This transcript accompanies Alyson Patsavas, Theodora Danylevich, Margaret Fink, Aimi Hamraie, Mimi Khúc, Sandie Yi, and Corbin Outlaw, "Crip Pandemic Conversation: Textures, Tools, and Recipes," *Lateral* 11.2 (2022), https://doi.org/10.25158/L11.2.6

>> ALYSON PATSAVAS: Excellent thank you all for joining us and welcome to the roundtable introduction for Crip Pandemic Life. My name is Alyson Patsavas I'm one of the co-editors of the Crip Pandemic Life issue. This video conversation is going to serve as one possible entry point into the issue. Which provides a collection of material that explores, reflects on and seeks to archive crip experiences during the ongoing COVID-19 pandemic.

I want to begin by acknowledging the University of Illinois Chicago's Institute for the Humanities whose Humanities Innovation Grant is making today's conversation possible.Thank you.

Thanks also goes out to UIC's Department of Disability and Human Development and UIC's Disability Cultural Center.

Taking part in the conversation, we are extremely fortunate to have Dr. Mimi Khúc, who is a writer, scholar and teacher of all things unwell.

Her work includes "Open in Emergency", a hybrid book-arts project decolonizing Asian American mental health, and her forthcoming book, "dear elia: Letters from the Asian American Abyss”, is a journey into the depth of Asian American unwellness and an exploration of new approaches to building collective care. Welcome, Mimi.

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We also have Dr. Aimi Hamraie an Associate Professor of medicine, health and society at Vanderbilt and director of the Critical Design Lab. A disabled, diasporaic Iranian/SWANA designer and scholar. Hamraie is the author of "Building Access: Universal Design and the Politics of Disability", co- curator of the Crip Ritual exhibition out of Toronto in 2022, and host of the Contra* podcast. Welcome, Aimi

[And Dr. Sandie Yi who is an Assistant Professor -- clip.

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So many video lecture editing I feel like I'm on this.]

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Dr. Sandie Yi is an Assistant Professor at the School of the Art Institute of Chicago and a disabled artist and culture worker whose work “Crip Couture” focuses on collecting and archiving disability narratives by collecting bodily artifacts, including skin flakes and hair. She is a Program Director of Disability Culture Activism Lab and a co-director of Bodies of Work.

Dr. Margaret Fink who works at UIC as the director of the Disability Cultural Center, a space devoted to building Disability Community, exploring social issues, and dreaming more accessible futures. Her background is in cultural studies. She's written about comics, disability and ordinariness, she's taught courses on reality TV, Asian-American literature and the mind/body distinctions in trans and disability narratives.

I forgot to welcome Sandie so welcome both Sandie and Margaret.

Also on the call today we have Corbin [ ] Outlaw who is lending their logistical support as a GA on the project, And our interpreters Faith and Michelle, and our captioner Cindy.

Welcome, everyone, we are extremely grateful to have you.

And last of course but not least I will hand it over to my co-editor Theodora.

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Oh, no.

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We lost Theodora.

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>> MARGARET FINK: This is Margaret, I think we might

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have lost her.

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>> MIMI KHUC: Yeah, this is Mimi, Dora just

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dropped off like a minute ago.

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>> ALYSON PATSAVAS: Just perfect timing.

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That's okay.

00:04:03.953 --> 00:04:13.453
She will be back I'm sure.

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It's a good moment to take a break of breath.

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Excellent.

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Welcome back.

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You missed your handoff.

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So I will --.

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>> THEODORA DANYLEVICH: Oh, geez, this happens

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every Zoom meeting at Georgetown it's like I'm good, I'm

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good, I drop off and hopefully I'm good for the rest of

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it.

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>> ALYSON PATSAVAS: Oh, good.

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I have unceremoniously handed it off to you for your

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introduction so I'll just pass it on over.

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>> THEODORA DANYLEVICH: Okay. Thank you so much, Aly, this is Theodora speaking. And I am so excited to have everyone here. I will read from our original call to sort of contextualize and introduce things. Um, So without further ado, the COVID-19 pandemic and its many stages has amplified the forms of ableism, racism, sexism, classicism, xenophobia and transphobia that
measure lives and deaths differently. As a result many disabled and disabled adjacent people find ourselves negotiating intensified levels of grief, precarity, risk, fear, isolation, and anger.

