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/)

Speaker: Hi everyone.

Thanks for coming to the webinar today.

We are having a little bit of technical

difficulty with the screen share so thank

you for bearing with me.

Hi everyone.

Thank you for joining the webinar today.

We will start in just a minute.

Hang tight.

Hello.

Thank you for joining us today.

We will start in a second.

Hang tight please.

Hello.

Welcome to We Belong.

To Each other.

Disability and family making.

I'm Liz Bowen.

I'm a post doc at the Hastings center

and the director of this webinar.

Flourishing conversations on Disability.

I organized this series with Eric Perins,

and rosemary garland Thomson along

with others.

I'm a millenial,

a white woamn with blond hair,

and I'm wearing a black mockneck shirt

and a chain.

There is wall behind me along with my

living room.

We have closed captioning and ASL

interptrrn available.

You can turn on the CC at the bottom

of the screen.

There's a link to the full transcript

in the chat.

If a panelist is sharing the screen,

you can adjust the size and the

interpreters boxes if they are too small.

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 for accessibility.

If you are having trouble with the

accessibility please access the Q&A at

the bottom of the screen.

Today 's event is recorded.

This will be posted to the Hastings

Center site afterwards.

The chats are closed because we have

so many attendees and for security purposes.

If you have questions,

please submit them in the Q&A feature

at the bottom of the screen.

There will be a Q&A at the end.

I will turn it over to Eric Parens now

the director of the national humanities

bioethics at the Hastings Center.

Speaker: Thank you so much associate

director of this program, Liz Bowen.

Regarding visual description,

I am a white man,

and not a millenial!

I have gray hair,

gray beard and tortoiseshell glasses.

Thank you to the senior project

advisor rosemary garland Thomson and to

Joel Michael Reynolds and thank you to

you all for joining this 6th and final

conversation on the art of flourishing

conversations on disability.

The purpose of this Hastings Center

series is to highlight fundamental

themes and that people can flourish in

all kinds of body minds.

To flourish means to exercise the

capacities we have in pursuit of the

purposes we find meaningful.

We don't need different body-minds to

flourish but what we need is more supportive environments.

No one ever articulated our theme,

more powerfully than the late

disability rights activist,

Adrian Ash.

They introduced the social disability

model to bioethics back in the 1980s.

Way back in the 1990s Adrian and I

led a project built around the

bioethical dilemmas that happen when

non-disabild people abort fetuses based

on disability status.

When Adrian 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.

The 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 teaches.

technologies.

Over the course of the series we feel

more need to use a bioethical dilemma

about a technology as an alibi for

articulating our fundamental theme.

We have become ever more eager to

explore how people can and do flourish

within supportive environments.

In previous events our speakers

reflected on their own ways of engaging

in various activities that promote

flourishing like communicating and

navigating and enjoying.

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 fndmnrl

theme would place non-disabled people

at the center of the conversation.

And 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.

But today our theme fairgrounds the

lived experience of disability and

invites others to recognize its richness.

This is saying,

look here.

This is how disabled people are flourishing,

making families and expanding what it

means to be with others.

We will hear three presentations today

from 6 contributors.

For more information about our

contributor's backgrounds and accomplishments,

go to the registration page in the

chat at any moment now.

The creators of our first presentation

is a professor of gender and womans

studies are

Jina Kim,

Jess Waggoner,

and

Sami Schalk.

They will focus on what we call

queercrip doulaing.

This is in a reference to queer and

transgender people bringing young queer

people into kinship with those who

share their identities.

The creators of our second presentation

are Leah Smith and Joseph Stramondo.

They are both activities and joe is a professor.

They will talk about what it's like to

be parents of children with

disabilities like their own.

Mia Mingus is an educator and trainer

for disability justice.

They will talk about the kinship that

grows around Access Intimacy.

Mia Mingus will talk about how to

recognize the access.

needs of others.

This gets beyond the nuclear model of

the nuclear family.

We are talking 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 Spelser said about the

activity of enjoying.

She said there are risks when we talk

about joy,

that we make joy a prescprtn,

a requirement and a precondition for belonging.

They continued there's a risk that

the joy becomes another way to judging.

If you are not happy then you are

doing it wrong.

End quote.

Plainly today,

that's the risk we tend to avoid.

But it might be one that's of concern

to people and one that people are

welcome to bring up in the audience

discussion after the break.

