The Hastings Center Transcript for [**We Belong To One Another: Disability and Family Making**](https://www.thehastingscenter.org/we-belong-to-one-another-disability-and-family-making/)

**Liz Bowen:** Thank you all for joining us, and welcome to “We Belong to One Another: Disability and Family Making.”Thank you all for joining us, and welcome to “We Belong to One Another: Disability and Family Making.” My name is Liz Bowen. I'm a post doc at the Hastings Center and the director of this webinar, The Art of Flourishing: Conversations on Disability. I helped to organize this series along with my colleagues, Erik Parens, Joel Michael Reynolds, and Rosemarie Garland-Thomson. To start us off with a quick visual description, I'm a millennial, a white woman with blond hair, and I'm wearing what I call my academic uniform, black mock neck shirt and a silver chain. There is wall behind me and some various parts of my living room. Today’s webinar has both closed captioning and ASL interpretation available. You can turn on the captions using the closed captioning or C button at the bottom of the screen. There's a link to the full transcript in the chat. Please note that if a panelist is sharing the screen, you can adjust the size and the interpreter’s boxes, if they are too small to see. There's a divider between the slide and the gallery of speakers’ images to change the size. We do recommend watching this on a computer screen rather than a mobile device for maximum accessibility.

If you are having trouble with the accessibility features today, please access the Q&A at the bottom of the screen so we can trouble shoot. Today 's event is recorded. This will be posted to the Hastings Center site after it ends, along with a link to the full transcript. Due to the size of the events – we have hundreds registered – we need to keep the chats closed and attendees cameras and microphones off for security purposes. If you have questions for today’s panelists, we very much encourage you to submit them in the Q&A feature at the bottom of the screen. There will be time for Q&A in the second half of the event. With that, I will turn it over to my colleague Erik Parens, who is director for the National Endowment of the Humanities funded initiative in bioethics at the Hastings Center.

**Erik Parents:** Thank you so much Associate Director of this program, Liz Bowen. Regarding visual description, I am a white man, and not a millennial! I have gray hair, gray beard and tortoiseshell glasses. Thank you to the senior project advisor Rosemarie Garland-Thomson and to project co-director Joel Michael Reynolds and thank you to you all for joining this 6th and final public conversation in this series, The Art of Flourishing: Conversations on Disability. The purpose of this Hastings Center series is to broadcast and explore one fundamental theme and that people can flourish in all kinds of body-minds. To flourish here means to exercise the capacities we have in pursuit of the purposes we find meaningful. We don't need different body-minds to flourish, what we need is more supportive environments.

No one ever articulated our theme more powerfully than the late disability rights activist, Adrian Ash, who introduced the social model of disability to bioethics way back in the 1980s. Way back in the 1990s, Adrian and I led a project built around the bioethical dilemmas that arise when non-disabled people selectively abort fetuses based on disability status. Indeed, when Rosemarie, Joel, and I conceived of this in 2018 we felt to get at the project's fundamental theme that we would look at dilemmas that would resemble these dilemmas in the prenatal context. Indeed, the original plan was for this final event in the series to return to the dilemmas that arise who people who are advocates for reproductive choice and disability justice contemplate using prenatal technologies. Over the course of the series, we felt ever-less need to use a bioethical dilemma about a technology as an alibi for articulating our fundamental theme. We have become ever more eager to simply explore how people can and do flourish within supportive environments.

In previous events our speakers have reflected on their own ways of engaging in various activities that promote flourishing, including communicating, navigating, and enjoying. And today, instead of focusing on the prenatal dilemmas we will focus on the activity or activities of family making. This shift strikes me as important. There is a way in which using the prenatal testing dilemmas as the occasion for articulating our fundamental theme would place non-disabled people at the center of the conversation. It would have placed disabled people in the position of having to say things like, "You nondisabled people, in acting out of ignorance of what life without disability is like, are making an ethical mistake when you refuse to welcome babies with disabilities in your Families." End quote of hypothetical speaker.

Instead, today our theme foregrounds the lived experience of disability and invites others to recognize its richness. This is saying, look here. This is a way in which disabled people are flourishing, making families, and expanding what it means to be in kinship with others. We will hear three presentations today prepared by a total of six contributors. For more information about our contributor's backgrounds and accomplishments, please go to the registration page which should be in the chat at any moment now.

The creators of our first presentation, each of whom are professors of gender and women’s studies are Jina Kim, Jess Waggoner, and Sami Schalk. As many of you know, doulas support pregnant people as they bring babies into the world. Jina, Jess, and Sami will focus on what they call queercrip doulaing, which refers to queer and transgender people with disabilities bringing young queer people into kinship with those people who share their identities.

The creators of our second presentation are Leah Smith and Joseph Stramondo. Joe is a professor of philosophy and Leah is an activist. They will talk about what it is like to try to adopt children with disabilities like their own.

Mia Mingus will offer the third of our presentations. Mia is an educator and trainer for disability justice who will talk about the form of kinship that can grow around what she calls “Access Intimacy.” Mia will speak about how having the access needs recognized and recognizing the access needs of others can give rise to forms of kinship not dreamed up in the traditional model of the nuclear family.

So again, our aim is to talk about disabled people flourishing. But this is not without its dangers. We might say about our conversation on family making today something like what Julia Watts Belser said about the activity of enjoying. She said, “There are risks when we talk about joy, that we make joy a prescriptive, a requirement and a precondition for belonging.” Julia continued, “There's a risk that the joy becomes another way to judging. If you are not happy then you are doing it wrong.” Plainly today, that's the risk we intend to avoid. But it might be one that's of concern to people and it is one that people are welcome to bring up in the audience discussion after the break.

 So, after Mia finishes her talk, Rosemarie Garland-Thomson will facilitate a brief conversation among our presenters. We will then take a five minute break and after that, we will open it to audience conversation. That conversation will be led by our colleague and friend Joel Reynolds. So then, it's my pleasure to turn the mic over to Jina. Jina?