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Necropolitical practices have become explicit and institutionalized across medical rationing, refusals of care, reopening plans, vaccine distributions, calls of the pandemic's end, and the accompanying rhetoric positioning deaths of entire generations of communities and communities of color as either acceptable prices to pay or simply unremarked-upon consequences of public health and state responses. Crip futures are, again, were always already marked by supposedly past eugenic practices and state-sanctioned abandonment.

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[>> ALYSON PATSAVAS: Theodora I'm so sorry I'm going to

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interrupt before you head to the next paragraph we're

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getting a little bit of the paper.

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00:06:30.302 --> 00:06:34.103
>> THEODORA DANYLEVICH: I think if I move it below the

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computer it's okay I'll look down a little bit apologies.]

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So in the face of this dizzying and devastating reality, many of us have returned to community knowledge and shared survival skills to live through the crisis, which is compounded by ongoing crises already woven into our lives. Crip knowledge plays a crucial role in sustaining lives, care, and relationality amid state-sponsored neglect.

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[The conditions -- sorry.]

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As the proceeding crip epistemologies of crisis special section of Lateral noted, the conditions of created and perpetuated crises often make such knowledge as precarious as it is precious. The essays in the prior crip epistemologies of crisis issue articulated the importance of building crip crisis knowledge from unstable, fractured, and hyper-empathetic crip space-times and lives as starting points for critical Disability Studies methodology in service of justice.

With this current issue that we are now introducing, we have asked contributors to evidence their ephemeral and everyday modes of living and surviving. In doing so, this collection aims to build an archive or a tapestry that collectively addresses and exceeds the following questions: How do we evidence our survival, grief, loss, joy, and pain in the face of escalating and ongoing precarity, and loss? How have already precarious yet deeply interdependent modes of living been reshaped or reoriented in the present crisis? In what ways has this fostered or frustrated the inventiveness and resource sharing that are crucial to our survival? Alternatively, how have the conditions of our lives re-framed what counts as theorizing and the stuff of knowledge production within crisis? How does this relate to, challenge, and crip our very understandings of evidence? Perhaps putting it more plainly, what do we need to not forget?

So with that, hopefully we can sort of percolate on these questions as we proceed. And so you've each in your own ways, Aimi, Sandie, and Mimi, thought deeply about some of these core questions, navigating crisis modes, crip ingenuity, community making, crafting survival, cultural and creative modes of knowledge production and leaving evidence.

So we invite you each in turn to reflect on how your existing practice or thinking was already engaging these questions before the pandemic, and how the pandemic reshaped your thinking or just affirmed it, took it down another path, or however you might characterize that interaction of your work and our context.

And so I want us to start with Mimi, because I am so excited that we're now coming a bit full circle here. Because I actually consulted with you two years ago as we were getting this project going from just an idea into a thing. So I'll hand it off to you now.
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>> MIMI KHUC: This is Mimi speaking, thank you so much.
Thank you for inviting me to be part of this conversation. And yes, I remember two years ago. Was it really that long? Time is not a thing anymore. Yeah, I'm super excited to be here and to talk about this project. And the kinds of unwellness and Care Work that we have been seeing during the pandemic. So I'll say a little bit about my work. I've been thinking about unwellness for a long time now. Though not always with that name. The questions that have animated my work over the last decade are, what hurts? And how do we go on living while it hurts? "Open in Emergency" as you mentioned before is my book arts project on Asian American mental health, that was a creative and collaborative effort to name and capture collective unwellness, to