So,

after Mia finishes her talk then

Garland Thompson will facilitate a

brief conversation.

After the break then we will open it

to audience conversation.

That is led by Joel Reynolds.

It's my pleasure to turn the mic over

to Jina.

Jina Kim: Hello everyone.

Thank you for coming.

Our joint presentation is titled

sustaining queercrip kinship.

We will provide a warning.

This is Jina speaker.

I am a Korean American woman,

glasses and frosted blonde tips.

I'm wearing a vest and a blue button

down shirt.

Jess Waggoner: I am a white person

with pink hair and pink lipstick and I

have a dolly Parton pillow behind me

with a black lives matter sign.

Sami Schalk: Hi.

I'm a fat black woman,

short curly hair,

teal dress lace at the chest,

and pink glasses with a cat on my desk.

There might be on in front of me

during this talk. [Laughing.]

Jina Kim: Before we begin we want to

give notifications for discussions of

ableism and trnsfphba so do what you

need to take care of yourself.

Jina reading.

In staying with the trouble harroway

says make kin not babies.

Harroway's call reminds us of queer

studies around family and affiliation

beyond blood and biological relationships.

But what about disabled people and

queer and trans disabled people to make kin?

And what about systems of heterosexism

and white supremacy disrupt our ways of

life and how we love each other despite

these systems that insist otherwise.

How do we forge these lines during

the pandemic?

In traditional ideas around life and

household shift mainstream discussions

around public health and safety and responsibility.

We want to share with you the ways we

have learned to create and sustain

kinship ties in queerness and queer politics.

Making queercrip kinship and not just

about the what,

but also about the how?

That is,

the practices we engage in 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 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 wassy to make queercrip kin.

Like Keffer,

and Kefie,

define these in their writings on this topic.

For our presentation we focus on the

practice most relevant to us during the pandemic,

queercrip doulaing work.

We build on the work of does justice activist,

PEIPZNASAMARASINHA.

And Stacy park MILBERN.

They coined the term disability

doulaing to describe birthing and

ushering people into a new disability identity.

We issue a queercrip chlnlge to

family expansion birth and reproduction.

Especially with a mass disabling

event to those we consider queercrip.

kin.

During the best practices for reducing

viral transformation have disrupted

traditional family.

Like how we count those who count as kin.

The discourse framed those outside

family as hazardous to family.

As disabled queer people who live

alone relying on local community ties

for people with robust chosen families

and maintain dsntce from our families

are origin,

these recommendations were

very distancing.

They formed our ways of relating as

potential threats for contagion.

Quarantine provided some relief to us

looking to avoid our families

especially during the holidays.

\*\*\*

We try to maintain connections while

living under forced isolation.

Queer and Crip people have long

endured this.

This has helped us cultivate our

chosen family networks at a time where

social interaciton and touch is not

very allowed.

Nibbling is an all gendered term we use

to

as queer aunties,

gay uncles,

and fairy godparents.

Some of them are biologically related

to us and some are not.

Is

They are people who are in caring

relationships to us as adult childs.

Jess Waggoner:

[Reading: Gay bacon,

a call across space an time with

queercrip results.

These modes of connections are

specially present access of technology.

Binders to flatten the chest can be

out of reach for disabled trans people.

Some masc clothing are constraining.

We elevete stretchy fabric for trans people.

It has also helped me accept my

disabled body as a trans body.

We generally exist in Crip space.

We hang on video.

The show and tell of objects in our space.

The way we have service dogs.

Under the temporalities some young

people have found the space to thrift.

Some people are trapped in

unsupportive family dynamics which are

indeed disabling.

They target trans youth,

and question if they are indeed really trans.

This loss is linked to anti-trans

legistlation that invalidities trans

youth while the pandemic traps them in

unsafe living situations.

It impedes their access to life

saving care.

As the pandemic reshapes many of our

relationships with outdoor spaces.

Never being an outdoor kid,

I will sit outside.

King of the Hill's Bobby hill or

propane tanks against a queer flag.

They weave queer literacies into 90s cartoons.

He prefers strange juxtapositions.

Some

media readings are downright queer hostile.

Don't mess with me,

I'm a big boy now.

Dropping myself over the camp chair.

I joke to him that I am always Bi,

my pain levels make it so that I can

never sit in a chair properly.

