned that only people with certain bodies will be embraced and that sometimes some old fashioned technologies have been forced on people with atypical bodies, in an effort to fix something that doesn't need to be fixed.   
  
We have often emphasized that these technologies have been part of systems that can thwart the flourishing of many people, particularly disabled people. We have not always given equal attention to the myriad ways that people and people with disabilities in general use technologies to promote their flourishing. When we conceived this series, we said we wanted to explore the simple fact to promote flourishing. We were trying to use the term technology as a hook to get to our fundamental theme, that people can flourish in all type of bodies. It's not crystal clear to me today that the term technology is the right hook, but a great thing about being in conversation today is that we have an option of revising our thinking.   
  
Indeed the question of the usefulness of the term "technology" might come up in the discussion or it might come up in the conversation between all of you in the audience and our speakers.   
  
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 function for flourishing. Each of our speakers today will consider the activity of navigating.   
  
Our first speaker is Yomi Wrong, a freelance journalist and justice activist who will explain choosing technology that fits for oneself and allows people to navigate freely. Before I turn it over, please remember you can use the Q&A function. Now it's my pleasure to turn the screen over to Yomi Wrong. Over to you!   
  
Yomi Wrong: Hi everyone, I'm Yomi Wrong joining from northern California. I am an African American woman with shoulder length hair, I am a little person sitting in a power wheelchair. I am excited to be here invited into this conversation in navigating.   
  
The story I chose today is very tender to me and I am nervous to share it.   
  
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, mastering long division, reading above my level, beautiful penmanship and performing at the top of my class. I was also cute and popular! There is a picture of me on the bookshelf over my left shoulder, that's me at nine years old in 4th grade. It's black and white, I have pigtails and bangs, I'm smiling and wearing a velour shirt because this was 1981 or so and that was the fashion.   
  
At that age, kids gravitated towards me. I was outgoing and a natural leader who tried to include others. I was often paired with shy kids, my task to draw them out. Or a study buddy for helping someone excel. This is how I straddled two different realities at my school, leading to an unfortunate incident.   
  
My 4th grade teacher thought I needed some more educational vigor and mainstreamed me into a 6th grade class, a process of streaming kids with disabilities into mainstream able bodies schools. I liked my school and my teacher but the experience of being bussed 20 minutes away while my friends got to walk together built up a longing. Going to a different school excluded me from their world and the divide was becoming harder to overlook. For instance, when they laughed about the antics, I couldn't follow the joke. After school when kids charged into the bodega for candy or to get pizza, I was never included because I was never with them. I knew nothing of their games, team sports or how to navigate a cafeteria. What happened to the lunchroom? In my special education school, we took our meals in the classroom. Except for PT we rarely left the classroom. I guess we were too fragile to rip and run.   
  
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 environment to dwell with able bodied children felt like a golden ticket.   
  
The school I added had upper flowers of an upper elementary school with kids we never interacted with. Each week, I left my campus on the first floor and rode an elevator up to the higher floors. I was a freak at first, kids laughed and giggled. Soon, I was paired with a boy who needed help with math and we became great friends. I remember his kindness and smile, the happiness I felt when the elevator doors opened and he would be waving, we would have so much fun.   
  
A few months into the schoolyear this perfect boy asked if I wanted to go to a movie. Calm down, was not a date, I was 9, but it was a big deal. Meeting up for activities outside of school was a milestone I was missing out on. Some of the details are fuzzy, but it was somehow worked out that our older siblings would escort us to a matinee. I feel like they must have hijacked the encounter because they brought extra people. The day came, my mom left money for snacks and cab fare. This was critical. If we took the bus, I wouldn't be able to go to the movies in a wheelchair, it was impossible to haul into a bus or subway in the Bronx, a full decade before things became accessible. But with cab fare there was no need to leave my chair behind.   
  
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 and a lightweight toddler sized stroller.   
  
Navigating NYC was much easier to do with me in a stroller, unlike my wheelchair one person could pick me up and collapse it in seconds, run up steps or get on a bus or get a cab quickly, the stroller was light.   
  