explore its shapes. And to see how the community is finding ways to survive. Beyond the medical models dominant in psychology and psychiatry. So mental health from an arts and humanities perspective.
In weird ways.Since OIE's emergence that was in 2016 I've tried to track the landscape of student unwellness in particular. I visited at this point dozens of universities and I've met with thousands of students. As a result of "Open in Emergency". And I've listened to them, listened to the students, that I've met while on the road and now in the Zoom in the pandemic has really shaped how I think about unwellness and my current book project, forthcoming from Duke, woohoo. I just signed the contract. And it has helped me really develop this framework what I call a pedagogy of unwellness which is the recognition
that we are all differentially all unwell if you start from there if you realize we're all unwell in different ways in relation to the different structures in our lives , what knowledges do we gain from there? What needs do we recognize what structures do we need to build? So then cue the pandemic, which was unwellness and a crisis of care as unprecedented shape and scale. So my questions felt even more urgent. Like what does it mean to track unwith -- unwellness and hurt now. And what kinds of structures of care do we need now? And the pandemic for me made the tensions of access andcare in our institutions ever more acute. And I saw this most clearly in the university.
And in the classroom. Where I've been teaching. I've been teaching at Georgetown University throughout the pandemic. With a short virtual stint at University of California Santa Barbara. And what I noticed and I would love to hear what other folks have seen at their institutions, was a -- early on in the pandemic, a sudden recognition of need, an expansion of access and care and what we call accommodations, right? But I sensed an underlying kind of panic around deviating from business as usual. Right? Around not doing the normal and the normative anymore. And so while I was hopeful when I first saw this expansion of accommodations now over the last year, I've watched all those things get rolled back. So we did not learn as I had hoped that we all have needs and should have those needs met.
I was hoping that would be a lesson out of the pandemic. And I think many of us have learned that. But not all of us. And definitely not our institutions. So I've seen universities and faculty double down on ableism. And so the work continues of witnessing what hurts, finding new ways to care for those and as I witnessed my own students' struggles, I realized that I myself needed to find new ways to care for my students, the classroom felt like it had transformed beyond something – anything I had recognized before. Because of the conditions that we were expected to continue learning under. Instructional continuity, whatever the fuck that is, right? And so the pandemic really forced me to reckon actually with my own access practices and pedagogy in the classroom. And realizing, though, what I had been doing in the before times wasn't as caring as I thought it was. And so I've had to really rethink access and care and need in the classroom, especially over the last year.And so I explore both of these things, the university's ableism, and the transcendental of my teaching, during
the pandemic. In the new book.
Plug.

And I'm happy to talk more about what that has looked like through some concrete examples and on the ground.

Thank you.

>> THEODORA DANYLEVICH: Thank you so much. So I'll just I guess read off like the order to keep us going. So Sandie is next on my printout for order.

>> SANDIE YI: Hello, everyone, this is Sandie speaking. I was really thinking about what did we learn from the pandemic and what not to forget. And a part of me feels like whoa it feels like a long time, I kind of forget what's happened already and I think many of us have experienced this pandemic fog and things have become really hard to capture at many, many levels. And I will start by kind of describing a little bit of my work. So at the beginning of the pandemic, I was finishing my dissertation. And I started working for Access Living an independent living center here in Chicago as coordinator for an arts and culture program. And, We have a history in the arts and culture program and also Bodies of Work , a network of disability art and culture to feature and promote disabled artist work. So focusing on gathering support and finding professional training opportunities for artists with disabilities who mostly prioritize their identity as disabled artists. And my job coming in as a Program Coordinator also brings in my background as an arts therapist whose work focuses on community engagement.

And my practice was never really set in like a treatment setting. I think this was something that I found myself like kind of struggled with at the earlier stage of my own career. So when the pandemic hits, I remember having a conversation with Margaret, that how do we build a community together? And so we organized like online workshops, and trying to just bring people together through various forms of art. And during that time, I started running the Disability Culture Activism Lab for my arts therapy students as well as the Art Institute of Chicago where a lot of students coming to the program wanting to help other disabled people. And there is a huge number of students who do come in with their own disabilities. That oftentime this is something that, you know, like within the larger field of art therapy doesn't really pay attention to. So I will find students who come in like bringing this passion that, yes, I want to help people. I want to help people who are going through struggles. And -- but, you know, the professional expectation in any mental health field is about, well, you need to show that you can actually, you know, be the professional. And so there is oftentimes a line separating, well, you are either the client or you are the expert who is the therapist. And so I do find like, wow, there's like a line between that, you know, wanting to be professional. But how do you help people to be professional if they cannot embrace their connections to the disability community? So I will have students coming in with, you know, maybe they are more aware of yes, I am someone with a disability, Or like I don't know what it is that I have but I'm definitely like struggling with the system. So at this lab, we oftentimes pair people up from the community engagement events, And then students will work with participants. And oftentimes they are checking -- online checking during the pandemic with a health -- a mental health check-in time. Where I would ask them to you can create a portraiture of each other, which I would be happy to talk more about later.