He revels in the deepness of strange posture.

Instead of Asking,

"what are you,

how do you Identify" this re-routing

of queer

absurdity asks me to use a new name.

I am going to hand it off to Sami.

Sami: Vignette 3,

community consultation.

[Transcriber's Summary:

Calls his brother to pop back in a shoulder.

Wanting to help E,

we connect him with a friend who is

also trans and queer.

On a Saturday afternoon we hop on Zoom.

Our disabled queer and trans friend

helps E.

He talks about mobility aids and how

to practice them.

They learn which one works for ones

body before there is a desperate need

or emergency.

It teaches you how to advocate for oneslef.

neself.

It shares the wisdom of the queercrip community.

We leave the convo nourished.

There is a process of bringing a

nother person into the family.

E calls these new connections his cousins.

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 helped us to

move with the time.

We try to move with each others

access vibrations.

We remain open to peoples ever

shifting need.

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.

Loving our queer,

trans and disabled nibblings are a way

for us to love our queer disabled

people as we were.

We were with biological family but

with no kin.

Our nibblings have shown us the power

of our vulnerability.

We have seen each other.

Thus we can understand ourselves better.

Queercrip has shown us a better world.

We can understand our identities.

We don't have to experience the same isolation,

stigma or fear.

Many of us have felt years undoing.

Thank you.

I will hand it off to Leah and Joe.

Joe: Thank you!

That was so critical important and interesting.

We will shift gears to talk about a

more traditional view of family making,

that can be problematized and brought

into conversation.

Before we get into the meat of our presentation.

I will do an image description.

I am a white man with dwarfism with

thinning dark hair,

I have glasses with 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.

Behind us is a window and door.

Joe: our talk is called Parenting while

Disabled: From eugenic deficit to

disability gain.

We are talking about how disability

is a liability when being a parent.

I will start with some quick comments

about the history of eugenics.

We have the famous Buck vs Bell case.

Supreme court

Wendell Holmes had a content

where they framed disability as part

of a eugenics movement.

A primary feature of historical

eugenics had a prime emphasis on the

idea of who is fit to raise children?

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.

It wasn' just about passing

hereditary traits,

but 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.

Some of the qualities can be traced

back into the history of eugenics in

the United States.

We have White,

upper middle class people who speak English.

Cis-gender people.

People in traditional family roles.

And of course,

non-disabled people are all the

characteristics of 'good' parents.

Leah: I googled "good parent" to see

what showed up.

These are the images on the right.

They all fit the description Joe just mentioned.

White,

Upper middle class,

cis-gendered,

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.

They lost a lot of

There was a disproportionate

high rates of disabled people losing

parental rights through the welfare system.

Joe: There are additional ablest barriers.

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 employment is tied to health insurance.

There is a problem with

reproduction healthcare.

The reasons are complex.

It is worth to note though.

Another barrier to parent hood is SSI

marriage penalties.

So disability benefits can be put at

risk by marriage.

Marriage should not be a

pre-condition to parenthood.

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.

A lot of times,

the assistive technologies are not

easy to come by,

such as cribs.

Leah: The image to the right is a

photo of 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 is why it is so difficult to get

these technologies.

\*\*\*

I want to shift gears 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 the term is disability gain.

This 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 Smith: 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.

I

We wanted to adopt a child with our

same disabilities.

We believe in the notion that

disability is a chain 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.

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 afterall.

But this showed us,

this wasn't fun for us!

[Laughing.]

and a very expensive situation to go

through in order to teach.

We need better understandings of

disability and parenting.

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 were not done from the diagnosis itself.

It develops an understanding of

disability as a neutral or even as a

positive for them.

Next slide please.

Joseph Stramondo: 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.

1.

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,

offer something to our children.

2.

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 and how

it would have name so much more narrow.

To get to ideas like the difference

and inclusion,

social justice,

and fairness,

self acceptance,

interdependence,

and so I,

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 exctpn to that rule.

I think disability SHOULD exist when

you teach lessons about your kids.

Child rearing is in fact a giant

experiment in teaching moral lessons.

So if you could use disability as a

resource as Garland might say,

through parenting and opening up the

world to our children and thinking

about inclusion and difference and that

moved on to other marginalized

identities and social justice,

for example.

That's a good thing I think.

Leah Smith: The other parenting gain

is some disability as embodiment.