In the NY of my childhood, a toddler stroller was the most adaptive piece of adaptive technology because it allowed for greater access but it also changed how it showed up in the world. Tucked down low in the ground, everything about me became obscure. My age, my size, even my disability. Strangers could easily take me for a toddler or a little kid.   
  
Let me say, this worked brilliantly at amusement parks that let kids in for free, but I don't think this was the motivating factor for the person taking me out that day. It was the carrying me down the steps, putting it together at the movie theatre and then repeating 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 this way, but it didn't happen to them. Emotion imprints memory and this is how I remember it.   
  
Someone said we were going to take your stroller. I said no, I will not go to the movies in a stroller. "But you've done it before!" Not today, I said. My mother was called to mediate. I wanted her to force these people to bring my wheelchair! Someone said, "if he's really your friend it won't matter how you show up!" They were right, and I had no counter argument at nine. I do remember not wanting to go anymore but being forced to anyway. I remember feeling so sick in the cab, hot tears running down my face. Praying we would crash, dramatic I know but for me, seeing a school friend out was a big deal, must we make it awkward?   
  
I feared my friends reaction, seeing me infantilized and out of context. Would it be too much? Indeed it was.   
  
I recall this next sequence in slow motion. That sweet boy dancing nervously, rushing to greet the cab. My sister emerges, whips out the stroller. My friend looks confused. Then she lifts me, plops me and straps me in. My friend looks horrified. The older boys with him look befuddled, unsure who has shown up, certainly not the girl he's been talking about.   
  
The moment turns rancid with my mortification. My sister, ever my champion, starts confidently to the ticket counter. 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, looking at each other, stopped being friends.   
  
Like I said earlier, I've hardly spoken of this, but it has stayed with me and I have spent 40 some years trying to get over it and make sense of it. My wheelchair, more than any piece of assistive technology is the thing I will fight for. There are real and unforgiving consequences when we are denied technology of our own choosing, physical and emotional scars. When I choose for myself, I maximize my function and make 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, but my chair gives much important information at the start. Thank you.   
  
Speaker: Hi everyone, we're going to pause for a moment. Our ASL needs to switch, we know there are some problems with the closed captioning as well. So far we have not had any luck. I will reiterate there is a link to the full transcript in the chat but we understand that's not adequate for everyone here, we're doing our best to resolve. I think it may be an issue with the Zoom webinar format, the toggle option is not showing up for people it seems. If anyone has any wisdom on the problem, we appreciate you letting us know.   
  
Okay, I'm going to let the interpreters switch now. Thank you.   
  
Speaker: While our interpreters are switching I will thank Yomi for such a wonderful talk and introduce Rod Michalko, a disability studies theorist who lives and teaches at the University of Toronto. As soon as Liz says we're ready, we'll switch it over to you.   
  
Liz: Apparently the closed captioning has just shown up, thank you for bearing with us.   
  
Rod Michalko: Correction on the introduction, although I am mostly retired. Also, Yomi that was a wonderful talk and I have to remind myself never to follow her again in the future, a touch act!   
  
I'm a blind white guy and I think about average build. I think I have long wavy hair and I'm wearing dark glasses that are blue and hopefully match my purple Tee shirt, otherwise I blame my partner Tanya. I'm going to talk about a Dictaphone, which has a tape of what I'm about to say. I'm going to repeat it with this ear thing in.   
  
Please indulge me for your time. And by the way welcome, I'm glad you're here.   
  
The freedom of movement is something many people take for granted. Some have the freedom to move from one country or region to another, between careers and jobs and many have the freedom of bodily movement, to sit, to stand, to walk and run. The freedom to move freely in a city like NY or Toronto. The freedom to negotiate a flight of stairs, drive cars, take public transit and negotiate the rest of the environment, built to the specialty of those who take movement for granted.   
  
There are some however whose freedom of movement is restricted beyond limitation and for whom free movement is not taken for granted, I am speaking of disabled people. We negotiate everyday. I want to talk about how my blindness guides me and I moved freely with it in this world.   
  