So overall, like my practice is about sometimes I feel like I'm an agent connecting people, or like, oh this resource, connecting to the other resources, and making our community maybe bigger, or try to discover how can we support one another. Knowing that as you are a professional mental health provider, you do not have to do every single thing, because we as a disabled person, we don't know everyone' s disability. And oftentimes people forget that, and are thinking that we have to do everything because we're the caregivers.

Yeah, I would love to hear about how other people have practiced care during the pandemic. And then before the pandemic, as well. But I think care is definitely a-- sometimes it's really sticky. And sometimes it's -- sometimes it happens when we don't know it is happening, and therefore, we exhaust ourselves a lot from all these emotional labor and kind of like wear ourselves down. So yeah, that's what I have been working on.

>> THEODORA DANYLEVICH: That sounds so fantastic. I would love to hear more and see more about that.Thank you. So I actually messed up the order already, So Aimi was supposed to be next. But now let's hand it over to you, Aimi. Thank you so much.

>> AIMI HAMRAIE: Aimi here thank you so much for having me and thanks to the editors for putting together this awesome issue and organizing this event. So I guess where I'm coming from with all of this is that I've been fortunate enough to be in disability culture and community for a while, And to be connected to other disabled people through organizing and other things. And part of participation in disability culture for me before the pandemic that was really normalized and important was the option to participate remotely or asynchronously. Especially in chronic illness communities, I think there are a lot of practices in technologies around that, And also in autistic community.

And so you know, I was kind of like learning and watching and absorbing the way that it was expected and typical to have something like a livestream, or to have something like a listserv or like a Web Forum prior to the pandemic, and all of the ways that affected our pedagogy as Disability Studies scholars. You know, there was like, quite a bit of–my courses were kind of already built out online and things like that for students who couldn't be there in person. So I was -- for a long time I was watching like how disability communities were responding to for example, Occupy Wall Street–Which was the first place I really think I was doing disability justice organizing with other people. There was like a lot of discussion in our local Occupied chapter about how there wasn't a need to facilitate access, because disabled people weren't present and there were a group of disabled people that were like, ‘hey, here we are, and also there are more of us, and they are not present because they need to participate from home, and sometimes we do, as well’. And so just kind of like learning about different techniques of facilitating remote participation has been like a really big part of disability culture and access for me.

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And in my scholarly work and in my design work, I've really been trying to identify the practices and values and techniques that underlie these types of cultural norms that we have. And learning from the history of disability movements and communities, and also challenging our historical communities to do better and to embrace intersectionality and the anti-capitalist approaches.

So, in–I think it's probably been six or seven years ago–I started the critical Design Lab, which is a group of disabled artists, researchers and designers and we address design from a disability culture perspective. And what we have -- part of what we have learned through the work that we do is that access work isn't just about producing like an accommodation. It's also something that's culturally productive and transformative. And it leaves evidence. So when we transcribe something that leaves evidence, we can archive that. We develop different tools and techniques for producing access according to the kinds of spaces -- according to the kinds of spaces and opportunities that we're working within.

I'm also a material culture historian, so I work a lot with the physical things and objects that disabled people have created, And sort of left behind and try to make sense of them. As part of history. And as templates for media making. And so you know, before the pandemic, in the Critical Design Lab, we always did our meetings remotely because we had members who were kind of scattered all over the world in different time zones. We developed practices of media making that were enabled by that kind of remote use of technology. Like we have a whole protocol for creating accessible podcasts for example. And then the pandemic started. And I kind of found myself in this weird space between I had just got tenure like literally the week before the lock downs or something like that. And I was like put on all of these committees about campus reopening and stuff. And at the same time, I was working with my colleagues in the Accessible Campus Action Alliance to actually promote hybrid and remote forms of university teaching and learning. Because, I mean, this was also like premasks, pre-vaccines, like all of that stuff. And trying to like give like a justification or a set of roots for addressing accommodations around that.