**Jina Kim:** Hello everyone. Thank you all for coming. Our joint presentation is titled Sustaining Queercrip Kinship in Pandemic Times. We will begin with a visual description of the presenters and a content warning. This is Jina speaking. I am a Korean American woman, with glasses and frosted blonde tips. I'm wearing a dalmatian sweater vest and a blue button down shirt.

**Jess Waggoner:** This is Jess Waggoner speaking. I am a white person with pink hair and pink lipstick and I have a Dolly Parton pillow behind me and a black lives matter sign. And my pronouns are they/them.

**Sami Schalk:** Hi. I'm a fat black woman wth short curly hair, teal dress with lace at the chest, and Lisa Frank glasses and also there is a cat on my desk right now who might be in front of me during this talk.

**Jina:** Before we begin we wanted to give content notifications for discussions of ableism and transphobia and brief references to suicide. Please, do what you need to take care of yourself. Now to begin, this is Jina reading.

In staying with the trouble, Donna Harroway urges readers to “make kin, not babies.” Harroway's call reminds us of longstanding discussions in queer studies around family and affiliation beyond blood and biological relationships. But what does it mean for disabled people, in particular queer and trans disabled people, to make kin? And what does it mean to make kin when systems of heterosexism and white supremacy disrupt our life sustaining ways we do create? And how can we love each other despite these systems that insist otherwise.

Finally, how do we forge these lines of intimacy during a pandemic? In traditional ideas around life and household shift mainstream discussions around public health and safety and collective responsibility. Driven by these questions, we want to share with you the ways we have learned to create and sustain kinship ties in through practices grounded in disability and queer politics. For us, making queercrip kinship and not just about the what, but also about the how? That is, the practices we engage in in order to forge these ties. We define the queercrip kinship practices as the things we do to create and sustain close relationships as queer and disabled people with in ways that are familiar to family making but that challenge the traditional notions of family and what that means, is, or does. This is not a comprehensive overview. There are many many ways to make queercrip kin, some of which disability scholars Allison Kafer, and Shayda Kafai define these in their writings on this topic.

For our presentation we focus on the practice most relevant to us during the pandemic thus far, queercrip doulaing work. We build on the work of does justice activist, Leah Lakshmi Piepzna-Samarasinha, and Stacey Park Milbern, who coined the term disability doulaing to describe birthing and ushering people into a new disability identity. We issue a queercrip challenge to the concepts of family expansion birth and reproduction, especially with a mass disabling event that might expand the ranks of those we consider queercrip kin.

We issued challenges for the COVID-19 pandemic and the suggested best practices for reducing viral transformation have simultaneously reinforced and disrupted traditional family. Like how we count those who count as kin and how we value those who do count. In 2020, the discourse framed those visiting those outside family as hazardous to family, elevating the nuclear household to the pandemic gold standard.

As disabled queer people who live alone, relying on local community ties for survival, have robust chosen families and maintain distance from our families are origin, these recommendations were very distancing. They framed our ways of relating as potential threats for contagion. On the other hand, quarantine provided some relief to us looking to avoid our families especially during the holiday season when feelings of obligation run high. All the while, we rely on time-honored queer and crip strategies to maintain connections while living under forced isolation, which, we may add, queer and Crip people have long endured. These strategies such as social distance and digital communication helped us cultivate our chosen family networks at a time where social interaction and touch is not guaranteed. Throughout our presentation, we draw on our queer experiences with crip doulaing with our niblings.

Nibling is an all-gender term to refer to the queer teens and children in our lives that we use as queer aunties, gay uncles, and fairy godparents. Some of them are biologically related to us and some are not but they are all our niblings simply by being in our lives. They are people who are in caring relationships to us as children in adult-relationships. Passing it on to Jess.

**Jess:** Thank you. Vignette one: gay bacon. Eve’s message appears in a discord server he created for us. “Bacon. Voice chat, anyone?” a call across space and time through mundane space, with queercrip results. At a time when sharing air has become an increasingly dangerous habit, these modes of connections are especially present access of technology. We discuss the ways our disabilities gently shape or interfere with our desired gender presentation. Binders to flatten the chest can be out of reach for disabled trans people. Some masculine clothing such as pants are constricting and difficult to navigate with a disability. We elevate stretchy fabric as a trans crip revelation. I disclose that my desire to bind and wear more restrictive clothing has also helped me accept my disabled body as a trans body, as is. We try on pronouns, discuss the possibility of keeping our names of origin. We generally exist in Crip space. The familial rhythms of play hanging on video. The show and tell of objects in our space, sharing music and gushing over service dogs and ESAs, between tough questions such as, “How do I really know I’m trans?”

Under the mossy growth of pandemic temporalities, some young people have found the space to thrive. Others are isolated from their friends and queer kin, or trapped in unsupportive, oblivious, or phobic family dynamics, dynamics which are indeed disabling. They witness the unfolding of harmful legislation targeting trans youth, and they question if they are indeed really trans, some of whom they have lost or are losing. This loss is linked to an uptick anti-trans legislation that invalidities trans youth while the pandemic traps them in unsafe living situations. These bills send a message to trans youth that they should not exist, and impair access to life saving care.

Vignette 2: Cripping the Bisexual Chair Meme. As the pandemic reshapes many of our relationships with outdoor spaces, A, never an outdoor kid, will still deign to sit outside in a camp chair and make absurdist queer art with me. King of the Hill's Bobby Hill radiating rainbows, or propane tanks emblazoned against a queer flag. At 11 years old, A is a constant stream of self-educated, neuro-divergent queer literacies, in which he weaves his love of 90s cartoons, despite the proliferation of current queer cartoons for young adults at his disposal. He prefers strange juxtapositions, queer takeovers, and reparative readings of media that are sometimes downright queer hostile.

As we listen to queer trans musician Cavetown gently destroy toxic masculinity, “Don't mess with me, I'm a big boy now and I’m very scary,” A is draping himself over the camp chair at the oddest angles, and I’m compelled to share with him the “bisexuals can’t sit in chairs properly” meme. I joke to him that I am always Bi, because my pain levels make it so that I can never sit in a chair properly. Something clicks, and in communion with me, he is intentionally reveling in the chair’s contortions, reveling in the deep bi-ness of strange posture. This gentle playspace, instead of the blunt edge of asking, "what are you, how do you Identify?" This gentle re-routing of queer identity, neurodiversity, puts us on the twisting path to the current moment, where he asks me to use a new name, and he/him pronouns, for the very first time. And now I am going to hand it off to Sami.