First thing I want to say is that while it does impose some limits, it is sight and the way it organizes the environment that limits my ability to move. The material world is built by and for those who see, this is the world I negotiate with my blind wife.   
  
Movement in the world is almost always accompanied by technology. Whether with footwear, with trains, wheelchairs, canes or with guidelines, negotiating the world with quick eyes on a screen, software that imitates movements, we move with technology on our side.   
  
For many years I moved with my guide dog Smokey. He moved me through and in the world, accompanying me in my movement. 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 just that he accompanied me, we accompanied each other, blind man and dog moving together, negotiating a world not strictly ours. One where people looked and saw, 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 from which Smokey viewed the world.   
  
A human world, 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 complete strangers to the world, 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 he 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 valuable member of society, in a world fashioned by sight.   
  
I in contrast am human yet there was something unnatural about my humanness. It is natural for humans to see, I don't. Therein lies my unnatural human status. Whereas Smokey represents domesticated nature, I represent the unnatural state of the human, with eyes gone wrong. The estranged familiarity that Smokey and I were experiencing life together and the unusual opportunity to see some of the ways our world is put together.   
  
Ways as invisible as sight itself. Smokey not only showed me ways of negotiating, he gave me a glimpse of that world from a different viewpoint, one that revealed some of the invisible features of the sighted world. The most crucial thing he gave me was a further reach into the human world and firmed up my contact with it. Until then, I had three points of contact, my cane and my two feet. Smokey gave me six with his four paws.   
  
My reach into the world was now extended by the length of his body and grace of his movements. I did so much following him as I moved with him through the world, with a habitual rhythm that came close to moving confidently and surprisingly, with joy.   
  
We had many close calls. Such as the time he cut across my body and moved me from a speeding car. There were fun times, like the times we visited a fare in Nova Scotia. He loved animals and walking through a barn was his 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. His intricate movements around the intricate grounds were too much for me and I allowed him to show me in the way he chose. I got caught up in his flow, clearly his intention. In a few moments, we were back at the bar.   
  
He freed my blindness in the world amidst the stereotypes and bizarre representations of blindness. But as Smokey and I moved, it released yet another freedom, the freedom to belong in this world and on our terms. Smokey did help me negotiate this world and made it clear the world we were moving in was our world. We belonged there. And we belong moving together as human and animal, forming the basis of this strange yet familiar movement of life.   
  
My left hand on his harness and a simple, "Forward, Smokey" we entered places that were our world. We were one of those places and spaces, we were not merely one more of "them." We were distinct. We were the sight of blindness, not as the banality 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 Smokey, and then speed, movement, grace, the world opened for us and Smokey and I elegantly entered it.   
  
Thank you.   
  
Speaker: I'm sorry, Liz I thought you were going to give a chance to switch interpreters but I think we're going to turn it over to Kim, thank you so much for another spectacular talk. Kim, our third speaker is a philosophy professor and women’s studies at Appalacian University teaching full time. Over to you Kim!   
  
Kim Hall: Thank you and thanks everyone for these wonderful talks.   
  
My walk has always been a problem, or always made me a problem. I was born with what has been referred to as a malformed hip joint, meaning my hip socket did not completely curl around my femur on the left side. It was a case of arrested hip development. Not enough hip, not hip enough. My birth defect was diagnosed during a routine exam meant to check for such anomalies. When the doctor bent my knees, he heard the sign of my femur popping out of joint and when my mother changed my diapers, my leg would fly out. I have memories of treatment, being casted and braced, having my cast changed, appointments with the surgeon and the dreaded trip to the shoe store that was I never allowed to get the shoes I wanted.   
  
I was two when I had surgery on my left hip, received a brace with a metal bar that kept my feet fixed in position pointed outwards. One of my uncles made me a device so I could roll around the house. My mom said I was hard to catch. My first grade, I was not braced at night but still had to go to the clinic where I was required to walk in front of my mother, resulting in an orthopedic conclusion that I was fixed. I walked, but with a difference. In my remarks today, I want to reflect on why this difference matters.   
  