We have seen this with our two kids.

1.

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 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 evene 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 and fused.

I cannot wrestling.

rslte and that's just the tip of it.

They must be careful with me.

sylus

Sylus 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.

Then all these people said how would

you navigate that?!

How will you teach her to ride a bike!?

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.

The riding a bike 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.

Joseph Stramondo: 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,

but remembering 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 chilled,

hild 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.

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.

Leah Smith: 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?

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 takes many forms.

It's not just the traditional nuclear

parenting and child raising - wait.

A visual description.

I'm Korean American woman presenting person.

I have a sleeveless black shirt on.

My hair is pulled back at the top only.

I have a large shell-like moon

earrings on.

Sitting in a black office chair with

a very very boring white wall behind me.

I will paint at some point!

I have black glasses on too.

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.

A disabled queer adoptee of color I

understand family to be more expensive

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 indstrcl complex part of my

childhood until I was 18.

I was understood to be disabled by

everyone who met me.

I was a disabled baby,

child and teen.

This shapes how I understand disability.

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 is

both world altering,

transformative and transcendent but

also incredibly scarrring and

heartbreaking and sometimes 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

for me in a young age.

And for us all,

these sentiments were widely

understood and enforced.

This is more compounded for those who

are disabled with multiple identities.

So we rush forth with a intensity for connection.

We are familiar with the crash and

burn of these experiences.

We long for relationships where we

belong that when they fall apart,

it can be nothing less than soul crushing.

On

Our longing for family is an ache.

It's shaped by ableism and abled

supremacy and isolation,

loneliness,

stigma and in-accblty.

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.

onflict.

We are sold family through traditional

family making.

It says that family is the only place

where belonging happens even if that

conflicts with our own experience.

For many 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 or heartbreaking.

The loss of disabled family has cut me

to the bone.

There are still winds that throb when

I think about them.

t was difficult to come by. We were gifted it by another disabled parent from Minnesota. That is why it is so difficult to get these technologies.

\*\*\*

ou

nds that throb when I think about them.

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There is a contradiction when we talk

about disabled families.

Most disabled people don't have

access to this,

they don't have connection to a

disabled community.

They don't live in communities with

large politicized communities.

Or they have been ostracised from

these comments.

ommununities.

There is envy and shame sometimes in

these communities.

I think many of us have been on both

sides of this.

I want to acknowledge the quiet river

of grief.

Access to intimacy has been a key

part of a disabled need.

Building a disabled family means to

build an understanding of access to intimacy.

In my essay,

I describe the access to intimacy as

the elusive feeling someone gets when

someone understands your access needs.

Sometimes it happens to complete strangers.

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 total understanding.

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 access of

intimacy that is ground-level.

Instantly,

we can hold the weight emotions,

trauma fear and anxiety of access.

We are able to start from a place of

steel vulnerability.

It has taken the form of long talks

into the night after a first meeting.

Or the feeling of instant familiarity

to be able to ask for support.

It is an unspoken language between

two people.

Similar to meeting someone you just

click with,

it can take the form of an attraction,

desire or energy as of itself.

As I write,

" In my life access intimacy has been hard,

organic or sometimes magical has taken

me by surprise."

Sometimes I don't expect it to happen

with people.

It is exciting and relive.

elieving.

Access intimacy holds a feeling or home

or comfort,

where I can take off my armour and

become truly known.

This is how family should feel.

To be understood fully means that

access intimacy is present.

It is a familial presence.

Even in small moments it is impactful.

Once I was travelling and getting of a

plane with other disabled passengers.

We were put in an electric cart.

I was the youngest person there.

There was another women who was 10

years older than me,

and three elders.

We were to be whisked off to our

respective gates.

A woman asked if she could use the bathroom.

The driver flatly Said,

"no."

She asked,

please sir.

She knew she would not be able to use

the restroom again in her connecting flight.

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."

We stated that he should not drive away.

We were yelling at him as gates flew

by us.

Finally he pulled over.

The woman

got off the cart and thanked us through tears.

We stayed on the cart with one leg

off so that the driver could not move

without hurting us.

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

routes ran deep.

These moments leave me a little more whole.

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

access intimacy 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.

I think the

access

We have a relationship that is routed

in family and partnership.

Access intimacy is both an Intergirl

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.