**Sami:** This is Sami speaking. Vignette 3, community consultation. E has received a new disability diagnosis, hypermobility. The nurse at school calls his brother when his hip comes out of his socket. Wanting to help E with a practical access problem as well as a new disability identity, we connect him with a friend with a similar disability, a friend who is also trans and queer. On a Saturday afternoon we hop on Zoom call, E in a room with his mom asks questions, takes notes. Our disabled, queer, trans friend works as an advocate and helps E prepare for an upcoming accommodation meeting with the school. But he talks to E about mobility aids and the importance of being open to them, practicing with them, and learning which one works for one’s body before there is a desperate need, an emergency. This queercrip doulaing conversation teaches you how to advocate for oneself. It shares the wisdom of the queercrip community. We all leave the conversation nourished, fortified by connection in this process of bringing a another queer person into the family. E begins to call these new connections his cousins, understanding these connections as forms of kinship long before we teach him the words we use to describe it. Welcome to the family, kiddo. We love you as you are. We welcome you as you are. There is a place for you here, with us.

The COVID-19 pandemic has taught us to move deeply with Crip time, to revel with joy of togetherness in whatever medium we need it. We try to move with one another’s access vibrations, to remain open to people’s ever shifting need. Being a part of these conversations with our niblings has been healing for us. At times, we think, what could we have done, who could we have been? If had had a queer or disabled adult around to let us know we were perfect as we were, that we were going to be okay. Someone who gave us words for what was happening with our body-minds. Loving our queer, trans and disabled niblings is a way for us to love our queer disabled people as we were, who had to hide, who experienced so much shame and isolation, surrounded with biological family but with no kin. Indeed, this process of queercrip doulaing is not a linear distribution of knowledge from elder Crip to queercrip youth. Our niblings have shown us the power of our vulnerability from queer, disabled adults. By allowing ourselves to be seen by them, and seeing them in turn, we have come to understand ourselves better.

Queercrip doulaing has shown us better queercrip worlds are possible. When people are connected to loving, safe community, including digital communities, we don’t have to experience the isolation, stigma, or fear many of us have have spent years undoing. We heal as we usher others into community, and into Crip kinship. Thank you. I will hand it off to Leah and Joe.

**Joe Stramondo:** Hi, everyone. Thank you for that wonderful talk on Crip queer kinship! That was so critical, important, and interesting. We will shift gears to talk about a more traditional view of family making, that nevertheless can be problematized and brought into conversation with some of these questions that were introduced in the first talk.

**Leah Smith:** Let’s do our descriptions first.

**Joe:** Yes, before we get into the meat of our presentation. I will do an image description. I am a white man with dwarfism that has a dark beard and thinning dark hair. I am wearing round glasses and a white and blue checkered shirt buttoned up. We are sitting in a bedroom office.

**Leah:** I am Leah, I am sitting next to Joe. I have brown hair and glasses top on. Behind us is a window and door.

**Joe:** The name of our talk is called Parenting while Disabled: From Eugenic Deficit to Disability Gain. The plan is to try to turn on its head the presumption that disability is a deficit or liability when being a parent. Next slide, please.

I will start with some quick comments about the history of eugenics. We have the famous Buck vs Bell case, where Supreme Court Justice Wendell Holmes made his famous comments, “Three generations of i----s is enough.” This case and others like it, that framed eugenics as part of the disability movement, really focused on this primary feature of historical eugenics – its emphasis on, “Who gets to become a parent?” Who is fit to raise children?

Of course, eugenics isn’t one thing. It’s many things. But one of the prime pieces of eugenics was that it determined and tried to articulate what qualifies a person as a parent, and what quantities they should have if they are going to be good parents. It wasn't just about who was passing on what hereditary traits, but also the qualities of the parent. Next slide.

As you know, the qualities of a good parent as articulated by the eugenics movement continue to present day. They are still very common when thinking about what a good parent looks like or who a good parent is. We would like to suggest that some of these qualities can be traced into the history of eugenics in the United States. We have white, English-speaking people are good parents, intergenerational wealth, upper middle class people, Cis-gender people. People in traditional family roles. And of course, non-disabled people are all the characteristics of 'good' parents, that we can see the eugenics root of.

**Leah:** When we were creating the slide for this, I googled "good parent" to see what images showed up. These are the images on the right. I didn’t do any more searching. They just all fit the description Joe just mentioned really well. White, Upper middle class, cis-gendered, heterosexual, uphold the idea of traditional family roles. Next slide please.

About a decide ago, "Rocking the Cradle" which was a National Council on Disability report on disabled parents, had a lot of assumption about the ability of disabled parents. There was a disproportionate high rates of disabled people losing parental rights through the welfare system. Of those, psychiatric disabilities were 70-80% and intellectual disabilities were 40-80%. Another finding was discrimination against disabled parents in custody or visitation disputes and also barriers for disabled parents to adopt children, domestically and internationally. Next slide, please.

**Joe:** There are additional ableist barriers that we thought worth mentioning. As we all know, access to healthcare generally is a real issue for many disabled people. They tend to be under or unemployed. With the current situation in the United States especially, employment is tied to health insurance. There is a problem with reproduction healthcare and access for disabled people. The reasons are complex. It is worth to noting that it’s a thing. Another barrier to parenthood is SSI marriage penalties. This is where you lose benefits from governments if you get married. So disability benefits can be put at risk by marriage. Certainly, marriage should not be a pre-condition to parenthood. But for many people, that is what they choose. So we can see marriage penalties as a barrier to disabled people.

Finally, there is parenting assistive technology. These are not always made for disabled people. Sometimes you need assistive technologies that look a little different than standard. A lot of times, the assistive technologies are not easy to come by, such as cribs, strollers, and so forth.