Also in the critical Design Lab, we did a lot of pedagogical work and we have a post about accessible pedagogy and remote pedagogy that I don't think I anticipated so many people would use. But it's been downloaded like 300,000 times or something like that. And I hope it's been helpful for people who haven't had to think about that kind of thing before. We have remote access dance party that some of the people here have been involved with . And that Moira Williamson and Kevin Gotkin and I wrote about this in the special issue and Margaret is in there, as well. And that's really an event where we try to use different technologies of access, And kind of hack into -- see what else we can do, what other kind of disability culture we can produce during the pandemic. Two other lab members Cassandra Hartblay and Jerah Moesch and I also curated an art exhibition that went up in Toronto after a year of COVID delays but also has this really cool virtual website that Cassandra and her Research Assistant created together, And Jerah did all of these amazing digital events as part of that. We had workshops for the artists and stuff. So through all of that, we kind of got to experiment with like what are the different possibilities like once we accept that remote participation is okay and good and necessary?

So the last thing I'll talk about really briefly is that this is all kind of feeding into a new project that we're doing now called the Remote Access Archive, Where we're actually trying to document different ways that disabled people used remote participation before and during the pandemic and we're finding all sorts of interesting stuff and finding that it's really led by disabled cultural producers and artists. And they are really like the technology makers in this situation, and there's just like a lot for us to learn from there.

So I'm excited to kind of see how that all unfolds, as well. And thank you so much.

>> THEODORA DANYLEVICH: Yeah, thank you so much, Aimi, it's so cool to hear you talking about this because it helps me see how your work does like access and archive in a simultaneous type of way. So I will now hand it over to Margaret.

>> MARGARET FINK: Hey, everyone, this is Margaret speaking.

I was just fantasizing that I should start talking without unmuting because it feels like that needs to happen at least at one time in this you know conversation. But yay, I'm super excited to just be together today. This feels slightly experimental in a lovely way to do an introduction this way. But okay so I was reflecting on my thought and practice and how it's been shaped in the pandemic moment. And I found myself really leaning on the before times, because I would say the kinds of questions and practices that I'm thinking about actively right now are all involved with what is it to build a Disability Cultural Center at an institution of higher education. And that project started I was hired August of 2019. So I was around for seven months or so before March 2020 when the pandemic hit.

And I was kind of connecting the most to the question from the call for submissions that was about, you know, that inventiveness and resource sharing that are crucial to our survival that was absolutely a huge piece of the before times 100%. But also the way that there was a sense of continuity from before the pandemic to now. So I think, like I said, we were really just trying to figure out, how do you hold space for disability culture? Like, if we're talking about like community, If we're talking about different disabled modes of operating, disabled modes of valuing things. Disabled modes of knowing that just come out of that magic that happens when disabled people get connected.

And that's something that I think is touched on a few times in this special issue. And so we're so lucky. We're a part of a collective of seven cultural centers at UIC. So they are called the centers for cultural understanding and social change . So that offers us a lot of possibility models to be trying to gather pieces from as we do this work of building. But I would say my intellectual life and the practices that we were working through were really -- it was mostly a project of confronting how institutions of higher education are just like–no surprise to anyone–

super inaccessible, full of bumps and wrinkles for disabled people. And so really, and I think this continued during the pandemic, but I'm kind of thinking of this pandemic moment at the beginning of this project. But I would say my thinking and my practice has been part of a grand experiment in what we might call interdependent cripistemology, which is kind of a mouthful. But I'm talking about the fact that I was dreaming and problem solving and building alongside of people, disabled people, that were working at the Disability Cultural Center. And I want to take a little bit of time to name them now. So I'm thinking, Lily-Diego Johnson. I'm thinking of Sylvie Rosenkault –I'm getting emotional – I'm thinking of Brian Heyburn and Jordan Alcantar. And I'm just going to take a minute–I'm that person on the Zoom that gets in their feelings– But okay, We're going to embrace a different set of values. So right. So we've been just having these really important conversations about how do we take up space in a university context when we're talking -- Mimi I was not here when you came to speak at UIC but your lecture had quite a ripple effect, quite an impact for giving people language to talk about unwellness and like lack of care in the university setting. So we were just figuring out how to be a center, How to be professional staff in a university where, you know, things like tabling, involvement fairs was hugely inaccessible to a lot of us. You know, trying to listen to people in a noisy room, Relying on visual cues to figure out if somebody wants to talk to you or not And so on and so forth.