Access intimacy has been a building

block of disabled belonging,

and a path to family.

I experienced Access intimacy as a

disabled child.

The;

The

ablest world swirled around me.

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 R

osemarie Garland Thompson.

Rosmarie: Hi I am Rosemarie Garland

Thompson 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 us.

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

re

Whether it is from a relatedness that

has to do with our mind and our bodies.

How does the distinctive resemblances

and likeness might help us forge more

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

aline one another.

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 acts towards intimacy.

I do think that experiencing

disability for me,

makes me more likely perhaps to

put into the foreground an Access

intimacy with others.

I am thinking about a set of

experiences I had with our mutual friend,

Stacy 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.

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 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 Stacy.

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.

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

nailpolish on.

I don't.

I thought,

wow all the things she could have said

in that moment,

she thought of purple nailpolish.

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.

TThose are the two thoughts that came

to my mind when you asked that.

Rosmarie: Others?

Sami Schalk: I have another disability

not as a parent.

The recognizing is not through a body.

Sometimes it is about

It is 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 queerkinship.

\*\*

Speaker: 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

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 one 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 Mingus: 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 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 Schalk: Mia what you said reminds

me of something attributed to Herston

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 Mingus: Are you done?

Speaker: 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 Mingus: Now I feel awkward about it!

Rosemary 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 helpful and making in the disability community.

Speaker: I know it's time.

But to affirm what Mia is saying,

I have a project going with folk in

the disability community,

one blind and one Deaf.

And I have different mobility impairment.

The interdependence of when we travel

and work together is moving.

The way we have developed exeprtises 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 it's effective

to the rest of the world.

So 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.

Speaker: Now a 5 minute break.

Or 4 minutes!

Come back at 4:32.

But if you need more time,

that's okay!

[Break until 4:32 PM EST..]

]

For those back,

turn your cameras back on?

[Beeping.]

Speaker: Am I good to go?

Speaker: Go ahead.

Speaker: Welcome back.

We are at the audience Q&A section of

our event.

I'm Joel Michael Reynolds.

I'm a white Pperson wearing a

Burgundy shirt that matches my nails.

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.

They ask,

what can you do if parent groups take

over your local disability community

and advance proprioseiulus that

contradict what actual disabled people want,

for example promoting a disability

registry with local police instead of

alternative crisis responses?

roposals that contradict what actual disabled people want, for example promoting a disability registry with local police instead of alternative crisis responses?

Which anyone like to take --

a stab?

But that's too violent.

A jump?

No.

Would anyone like to respond to that question?!

Sami Schalk: 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.

Speaker: 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

first hand 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.

Joseph Stramondo: 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.

Folk 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?

Speaker: Thank you so much for all

those responses.

Another question from the andce,

udience,

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."

J

ess Waggoner: 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 accblsty

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 workshop 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.

\*\*\*

Speaker: Rosemarie?

I think you are muted.

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 form a NY Times

language into plain language.

Mia: I want to add to this.

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.

Speaker: 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

your speakers.

We always save the questions in the

chat and send them to speakers.

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.

How can we incorporate disability and

reproductive justice in a wider set of practices.

Is it even compatibly with such

equity and inclusion Principles."

Speaker: This is a easy question to answer. [Joke/joking.]

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 ablest 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,

with 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 ablest 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 Kim: 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.

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-frame work is applicable here as well.

Sami Schalk: 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 childs disability,

they are connected to their

community and are prepared to raise

these children.

All of these other things around the technology,

a

and not just the tool itself.

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 Mingus: 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 Sslope.

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.

Speaker: 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."

Linked an essay by Joseph Stramondo.

"Disability and the master narrative

of an open Future."

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.

Liz asks,

"Mia's reflection 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

strange structurally,

to lessen us crashing and burning as

Mia puts this."

Mia Mingus: 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.

One that 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 Dknow 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 Helaleh

heal trauma.

There are so many pieces.

Trauma as disabled people is one of

the biggest

causes of the crash and burn.

Those are just some thoughts.

Speaker: 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 even.

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 years.

ours.

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 centre,

the sign language and cart services folks.

I want to thank 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 question.

What is human flourishing?

The NEH has given us a chance to ask

these question.

I cannot overstate my gratitude to

Patricia in particular and the NEH.

Thanks to all of you.

Hoping everyone stays well,

goodbye!