**Leah:** The image to the right is a photo of, spoiler alert, our two kids. They are sitting inside of an accessible crib. It is a barn door style crib that opens at the front so that we can reach them as babies.

**Joe:** It was difficult to come by. We were gifted it by another disabled parent from Minnesota. That’s how difficult it is to get some of these technologies. Next slide please.

I want to shift gears a little bit here and suggest that we ought not think about disability as a deficit or liability when it comes to parenting. To pick up on the theme of disability and the art of flourishing, let's talk about disability as a parenting gain. Here, we are using the term disability gain. The term originates in the deaf community where it inverted the idea of hearing loss and instead talked about deaf gain. Deaf gain was a term to refer to the value added to the world by deaf culture and deaf people. This term has been adopted more broadly beyond the deaf community itself and used by other disabled folk. Our claim is that the presumption that disability is a parenting deficit can be inverted. We should think about the ways in which disability is actually a parenting gain. Next slide.

**Leah:** A little bit about our story. We met 12 years ago. We dated and were discussing our future and about family and what we wanted that to look like. I fell in love with Joe because of his vision of family and how it matched mine. I didn't believe that disability was bad. I wanted to embrace that in our children as well. From the get-go, we had a strong desire to adopt a child with our same disabilities. We believe in the notion that disability is a gain in our parenting and we think we brought a different perspective to that than other parents. We went through the adoption process and went through 2 failed adoptions. In both cases, they were open adoption. We built relationships with the moms before the adoption took place. The diagnosis for the children were dwarfism. The mothers were confused and didn't know what that meant for them. I know it’s safe to say there was lots of fear there. They went into the adoption process and got to know Joe and I.

Interestingly enough, as much as we wanted the adoptions to go through, in both situations we became ambassadors of disability and what it looks like. From two biological parents that had never seen disability up close they had lots of stigma and ableism of what they thought it would be. They got to know Joe and I and they reversed their decision. Last slide please. They decided that disability wasn't so bad after all. But this showed us, this wasn't fun for us. And a very expensive situation to go through in order to teach. We need better understandings of disability and parenting and what this looks like for people. It's not about who Joe and I are, it could have been anybody, but advocating for more media and representation of what disability is, it removed the fears and disability as a deficit and allowed them to imagine life with their child. That they weren’t given from the diagnosis itself. It develops an understanding of disability as a neutral or even as a positive for them. Next slide please.

**Joe:** We want to unpack this. The next step on our journey was the birth of our two bio-kids. When we came up with the idea for this talk, we started kicking around ideas about what disability gain looked like as parents through our experience. Our experience is just a very narrow slice. I'm sure there are more examples of parenting disability gain. But we can give you a sense of what we have experienced here. There are, I think, two ways to think about parenting disability gain. Or two sources of disability gain that we have experienced as parents. One, gains from disability as a social identity. In other words, the ways in which we, as social persons and as a particular political position we occupy in the world, offers something to our children. And two, we will talk more about this one in the minute. But this is about the ways that our bodies offer a disability gain.

Before we get to the embodiment piece, I want to say that I think sometimes I imagine what my life would be like had I been born average size and not acquired a spinal injury. When I think these thought experiments and I'm a philosopher and love our thought experiments, I think about my perspective would have been so much more narrow, and so to get to ideas like the difference and inclusion, social justice, and fairness, self-acceptance, interdependence, and so and so forth, I could have gotten there but it's harder without the lived experience of oppression. There's a stereotype or idea that disability is just there to teach non-disabled people a life lesson. That's something that disability advocates push back against, especially those looking at narratives in the media and just saying, we are not here to just teach lessons to non-doubled folk. I want to support that. But there is a big exception to that rule. I think disability SHOULD exist to teach a moral lesson when you teach lessons to your kids. Child rearing is in fact a giant experiment in teaching moral lessons. So if you could use disability as a resource as Rosemarie Garland-Thomson might say, through parenting and opening up the world to our children and thinking about disability, inclusion, and difference and that goes beyond disability itself on to other marginalized identities and social justice, for example. That's a good thing, I think. Next slide, I think

**Leah:** The other parenting gain is some disability as embodiment. We have seen this with our two kids. One, if you read any parenting article, the first thing they say is get at eye level with your kid in conflict or if you are framing a situation or redirecting. Something that's been positive for us and a disability gain is that we have been at eye level the whole time with our kids. I see a difference. I see how and what a gain that has been for us. The other thing, we are proponents for positive parenting. But also having two average sized children is that corporal punishment is not an option for us. That's a huge gain in learning to use words only. There's no physical force. Our kids don't even know what that means. There's also a really - we found - understanding in bodily autonomy and consent more than some other children. Most of my back is fused. I cannot wrestling. Wrestling is just the tip of it. They know they can’t just jump on my back. They must be careful with me. Silas says mommy is a gentle flower. I love that in particular.

But it's an understanding that they must ask my consent with my body. I think that's important. And there's a greater sense of physical independence. I got pregnant with Hazel and found out she would be normal size, I was amazed by all these people said “How would you navigate that?! How will you teach her to ride a bike!? Or play on the playground?”

And we were like, we don't know! We will figure it out! Just because Hazel is the oldest has taught us lots of lessons and she has navigated that on her own and shown us what she can and will do on her own, without us prompting it. The bike riding is a good example. We waited for her to be ready to ride a bike without the training wheels. Last Christmas we bought the bike and we were like, okay, here goes! Christmas morning she got up and we went outside. She got on the bike and just took off! That was the extent of us teaching her to ride without training wheels. But it was on her, and that's huge. We didn't push it. We waited for her. So she really understands where her limits are.

**Joe:** Expanding on the gains of parenting and embodiment itself, like I said in the beginning, all we have is our own experience to refer to here, but one example that came to mind is an experience when coming up with this talk, there a philosopher who teaches at Gallaudet University she reflects in her book, that part of deaf gain comes from the physical embodiment not of just deafness but deaf culture. An example of hers, when you are a parent and communicating with a child, as a deaf parent, you must be very direct. You cannot communicate in a way that the child has divided attention. If you use lip reading or using sign, or whatever the mode is specific are to your family, you need to have all your focus on the child and the child must have all their focus on you. It's not just a "uh huh" from the kid as they play a video game. This is an example outside our example as Little People, but it's a disability gain focused on parenting. That's the extent of our talk! Oh yes, the image description.