We held each other in access intimacy when we were really exhausted with all of the access labor just to go to meetings, to show up for other communities on campus in solidarity. And we also talked a lot about how do we navigate certain unspoken rules and norms about what counts as success, Kind of on the university level, And what you're allowed to say and what's not appropriate to say in certain university contexts.You know so how do we operate from a place where we're like, wow, 'ableism is pervasive, And a lot of people are really struggling' ? And how do we hold our own success when we're aware that some of the rubrics for measuring success are not great for measuring our success, Like attendance numbers?

I mean, we did okay. We had some nice turnouts. But you know, attendance numbers. Trainings that are offered about, you know, how to be nice to disabled people, that kind of intervention. So okay.That's what we were thinking through. I realize I might be going over time a little bit. So I'll pivot. But I think our ways of understanding our success and our value and our impact were around some of the crip experiments that we were doing with having events. You know, as Aimi mentioned, some of these practices were very much standard or more usual or more typical in disability spaces that some of us were just really lucky to have already experienced and bring into UIC and the university space here. We're super just interested and invigorated by talking about how our workplace was unfolding and how our relationships were working and how they weren't necessarily the standard, But they aligned with our values.

And yeah, I think it was interesting to notice that a lot of people responded a lot to just having some kind of space that felt different from every other space that they were moving through at the university–The fact that we have lamp lighting in our lounge, The fact that we do an access invitation at the beginning of our events. We tell people, please feel free to get up and move around. All of these things just felt like they shaped a different kind of space in a way that was impactful. So yes, I think just trying to tie back to the question from the issue, these were all instances where crip community was a space for survival in a larger environment that maybe didn't feel quite so nurturing. And I've been thinking about that a lot in terms of like vulnerability and even it's a loaded term, exposure, to the experience of misfitting in the university. So I

would say when the pandemic hit, I agree with what has already been said that there was a sense of phases. There was kind of an initial phase of, you know, we have resources. Like we shared out Aimi's guide for sure. We have been kind of already Skyping people in in the pre pandemic times to our discussion groups. This was something that we had tried before. There was less of that panic that I think maybe Mimi I think you might have been the person to bring that up. That other people seemed to be experiencing and we did just kind of let ourselves experiment and play and let's just try these different things. But I think that as I'm reflecting now and in late stage pandemic if we want to talk about it that way, where you know there is this pressure this return to normal big air quotes kind of happening. It feels more like we are back in that position of needing to lean on one another, find these crip enclaves or coves. That support our survival to this exposure to these, you know, massive trends that I think Dora was mentioning earlier. Just much more apparent eugenics, it's been there the whole time. It's not something that is in the past. Absolutely not. And just disregard for disabled lives, all of those kinds of things.
So okay.I'm going to wrap up. But basically I think I've just been noticing that when we're trying to assess the value of different kinds of I guess work for the Disability Cultural Center, the pandemic has just been a major like push in the direction of like it is very, very valuable to just sit in what sustains you and your community. And we will hopefully find a really nice interface with some of the more legible forms of value on the level of the university for our own continued existence as a center. But I would say that's been a major trend for me.

THEODORA DANYLEVICH: There we go.

My unmute failed.

Thanks so much for all of that, Margaret. That was really -- I appreciate how you sort of brought us altogether in your sharing, Sort of bringing our different contributions.

>> ALYSON PATSAVAS: Welcome back.
We are going to switch tactics a little bit to actually move into more of a free form conversation so I'm going to say a couple of really short things to get us started but then we'll move more into an open space and kind of I think say push it -- not push it but have a collective care sort of responsibility to just make sure everybody gets a chance to say some things about the issue itself.

So I appreciate so much this space, [everyone] where everyone shared sort of the ways in which we were already thinking about some of these questions prepandemic. Because this also feels like such an important piece of archiving the knowledge that existed before and the ways that it changed.