My focus is not on whether technological intervention is good or bad. It can be informed by an ableist commitment or creative resistant ways for flourishing. But technology can also exceed these aims.   
  
Within ableist context, what is abled or disabled? A technology intervention moves one from abnormal to normal. How might we understand navigation at the edges of these categories? I focus on two points. First, how my gate troubles ableist assumptions and second how we might think about flourishing between ability and disability.   
  
I have what many call a limp or a Swagger, I have been chastised for walking like my father or a truck driver. My gate defies able and gendered expectations. Either way, my gate exceeds the balance of the normal. From an ableist perspective, the surgery was successful because it fixed an impairment that would have prevented walking. From this perspective, these technological interventions did not erase my body's experience, situating me between ordinary assumptions and the relationships they hold.   
  
The aim of curative technologies is disability elimination. The ones I experienced aimed to normalize my body. Still, my limping gate violates ableist and heteronormative expectations about how my body should move. While my gate might not count within medicalized expectations, it is shaped by disability experience. Walking does not make me anonymous, it's not uncommon to encounter a strangers stare that looks at my leg and then the rest of me. Sometimes they just stare. I confess think it's difficult to tell whether the gaze is about my nongendered gait or disability.   
  
I use the phrase queer Crip drawing on Nancy Meyers narrative about defining herself as a cripple rather than disable. The word has a history of being weaponized. Like queer, the term has been reclaimed to associate experiences and pressure to assimilate to norms. Both call for a better understanding for disability, attuned to experience that defy assumptions about who is included or excluded from a category like disability. Being disabled at birth then subjected to medical interventions meant to erase disability is not what most people have in mind when they think about disability experience. My experience might be categorized as an experience of cure.   
  
Nonetheless, in limping one stands out and when navigation is interrupted by questions like "what's wrong?" Communicating that one takes up a monstrous demonstration of space. The limping gate defies expectations of how able bodies move. But you had surgery and played sports? To limp is to defiantly move through space, unconcerned with what others might think.   
  
When it's part of ones gender nonconforming ways in the world, it might be predicated on ones shame or nonexistence. In characterizing my gate I aim to reframe beyond diagnosis and cure and understand how terms work to normalize. Orientations towards the norm won't cure what ails us.   
  
The term disability gain has been used to describe disability as a source of knowledge and creative being in the world. Perhaps what I am thinking about might be called Crip game, a perspective between ability and disability that troubles both boundaries. What can be gained from understanding childhood experiences of interventions and situating those between them, not making them disabled in a medical or legal sense but nonetheless positioned as queer Crip. I would like to offer expressions of how various terms forge paths of solidarity for others who are denied free movement in the world. Rather than aim for a fixed destination, queer Crip forge identities for belonging, suggesting another way to be.   
  
Speaker: Thanks so much. We are going to pause now for another interoperate switch. I want to thank all of the attendees again for coaching us through our captioning. Thank you for your patience, it seems to be working now but if you have any more problems we'll do our best to troubleshoot. Thank you for bearing with us as we learn to use this format.   
  
Okay, we can switch.   
  
Erik Parens: Thank you Kim.   
  
Liz: One second Erik we haven't switched just yet. We should be good now.   
  
Erik Parens: Thank you Kim for a terrify talk and Liz for shouldering these logistical matters. It's time now to begin the conversation among the speakers. Rosemarie Garland- Thomson will moderate followed by an opportunity for questions. Over to you Rosemarie Garland- Thomson.   
  
Rosemarie Garland- Thomson: Good afternoon, I'm honored to be here. Thank you to all who contributed and the Hastings Center and most of all my fellow panelists, colleagues, friends who have spoken. I am joining you today from my home office in San Francisco. 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 are my glasses and the machines and applications I need to use to be here to participate because I don't type.   
  