**Leah:** Oh yes, the image description. This image here, it's me and Silas, sitting on my lap. We are wearing masks but my lap is very full with only two kids. That's the last slide! Handing it off to Mia.

**Mia Mingus:** Thank you so much. Is it me yet?

**Liz:** Yeah, Mia. You’re up.

**Mia:** Okay. I don't know why I cannot see anything. Hi all. Thank you so much. I am going to talk about Access Intimacy. This is called Building Our Own Belonging. Disabled family making can take many forms. It's not just the traditional nuclear parenting and child raising - wait. Let me do a visual description. I'm Korean American woman presenting person. I have a sleeveless black shirt on. My long hair is pulled back at the top only. I have a large shell-like . . . they look like moon earrings, on. I’m sitting in a black office chair with a very very boring white wall behind me. I will paint at some point! It’s just taking me awhile. I have black glasses on too. Okay.

Disabled family making takes many forms. It's not just the traditional nuclear parenting and child raising. I want to talk about that more broadly, encompassing the many ways we are and bacon kin to each other, as best friends, partners, comrades or other loving relationships where we experience belonging no matter how big or small. As a disabled queer adoptee of color, I understand family to be more expansive than we are taught. I have had my disability since I was an infant, my entire life. My physical disability has been visible and formal. I was marked by disabled as the medical industrial complex part of my childhood until I was 18. I understood myself to be disabled as far back as I can remember, and I was understood as disabled by everyone who met me. I was a disabled baby, child, and teenager and these experiences profoundly and fundamentally shaped shapes how I understand disability.

In short, I haven't understood myself to be able bodied or abled. I have only ever known a disabled life. This is a particular experience and life and culture that's distinct in the disability community. Disabled family-making has been a powerful experience of my life. Powerful in its truest sense of a force that's able to cause effect. I say this because disabled family can be both world altering, transformative, and transcendent but also incredibly scarring and heartbreaking and sometimes it can be both. I don't want to lose the harder parts of family making when it doesn't work out or implodes or traumatizes.

Disabled people are so hungry for belonging and connection in a world that tells us we are wrong, undesirable or a burden. These sentiments were internalized from a very young age. And for us all, no matter when we became disabled, these sentiments were widely understood and enforced. And of course, this is more compounded for those who are disabled with multiple oppressed identities. Because of this hunger, we often rush forth with an intensity for connection. Many, myself included, are familiar with the crash and burn dynamics of these experiences. We so intensely yearn for relationships where we belong that when they fall apart, it can be nothing less than soul crushing. Our longing for family is an ache. It's shaped by ableism and abled supremacy and isolation, loneliness, stigma and inaccessibility. We live in a world that's not built for us. And the mere act of finding each other is hard and learning how to move through the world together if our access needs can conflict. We are sold family through a dominant culture that glorifies nuclear families and nuclear family making. It says that family is the only place where belonging happens even if that conflicts with our own experience in families without disabled children.

For most of us, our parents didn't know anything about disability outside of a medicalized understanding or how to raise or support a disabled child. My family was not a place that could hold or cultivate disabled belonging. I share this because I don't want to romanticize disabled family making. It can be magnificent, and it can also be painful. Some of my deepest heartbreak has come from family making in disabled communities. The loss of disabled family has cut me to the bone. There are still wounds that throb when I think about them.

There is a deep contradiction that exists whenever we talk about disabled family making, belonging, love, and community, because most disabled people do not have access to these communities.They do not have leaders with large politicized communities. Or they have been ostracized from these communities, often pushed out by other disabled people. When we talk about disabled community, we must talk about envy and shame sometimes in these communities even as it awakens longing, inspiration, and pride.

I think many of us have been on both sides of this. I want to acknowledge the quiet river of grief that moves through us in these conversations that is present alongside pride. Access intimacy has been a key part of a disabled need. Building a disabled family means to build an understanding of access intimacy and how it informs our lives, both in its presence and in the absence.

In my essay, Intimacy: the Missing Link, I describe the access intimacy as the elusive, hard to describe feeling someone gets when someone understands your access needs. Sometimes it happens with complete strangers, disabled or not, or sometimes it is built over years. It can also be the way your body relaxes or opens up, when someone understands your access needs. It doesn't require a political understanding of disability, ableism, or access. Some people have had no exposure or understanding to a political understanding of a disability. There are many ways ableism manifests in our lives.

Together we share an experience with access intimacy that is ground-level. Instantly, we can hold the weight, emotions, isolation, fear, trauma, and anxiety of access. I don’t have to justify that we are able to start from a place of steel vulnerability. It has taken the form of long talks into the night into the night on a first meeting. Or the feeling of instant familiarity to be able to ask for support. It is an unspoken language between two people, like an entirely unique way of being able to communicate. Similar to meeting someone you just click with, access intimacy can take the form of an attraction, desire or energy onto itself. There is no way to separate access from disability, no way to separate myself as a disabled person from my access needs. As I write, "In my life access intimacy is something that has been hard won, organic or sometimes magical has taken me by surprise showing up with people that I would have never been able to expect having that sort of access intimacy with. It has been exciting, relieving, like a long, slow exhale."

Access intimacy has felt like a kind of disabled belonging onto itself, a feeling of wholeness, as if I could take off my armor and be truly known. This is how family should feel. To be understood fully means that access intimacy is present. It is a familial experience, no matter the magnitude. Even in small moments it is impactful. Once I was travelling alone for work and getting off a plane with other disabled passengers while our mobility equipment was loaded onto a cart. I was the youngest person there. There was another woman who was 10 years older than me, and three elders. We were to be whisked off to our respective gates. As we left the gate, a woman asked if she could use the bathroom. The driver flatly said, "no." She asked, “Please sir,” explaining how our flight was delayed and her connection was tight, so she would not be able to use the bathroom again until after her next flight, five hours later. Again, the man said, “No,” this time a little more forcefully as the cart began to move. The woman was panicked when I spoke up and said, "she needs to use the bathroom, you have to let her."