But this special issue has -- or Crip Pandemic Life takes up a key thread from disability justice writer, educator and organizer Mia Mingus to assemble an archive of evidence and experience

emergent from crip lives from the pandemic as Mingus writes “we must leave evidence, evidence that we were here, that we existed, that we survived and loved and ached.”
And I think this need to gather, hold space for and preserve evidence, all of the things that you have all talked about: our angers, our fears, our griefs for many of us have felt increasingly urgent in the various ways of the pandemic, right?
And in this spirit, Crip Pandemic Life offers a unique digital archive that seeks to bring together creative and scholarly reflections to document the experiences of folks during the pandemic. And as such, it includes multimedia projects, personal narratives, digital renditions of sculptures, masks, zines, and critical interrogations of the pandemic policies and politics.
You have all had a chance to look at some of the evidence that the collection offers and contribute to it as well, in some cases. so I think we would open up to more of a free form conversation, what are some of the things that struck you? Were challenging? Apt? Lovely? Interesting? What do you want our readers to draw -- what do you want readers who are engaging with this collection to notice?
I'll just ask you to let us know who is speaking and we'll
go from there.

>> MIMI KHUC: This is Mimi. I'll make an overall comment first. First of all, the collection is fucking amazing. The kind of breadth of what you've been able to capture is stunning.
And some of the through lines that I saw through it that I really enjoyed was first seeing striving to survive what the pandemic has wrought. So new forms of danger. And new forms of abandonment–Of structural abandonment.
But then in response to that, this is for me what was really breathtaking about the issue, is seeing the different strivings to create care and connection through all of that–And how joyous it could be.
And I'm thinking here of the remote access right the crip nightlife party that Aimi was a part of, With Kevin and a bunch of other folks. The creativity behind all of the different ways to explore and create access and care in all of these different forms, all of these different virtual forms and then also hybrid forms and care for our bodies and our minds through all of that. Like access doesn't have to be the awful accommodations process, right that we encounter in institutions, that is the kind of bureaucratic drudgery, that everyone experiences it that way, even the people trying to get the accommodations, or maybe -- especially the people trying to get the accommodations.
What I saw here was like the joy that's possible in creating access together. By being creative. By -- by leaning on each other, by being vulnerable together and trying new and weird shit. That was amazing. That was so inspiring.

>> AIMI HAMRAIE: Aimi here. Yeah, I just want to echo Mimi in saying this is such an amazing collection of contributions, And essays, And creative work, And lots of kind of experimental text formats. I really appreciated everything I read.
And I was also noticing as I was going through it that like -- and it makes sense because of the intention behind the call–like there's quite a bit about remote access in this special issue. So I just kind of made some notes about a few of those that I'll -- that I can talk about that I think also capture some of the complexities and frictions around it, as well.

So you know, we know that of course many of the types of accommodations that were once made available for both disabled and non-disabled people at the start of the pandemic are now being taken away. And I think in this issue we get some of the textures of like why those forms of access are really important. There's quite a bit about the safety of home, for example, as an accessible space that's self-created. There are references to Leah Lakshmi Piepzna-Samarasinha’s idea of writing from bed, And a few different people who kind of made references to–that in -- for example in Sav Schaudleraff's creative piece or in Rebecca-Eli Long’s piece about kind of like the safety of knitting as a close embodied practice. Like these kinds of things that we get to do as part of our spheres of participation when we're able to do that from home.

There's also this thread about kind of webs of connection through the internet and other channels that I think has been talked about a lot in [disability,] disability media studies for the last like 20 years but there's a lot of really good primary source evidence of it here. Several different virtual worlds are mentioned: Animal Crossing, The glitch realm which is part of the remote access parties, the virtual network Sick in Quarters which I hadnt heard about before but I was excited to learn about. And then I was also really interested in all of the different digital zines in here–thinking about zine making that really started out as a very physical material process of cutting and pasting and then what becomes possible when we make a zine digital or call something a zine and what sorts of DIY communities and histories and genealogies that connects us to. I think in a few different places there are also really interesting methodological notes about the norms of access that are emergent and different digital formats and spaces.

So for example, the restorying autism writing collective talked about applying principles of relaxed performance, which is like for in-person performances, to a digital zine making workshop. I thought that was really interesting.