I have three questions I want to present to our team of speakers, these questions recapitulate or recap what the speakers have thematized in their work. I'll begin with the first question, if you don't get a chance to respond to all of my questions as fully as you would like, there will be ample opportunity from the audience.   
  
Each of you has offered a story that shaped your experience with your disability and get around in the world and how you use technology to get around as well as how technology makes a statement about who you are. These technologies are often understood as aides for what we can't do, your stories today show us how we use our technology very intentionally to use a world not built for us. We use technology to move from a segregated world to one where we can access opportunities like education, employment, housing to enter into a world where we have freedom of movement.   
  
I'd like to ask the panelists for more examples of how you use your technology intentionally that allow you to flourish as people with disabilities rather than people who are trying to become non-disabled?   
  
Ready?   
  
Yomi: The last part of your question about flourishing and being present versus not being disabled, I would say right around maybe a few years after the period in my story, I stopped participating in physical therapy. I stopped trying to use crutches and walkers, I was using those to gain strength and mobility. It seemed important to people and to the medical community that I walk. I have brittle bones and am a 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. In fact, my wheelchair became protective. I used it as a skeleton 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 resonates when you talk about showing up as disabled which for me is personal and political to my identity and a point of pride. Trying to approximate able bodiedness which I have no interest in.   
  
[switching transcribers]  
  
If I think about the piece of plywood my uncle made, that's something I loved throughout my childhood, it enabled me to get around quickly by rolling really fast out of the reach of adults but much faster than if I crawled. But, in terms of thinking about limping, swaggering and technology, I think shoes are incredibly important. Shoes for gendered and supportive reasons, not being able to choose the shoes I wanted was part of my gender identity, part of walking or navigating in the world is also about defying gender and abled expectations of embodiment.   
  
In terms of thinking about limping, swaggering, and technology that has been really important, I think shoes are incredibly important, for gendered and supportive reasons. not being able to choose the shoes I wanted.   
  
That was part of my gender identity that was gendered invisible.   
  
Part of walking and navigating the world means defying expectations.   
  
Rosemarie Garland- Thomson: Great, Rod did you want to address this?   
  
I think one small point I'd like to make. While it's true all of us who understand ourselves as disabled do use certain technology as a way to gain access to the world of economics and housing, etc.   
  
Rod Michalko: Sure, I think we use different types of technology for gaining access to the world but as Yomi said I view my blindness as political, technology for me is also how do I bring blindness into the world. I have done this all my life and not found ways I am satisfied yet, bringing blindness as a distinct way of being. To bring my world into your world.   
  
I also view my blindness as political. Technology for me is how I bring blindness in the world that's different from the sighted way of understanding it. It could be more as a difference rather than a deficit.   
  
I've done this all my blind life, bringing blindness as a distinct way of being, bringing that into the world and treating technology as way to bring my way into your way of the world.   
  
Thanks.   
  
Thanks.   
  
Rosemarie Garland- Thomson : Thank you Rod. We have been friends a long time and I love the way you talk about having a blind life.   
  
Thank you, Rod. We've been friends a long time. I love the way you talk about having a "blind life." I find it poetic. I'm an English teacher. It's particularly important for me to be able to be involved and hear your stories today.   
  
I will go to the third question. In the stories, you talked about flourishing as people with a disability. All three of you have used words that describe your lives and yourselves, which might be surprising words. People may not know too many disabled people well.   
  
Yomi talked about experiencing power. Rod talked about grace and joy. Kim talked 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 often understand not as power or gain or joy, but as deficit or defect?   
  
Hard questions.   
  
I'll start.   
  
Thank you, Rod.   
  
This is difficult. While I think Kim is right, there's a certain vein with disability. It's kind of a gain with most ways of being in the world. Rather than benefits or gain, one way I like to think of it with my blindness is while the world generally and typically gives me some sense of boldness as clearly somethings don't want to be, where you know nobody wants that-- it depends on my mood. During COVID-19 times, that's not always great.   
  
I think in terms of not being trapped conveniently with understanding, for instance, 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 as an opportunity.   
  