An elder waved his cane. I kept telling the driver to stop. The driver said, "Fine, I will let her but I will not wait for her. It’s her choice." The woman looked like she was going to cry, and the rest of us knew exactly how she felt. We stated that he should not drive away. We were yelling at him as gates flew by us and onlookers stared. Finally, spying the restroom, he pulled over and stopped. The woman got off the cart and thanked us through tears. Myself and one other elder stood with one leg on the cart and one so that the driver could not move without hurting us. We waited there like that until she got back and we were all safely on board. We all talked and laughed. We strangers when we got off that plane, but in that moment we were family. We were a disabled family. We belonged with each other. We created belonging through shared access intimacy.

That experience stayed with me and opened up new space for possibilities. It was a small experience but its roots ran deep. These moments leave me a little more whole, fortified, and nourished. I had an experience with my current partner of 11 years.

I experienced access intimacy when I met her. She had no previous experience with disability politics but she supported me to write about it. She also has became disabled in the last 5 years and it has only enriched our shared intimacy as two disabled queer Koreans. We have a relationship that is rooted in family and partnership. Access intimacy is both an integral part of building disabled family and a practice. Access intimacy is a recognition inside of me that is so deeply familiar. It is a part of me that has been lost and forgotten. It reminds me that there are other ways to exist beyond shame and fear. It reminds us of softness, care and understanding. It is a generative force that embraces need. It creates new worlds and possibilities. Belonging can change us at a cellular level. There is no way to explain the alchemy of belonging and there is no formula to create it. For me, access intimacy has been a building block of disabled belonging, and a path to family. I only wish that I had been able to experience access intimacy as a disabled child as the ableist world swirled around me. I dream that future generations of disabled children will be able to experience belonging born out of chosen family and forged out of access intimacy. Thank you. I will turn it back to you all.

**Liz:** Everyone can turn their camera back on while we move into our discussion with Rosemarie.

**Rosmarie Garland-Thomson:** Thank you very much for those wonderful presentations. I am Rosemarie Garland-Thomson. I am a pale skinned senior woman with red glasses. I am joining you today from my home office in San Francisco. I am going to bring the speakers into a 10 minute discussion about our papers. You will have an opportunity to speak with one another together. I want to offer one question about relatedness and resemblance. We have known after the number of years that calls for inclusion invoke an idea that people want to have more "people who look like me" in their lives. I thought about how that might work with disability kinship in terms of resemblance, relatedness. I want us to talk to each other for 10 minutes about the relationship between kinship circles and relatedness and resemblance. For the people who identify of as disabled, how we might resemble each other, be related to one another, how we might be biologically similar, whether it’s through geneticness, morphological and biological relatedness, or less that has to do with our mind than our bodies. How does the distinctive resemblances and likeness might help us forge more meaningful kinship networks? I hope we can talk about likeness, resemblance and how it operates specifically in disability kinship circles. Joe and Leah? Do you want to talk? Since you talked about the contract between resemblance in looking like your children? And maybe even looking like and not alike one another. And maybe the rest of us can follow in.

**Joe:** Wow, okay. I have been thinking about this question. I think it is a really interesting and risky question to ask. I think there is something there. There is something about disability embodiment that creates a tendency towards access intimacy, as Mia was talking about. I do think that experiencing disability for me, makes me more likely perhaps to put into the foreground access intimacy with others. I am thinking about a set of experiences I had with our mutual friend, the late Stacey Park Milburn. One time, when we were meeting up in Washington DC we were going to get on the metro. I dropped my metro card on the ground. Of course, she couldn't help me pick it up. While I was climbing out of the chair, she immediately parked her chair in front of me so people could not see me climb out of my chair. She intuitively knew that being out of my chair,e I was vulnerable. Being in my chair was a source of independence of power. Being out of my chair, would be too much intimacy for the people around me that are not Stacey.

I think about how the space is created with the intuitive understanding of our commonality and experiences. But here is a big “but,” I don't want to oversell that. There is a lot of hierarchy in the disability community. Especially as a cis, white upper-middle-class man I have to be in tuned to. Disability is not a unified monolith. I have to recognize my own power in my body. I must not flatten the experience to a fairy tale commonality that does not exist. So that’s my answer.

**Leah:** I had a conversation with my 5-year-old the other day. They said, do you know the ways that we are the same and different. My child said, “We are the same because we have the same eyes, we are both kind, we both like to put outfits together.” I said, “Yes that is true.” Then she said, "Do you know how we are different?" And she said, “You have purple nail polish on. I don't.” I thought, wow, of all the things she could have said in that moment, she thought of purple nail polish. Joe and I deal with this a lot when we are out, we are both little people but we are different types of little people. We often laugh about how people interact with us. His wheelchair is the first thing people see. They don't actually pay attention to anything else. My body is the first thing that they notice with me. Some of it is sexism, some of it is gender. There are a lot of things at play. Those are the two thoughts that came to my mind when you asked that.

**Rosmarie:** Others?

**Sami:** I have a non-apparent disability. For me, the recognizing kin is not through a body at all. Sometimes it is about the things people are doing, not just the bodies themselves. I am thinking about that. I am a mix-raced person who was raised by white people. For me, kinship is not about seeing people who do not look like me. I would watch cousins and people would think I was a hired babysitter. For me, kinship is about the shared connection and experiences that we have. It is important in queer kinship. \*\*

**Jess:** Jess speaking. I wanted to reflect on what was just said and the experience of trans disabled people. We have to leverage pathology or diagnosis to strategically access gender affirming care but sometimes we don't have access in the first place. I understand all these identities overlapping because of the discrimination we face everyday. For many reasons disabled trans people don't visually recognize that of one another and that is because of safety and how we can't present in the ways we want to. Or because of preexisting disabilities or medical trauma that shapes the forms of care we can access or want to access. Or a place where we don't want to change our presentation at all! So we have to generate different ways to find each other. Like virtual spaces or a glance, or a shift in tone. But that's one potential trans or Crip ethic to not just use the visual to find each other.

**Mia:** Mia speaking. I wanted to add, so many things that others said were things that came up for me. One more piece. I think for me, even if I do recognize someone as being disabled or a fellow Crip or fellow gimp, that's one piece of it. I think language plays a big part in recognizing. Especially if their disability is not visible or obvious for example. There's another piece where that's just descriptively recognizing someone, but it doesn't mean that they have a disabled identity. Whether it's politicized or that they understand themselves as disabled I have met so many, in particular women of color who are visibly disabled. Like who anyone would recognize as disabled in the tiny narrow terrible understanding of disability that exists in the predominant paradigms. But so many of them didn't identify as being disabled. It connects to stigma as well as having multiple oppressed identities. And if you are oppressed by gender or race identifying as disabled threatens our survivals. And this relates to how we find each other. I have conversations with these folk and they know what it means to live a disabled life but they didn't identify as such.

**Sami:** Mia what you said reminds me of something attributed to Zora Neale Hurston but it's a community Black saying. Not all skin folk are kin folk. Not everyone that looks like me are kin. I have met queer folk and I'm like, “Oh, we are not in the same community! We are in different understandings of our queerness.” That is clear to me with disability too. Other people in the queer community or the disabled community can break our hearts.

**Mia:** Are we done?

**Liz:** I did promise a 5 minute break before we move on to the audience Q&A. So when you are done Mia, I will put up the break slide.

**Mia:** Now I feel awkward about it! Rosemarie I wanted to say something to your second question. Yes, there's the new world making and meaningful questions in these subcultures under the large umbrella of the disability community and disabled community. There's tons of things. But when you find people and your access needs are different but they can complement each other, that's world altering. Like my follow folk in power chairs. They can come right back and get something zipping down the street that I might need! That's world making in the disability community.

**Rosemarie:** I know it's time. But to affirm what Mia is saying, I have a project ongoing with folk in the disability community, one blind and one Deaf. And I have crippled, mobility impairment. The interdependence of when we travel and work together is moving. The way we have developed expertises in using the world, and the way we work with one another to be a unit, a triad, a trio, or a triangle of weird women or witches if you will, is, as you have all suggested in our communities we make, our chosen communities, and our forged communities across disability identity and embodiment and experience, it's very moving. I think surprisingly effective to the rest of the world. So I want to thank you all for talking about all of this with us today. Have a good break. I look forward to these questions and the rest of the time. Thank you so much.

**Liz:** We’re going to take a 5 minute break. Or 4 minutes! Come back at 4:32. But if you need more time, that's okay!

For those back, turn your cameras back on?

**Joel Michael Reynolds:** Liz, Am I good to go?

**Liz:** Go ahead.

**Joel:** Welcome back. We are at the audience Q&A section of our event. I'm Joel Michael Reynolds. I'm a white person wearing glasses and a Burgundy shirt that matches my nails. I made sure I was matching. I have tattoos and I'm sitting in a chair in my apartment that's blurred a bit but not enough! We have fantastic questions from the audience. I want to start with one from Kathryn Hedges. Kathryn asks, “What can you do if parent groups take over your local disability community and advance proposals that contradict what actual disabled people want, for example promoting a disability registry with local police instead of alternative crisis responses?” Would anyone like to respond to that question?

**Sami:** This is Sami. I don't have this experience. But in thinking about other organizing communities that I belong to, there's not just one community. We say "disability community" or "queer community." But that's not only the case. So it's okay to say, you know what, you do that and we will do this thing over here! Allow people to come in and be a part of it. I would challenge the idea of taking over. Just say you will go do something different. I understand that's hard for when the thing they are advocating for is harmful. And it's okay to be clear about that and that you believe that. But in a singular local community it's okay to take different directions of what people want to do,or taking on different organizing work. Or educating people. But it's not your job to educate everyone.

**Leah:** It should be noted that there's a tension between parents and people with disabilities. Whatever the identity is, and this happens often. They are put at opposing views. So I think the more - personally because I am a disabled person, I feel I'm right! But I'm also a parent. So I understand the need to protect your child. But to push the narrative of our firsthand experience and of our understanding, I hope - and I'm sure it happens - I hope we wouldn't do this in other marginalized communities. We can compare. We can say we have the experience and we should be the experts. I know that's oversimplified. But I want to acknowledge that tension that happens in these groups.

**Joe:** To speak to Sami's point. That's a powerful and good point in so far as just not getting too worked up about it. Instead just doing your own work and going and doing your own thing. I think that's a really effective strategy. I have seen that happen in various disability communities across the country. Folks were doing something problematic and instead of confronting or fighting them, then you organize in your own way with your own goals. But the limit to that is when the struggle exists in a single institution. I have experienced this where there might be an advocacy organization or an institutional struggle for the soul of the organization so to speak. You have groups pitted against each other in a single structure. You would then lose something to leave and start your own thing. So I think you need to be careful with thinking to yourself, is it worth it? Is it worth it to have this fight in this particular structure? For its mission? Or should I set out and do my own thing? And not spend this energy on this particular fight?

**Joel:** Thank you so much for all those responses. Another question from the audience. This is from Felicia Spiess. "I would love to hear your thoughts on how we can make queer Crip space for those with intellectual and developmental disabilities. I don't see cross over in our community to make our movement accessible for those with different levels of cognitive ability or communicative skill."

**Jess:** Jess speaking. I can offer what I have done but I'm excited to hear what others have to say. With community work I think, we can start with urging queer and trans community centers and groups and social services and events can center accessibility for all disabled people. The way to do this on the macro is to offer to attend or generate listening sessions for the boards of these community centers. They often think about elder care in terms of disability access but not cross generationally or across disabilities. Or offer workshops on the intersectionality for these boards and on queerness and other identities. And that access will draw in more people and allow us to recognize that so many queer and trans people are already disabled.

**Joel:** Rosemarie? I think you are muted, Rosemarie.

**Rosemarie:** In response to the question about creating accessible community for people with cognitive and neuro-diversity. I am working on projects that hope to translate some of the work on disability studies into plain language. We are working with a bunch of people to translate the New York Times articles on disability from NY Times language into plain language. So that’s one important piece of work in terms of disability access, in terms of language.