It's given me the opportunity to realize that your sight is the furthest thing as natural possible.   
  
You need to show one another that you can see, in a sense. It's beautiful to "watch" from a blind point of view. Sighted people are so busy demonstrating they can see that sometimes it's humorous. Other times, it's sad.   
  
Nonetheless, it's interesting and a lot of fun 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 he answered.   
  
It's fascinating. Another example is looking toward people when you are talking. It's 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 love tricking sighted people with my accuracy.   
  
Yomi and Kim? Do you want to comment on joy, gain, power? Complicated as we say?   
  
I can comment on joy, I think. It's no fun not to be anonymous, having to be stopped and having your gate 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. I've found that incredibly joyful as a queer person.   
  
Yomi, did you want to give the last word?   
  
I'm good.   
  
I'm still thinking about it, so I'm not ready to take it on.   
  
Of course not, this format will give you that opportunity.   
  
Eric, why don't we and Joel move to audience questions? Obviously all three or four of us and participate in these questions. I think that will be very productive. Thank you all for this part of the program.   
  
Once again, we'll pause for an interpreter switch.   
  
I think we're ready.   
  
I'll add my thanks to Rosemarie and the wonderful speakers. Joel?   
  
Hello, everyone. This is Joel Reynolds. I would like to encourage people who are watching to submit their questions or comment session the Q&A. We've been watching that very carefully the entire time. We've got a number of questions written down we'll look through. Whatever comes to mind, please go ahead and submit it.   
  
We'll also look at Twitter and Facebook, but the Q&A inside of Zoom is easier to manage. I will 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 to 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 welcome to.   
  
Kim?   
  
It's hard to know how to jump in. That's a really important question. Ableism is systematic and institutionalized normalization and naturalization of abled-bodied mindedness. Having an abled bodied experience and way of moving through the world is seen as natural.   
  
Many people have written about this in disability studies. In terms of my thinking of ableism, I'm interested in how it is it both informs and is informed by other systems of oppression. One thing Robert McGruwer talks about is compulsory able bodiedness, that there's an imperative to fit within those norms.   
  
What's so important about that is no one really does. Most of us in some sense fail to embody that norm. It's also exclusionary and harmful. It informs ways to normalize the body, whether through medical interventions or surgical "corrections." It also informs violence in the world. I think understanding how the institutionalized pressures to be normal are part of what it means to inform ableism.   
  
Rod or Yomi? Would you like to jump in on this question?   
  
I feel Kim said it succinctly.   
  
And Rod, I think you're accidentally muted.   
  
I think Kim was really good with her comments. Also, one of the things is that's a systemic problem. That doesn't belong to disabled people. It's related to racism and sexism and various systemic discriminations and exclusions. It does often lead to violence.   
  
I think people speak of various oppressions like ableism, sexism, and racism as "systemic, but not me." "It's the system, not me." It's interesting with disability, or in my case blindness, how an ableist perspective is a sighted community acting and thinking as though they understand blindness in a complete way. First that it's an absence of sight, and secondly that the person leaving with blindness would rather have what they have. "You'd rather be me, but you're not."   
  
Then you the ableist version of gain. That we have somehow 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, people will say "you will appreciate this, having better hearing." Then I'll say "pardon" and they'll either get it or they don't.   
  
There are ableist things informing a more systemically ableist oppression.   
  
That is really powerful. I hear the way in which one effect of ableism is to create what you could call ableist common sense. "Of course I'd like to see."   
  
You have this default assumption that it's certainly better and more desired to be able to see. This ties back directly with Kim's citation of the notation of compulsory able bodiedness, this imperative. An almost command that operates often in the background of people's assumptions of the world.   
  
I'm talking too much. I'll 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 worth talking about. How do you think the medical field should change for a better response and relationship to and with people with a disability.   
  
People further specified how you think your specific disability could have been better related to.   
  
I work in healthcare and have the opportunity to see field from another view, working in healthcare but also being a subject and participant my whole life within the medical model.   
  