**Mia:** I want to add to this. This is Mia, and I don’t know where this lives. I also think that really having the queer and trans places that confront these politics is key. To make these spaces more accessible. I think it is good to confront the need to be desirable. Sometimes there should even be spaces to cruise, find dates, get laid or find hookups. I don't know the language kids are using today so I am dating myself. I think there is a stigma. There might be folks who have different kinds of communication skills. Whatever their abilities may be or however that may manifest. I know that is a very hard thing to do. I think a lot of queer and trans culture is built on this. I want to figure out how to do this in a non ableist way.

**Joel:** I will repeat this in 10 minutes. We have way more questions than we can possibly answer. We encourage for you to reach out to our speakers, reach out to us in social media or whatnot. We always save the questions in the chat and send them to pir s[ealers. By no means, do we want this conversation to end. This is just an opening. We have time for at least 1, 2 more question. This is from Mukher Jae. "This has been an incredible event. Do you have experience with pre-natal testing and how it impacts disability justice? Given how routinely testing is being implemented, sometimes without a pregnant person’s knowledge, how can we incorporate disability and reproductive justice in a wider set of practices? Is it even compatibly with such equity and inclusion principles?" This is a easy question to answer.

**Joe:** I will do my best. I think that this is the tension Erik mentioned in the beginning, the motivation behind this discussion. I think it is relevant to what we spoke of today. I am going to try to address this in the spirit of today's event and the spirit of this whole series and say, that, well the problem is more fundamental than the technology itself. The technology is yes, problematic, but it is something that has been created by a deeply ableist culture. Recognizing the technology and doing some kind of public education campaign focusing on the technology itself is not going to do the work. The problem with ableism existed early in human history than the discovery of the genome. An approach is to yes, write and think about bio- technology but we have to do this with the understanding that we are embedded in a deeply ableist culture. It is within the intersection of racism, sexism etc. These drive these technologies in the first place. I know this is a non-answer but it might be the best that I can do.

**Jina:** I wanted to add that I think this would also be a great place to consider how reproductive justice has created the framework of choice that often has driven the reproductive freedom conversation. I think Joe explains beautifully how choice is not a vacuum. It is shaped by border systems of ableism. It makes it unthinkable for parents to believe they could raise a child with a disability. I think the critique of the choice-framework is applicable here as well.

**Sami**: This is Sami. Some of my work is on speculative fiction. When I speak of this, I talk about how technology is a tool which is not inherently good or bad. I can imagine a world where genetic testing is used so that parents know about their forthcoming child’s disability, they are connected to their community and are prepared to raise these children. All of these other things around the technology, and not just the tool itself, matters. This is a way and hope that technology could be included in a just world. It could, but all these other things would have to change.

**Mia:** I think this is a both/and. I don't think there are any easy answers. I think when we get into the topic of reproduction genetic technologies and that world, we have to remember we exist in a world with binaries. There are more complexities. I don't think there is something wrong with pre-natal testing, but because of the entire world of reproductive technologies, and that world is moving faster than the laws can catch up with. Who cares about laws, I know. But it is a slippery slope. As someone who worked in the reproductive justice movement, I think we live both and/or lives. We can understand these things in positive ways. I want us to also understand all the nuance.

**Joel:** In the chat, I dropped two resources. There is so much good stuff out there. I want to highlight a book by Erik Parens, and Josephine Johnston titled Human Flourishing in the Age of Gene Editing has some fantastic resources that address this directly, including by our own Rosemarie Garland-Thomson. I also linked an essay that I love by Joseph Stramondo. "Disability and the Damaging Master Narrative of an Open Future." Before we will run out of time I want to ask a final question. We have 3-4 minutes. I want to continue this conversation after this webinar ends. This question comes from our own Liz Bowen. Liz asks, "Mia's reflection on the quiet river of grief really resonated with me. There is a tragedy that these relationships where are crucial to survival, can also buckle under the weight of the same failures. What do you think will need to most change structurally, to lessen us crashing and burning as Mia puts this?”

**Mia:** I can start. You know it is funny because I don't often think about structural things when I am thinking about the formations that happen around belonging, and disabled family making. I also think that community infrastructure could really help. It is less formal. One where we can actually have communities, where we don't just talk about that. I don't want it to be the few popular folks that have access to community. It should not be homogeneous either. I think, right now, there is a push for a de-institutionalization. We want to get disabled folks out of the institution. I know we can't guarantee people that there won't be harm or violence, if we take them out of institutions. Our communities are so messed up as well. I think that having a broader community can content with ableism. It can build cross disability relationships. I think about how disabled people can have access to mental health, to heal trauma. There are so many pieces. Trauma as disabled people is one of the biggest causes of the crash and burn dynamics. They’re interdependent and connected. Those are just some thoughts.

**Joel:** I wish we had time to hear from others, but this webinar will auto-shut down. I want to make sure everyone is aware that this is a 6-part event. There are resources, readings and all sorts of things on that website that I recommend people to go to. I will hand it over to Erik for final comments. Erik, the floor is yours.

**Erik:** Thank you Joel. I am trying to turn on my camera but I cannot. Is it possible for someone to put up the slide of thanks to the many people who have made this even possible? Thank you, so much. Joel really said it all. We are going to create a permanent record of this really marvelous series. It will include edited versions of the videos as well as some additional resources. I am eager to thank everyone on this screen, at the Hastings Center, the sign language and cart services folks. I want to thank the National Endowment for the Humanities and Patricia Brooks in particular. We live in a country where we spend 51 billion dollars a year thinking about how to enhance health and make people live longer. The budget of our NEH is minuscule in comparison but they give us an opportunity to ask an important question, for those who are fortunate enough who are able to ask questions. What kind of life do we want for each other? What is human flourishing? The NEH has given us a chance to ask these questions on an on-going basis. I cannot overstate my gratitude to Patricia Brooks in particular and the NEH in general. Thanks to all of you. Hoping everyone stays well, goodbye!