When it comes to disability and impairment, I think speaking the medical field and children, we need to be preparing people and addressing function. 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. How can we maximize function and independence, autonomy, and agency? Rather than looking how to fix my bones and straighten my legs-- some of which was beneficial since some interventions allowed me to physically thrive in certain ways.   
  
So much of my energy, time, and money was wasted in trying to make me blend into an ableist world. 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 for me to thrive? Not for my doctor or social worker or the other people who will look at it through an ableist lens. What does it mean for 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 should go.   
  
Kim?   
  
That's really great and important. To add from my experience-- not to assume when thinking about flourishing on one's own terms, not to assume heterosexuality or gender conformity. So much centers on what it means to have a "normal" walk, putting one foot in front of the other. The two are fused in my experience of having my walk commented on. I think flourishing has to be not separating disability from gender and sexuality. We should think of people as full beings, allowing for diverse modes of flourishing.   
  
I was an infant, but my parents were upset I might not ever walk. I think there's a lot to make it so people who are making decisions have access to communities and people who can communicate it's possible to flourish in all kinds of ways of being in the world. I think that's important, too.   
  
Rod?   
  
I think Kim and Yomi did beautifully. In my experience with the medical community, and in other people's experiences, the individual practitioners seem to be committed to a norm-made version of the body and sense. They come to their interaction with us generally with that notion of the normates, expecting us to want be other than who we are.   
  
There are assumptions such as around sexuality and gender. It sometimes comes to me as the quintessential protector of the normate. It's as somehow I'm an enemy that invaded that. I'd love at least a little bit of sense of humor from a practitioner. In graduate school, I had an ophthalmologist look at me. He reached for a gadget and he 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, letting go of some of the assumptions of what the human, in a moral sense, ought to be.   
  
That's really powerful. This opens to another question.   
  
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. Thank you for all of your patience. Go ahead and switch.   
  
Another question would be about each of your talks being in relationship to technology, technologies of multiple sorts, technological interventions and objects you'd use. One thing that stuck out to an audience member was Rod's talk, referring to what we don't typically think of with dogs as a technology. Yet it's also very natural to see why Smokey fits into the 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 what the concept of technology means and how you think about the relationship between your particular way of being disabled and being in the world and these objects or practices referred to as "technologies."   
  
Thanks for the question. 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 an intervention, then my blindness as technical thing.   
  
All of us can see in that way. We can see eating in 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'll do this stuff. How can do the stuff normates usually do. It's a fair question. I think Smokey was a technology in the sense I relied on him to get around. My life was in his hand, really. Smokey loved to work. 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. My blindness gave smokey a chance to do what he wanted to do. My blindness became a little bit of a source of joy, for both him and me. It was the kind of blindness Smokey allowed me to bring into the world. It was never a drag getting from one place to another safely. I enjoyed the trip. Thanks.   
  
Kim or Yomi? Are you understand in responding?   
  
It's a great question and very thought provoking. What Rod said was really amazing. We think of technology as something we use or is applied to bodies in order to make it so bodies can move through conventional spaces.   
  
There are all kinds of technologies in my experience as well, but I think about the one example of surgery. 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 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 more powerful in a disability critique of technology and what that means.   
  
Yomi?   
  
This leads us in some ways to the 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. 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 mean? And what are pros and cons of it? If 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. The relationship between disability, technology, and flourishing, the idea that one is living how one actually wants to and is able to carry out that life relative to how society is structured. I think that was complicated and less elegant than Eric.   
  
Crip gain?   
  
I would love to hear Kim say a bit more and then jump on it. I love hearing Kim talk about the.   
  
When I wrote it, I thought maybe not. Maybe. Maybe one might or 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 to 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 defying normalization, existing between disability and ability-- that this isn't just a scene of loss, but also of flourishing. How to talk about that in ways that rework an ableist distinction between ability and disability. It's not necessarily gaining a new skill or something. It's about creating possibilities for flourishing. Perhaps it isn't the best frame. I'm very open and willing to learn from others.   
  
I'm going to use it. We'll be talking about crip gain, just like with abolition, resilience, resistance, and freedom, joy, and flourishing. I really like the concept. You have given me something today.   
  
I mentioned 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 one. 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, 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. It's a positioning of me as outside the normal way of things. I see that as a gain.   
  
I like this concept of all the ways my disability has provided entry into spaces and experiences I wouldn't otherwise have. Also, I see my experience as who I am as Yomi as deeply spiritual. I feel it's an exercise of spirituality for me. I'm working out a lot of things in this lifetime and plane, at this moment right now.   
  
I feel this is the body and experience I was meant to have. I like this concept of crip gain because when I review my experiences and the way my mind and heart have been sharpened and smoothed over and over again by such experienced, I see that as gain. It's something I've been endowed and blessed with.   
  
Rod?   
  
That's beautiful, Yomi. I have some of Kim's and Yomi's unseating and feel about gain. I think what's interesting 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 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 center.   
  
As Yomi said, I would not be here at all if not for my blindness and who I am. 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 to look at the center in a way being in the middle of it doesn't really give you. It's like the saying the fish doesn't have any ideas in water. It gave me a chance to ask a question and revisit a question my partner and colleague asked. "Once we, as disabled people, are in, what are we in for?"  
  
It questions the Center's 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 and the idea of inclusion, to get in is one thing. To stay in is another. It's almost as if we're 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 look at that stuff as well. That's some version of a gain.   
  
Yomi?   
  
Thinking more about gains. [Laughter]   
  
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. 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 was very conversant. I was a good and clear communicator. I meant 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, 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. 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 break several 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 other verbal skills. I see its as crip gain. It's not because of big brains, but due to the adaptation, needing to be able to communicate to anyone touching or handling us so that we were not repeatedly injured. I see that as a gain.   
  
Before I ask another question or provide a comment, 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.   
  
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 moving incident. Everyone was doing their best. I need to say that in case any of my family members get a hold of this recording.   
  
Duly noted.   
  
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.   
  
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" 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 in. There are two artists, one blind and one not, Lane Manning and Austin Clark. They were both great friends. About 8 or 9 years ago, Austin was an award winning author and poet. He said, "you'll have to bring blindness out in fiction, my friend." I started writing fiction. The experience of being blind in the world, or as it seems like as a marginal way of being has given me a lot to work with.   
  
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.   
  
I'm going to let the interpreters switch. Think about that while we do that.   
  
Kim?   
  
In terms of gender and disability, thinking more broadly about class and race and disability as well, when we think about what body norms are, they're 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 one has, where you expect a heterosexual gender conformity. The experience of that in one's navigation of the world is also a performance ability. That's plays into compulsory able bodiedness and heterosexually and how they rely on each other. They're normalization and naturalization depend on each other. In 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, it's important. 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.   
  
That's wonderful, Kim. It brings me back to the theme 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 center metaphor.   
  
The way I think about all this and apply certain practices is by being a student 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 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 that I think really illuminate what you and Kim talked about. It's where my political heart and home are these days. The work is toward anti capitalist and abolitionist, to tear down white supremacy and ableist. That work is led by people of color and people who haven't been the standard bearers of the disability rights movement.   
  
I want to add one thing to that. When we talked about ableism, I should have said the best understanding of that term is from TL Lewis. They worked with Dustin Gibson and a collective to come up with a version that takes colonialism and capitalism seriously. It's really a genius understanding of the term. If you're interested more in that, I recommend Lewis' and Gibson’s' work.   
  
Those are our luminary thinkers. These are the people who gave us this gift of the disability justice framework. Then we have so many others who are carrying that work forward. They are the guiding lights for us and for me.   
  
Each of you are guiding lights also. I'm so pleased we got this time together. I don't know what happens, but I believe Liz will appear, or that we'll hear from her.   
  
We will wrap things up. Eric 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.   
  
Liz, my video isn't activated, which is fine. 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 third event.   
  
Be safe and be well. Thank you. \_