There are also -- there's a whole piece in there, a visual art piece, from Sam Fein about you know depicting people who are isolated and incarcerated and institutionalized and that's the sort of other side of remote participation. It’s that like for people who have connections to histories of institutionalization it can actually be really inaccessible or bring up a lot. And so I thought that was like a really important kind of reminder that we can't just like valorize remoteness.

And I kind of came away from a lot of these just I think having like a more -- kind of like a deepened closeness to the way that embodiment typically gets discussed in Disability Studies. And just kind of thinking about all of the different ways of being embodied, And how like proximity and distance and mediation relate to all of that.

So thanks so much for sharing these pieces with us. I really enjoyed getting to take a look at them.

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>> MARGARET FINK: This is Margaret, I will chime in. I agree. I really appreciate the analysis that you both already shared. And I was finding myself drawn to two patterns which is part of an overall pattern of just I thought there was a lot of texture for lack of a better word to the collection of the whole special issue.

Aimi was saying that yes there were a lot of new forms of accessibility that became possible in lockdown but then for some people, actually, the experience was quite different where there were new forms of inaccessibility and just maybe having to confront trauma related to carceral situations that they had been in.

But I wanted to maybe just point out that there are a few really cool examples of situations where smallness and being local is important And crucial to the project. So I'm thinking of Sandie, you and Alyson talked about the mass [maps?] for Crips project and how actually keeping it pretty confined to Chicago was an important piece of how that work unfolded for you . And I'm thinking about my experience as a driver like, that being a[the] one situation where I would traverse long distances of space in a situation where I was otherwise in lock down. But I really loved the way that you two pointed to that piece, being local, kind of being small. Like the people that you actually know being the people that were being connected to the project.

And then the other example that I'm putting in a similar I guess analytical relationship is the “Corona Look of the Day” that Bethany Stevens and Sarah Palmer shared. And I was just impressed that they did it every day . I am not a person that can stick to those kinds of daily rhythms. But I thought having so many small instances ended up painting a really complex picture of you know this life that they wanted to leave evidence of.

So I just appreciated that a lot. And I will -- I'll stop there.

I wanted to ask about the tapestry word in the title. Does that have a story? Because I kept thinking about it when I was reading the issue.

>> ALYSON PATSAVAS: Theodora, this is yours.

>> THEODORA DANYLEVICH: Usually I do space bar to unmute but it won't let me do it for some reason now.

I'm sorry.

Yeah, well, I -- well, it was in one of the threads from "Open in Emergency", Mimi's project, that I thought was so compelling. Because that was part of your project, too. Like having it -- a literal tapestry as one of the things And I -- yeah, so trying to imagine what -- how a digital archive can also be a tapestry. You know, obviously evocative of the AIDS quilt.

So yeah. Just sort of like, you know, the literal -- or a concretetization of like how communities can hang together. Yeah.

00:57:02.382 --> 00:57:06.082 (corbin’s timestamp 1:02:24)
>> ALYSON PATSAVAS: Yeah, I think I will just add that I also like like thinking about it materially like the tapestry is sort of you're working with the materials that you have. To build something that isn't encompassing right like the archive has its own sort of problematics of sort of presenting something that's comprehensive, that is full, that is sort of speaking to like all of a set of experiences that of course that's not what this collection is or even can be.

There's lots of voices that by virtue of like the sort of precarity of our lives are absent from the collection. And so I think as -- I think this is more of a subsequent post decision, to use the word reflection. But there's a kind of materiality there that like the tapestry is what you built with what you have. And I think that's what this collection is In some ways. There's of course pieces

missing and pieces that we can add onto to make other fabrics that I think is -- isn't always an ongoing project that just sort of fits I think from my perspective.
But of course I should give the space to Mimi to talk about the concept and the word, as well.

>> MIMI KHUC: This is Mimi. Thank you. No, I loved hearing about both of your theorization of tapestry as a physical and textural way -- the word texture has been coming up and I really, really love the word texture for this collection. Literally, Because there are textures being depicted. But I also find the textural language floating through it quite a bit, too. So yeah tapestry as metaphor just feels both capturing the kind of almost somatic nature of some of the issue. But also I like, Aly, you're saying the kind of way that it is also as an archive temporal and just you make with what you have right then and there. But it can always grow.
You can always keep adding to it.
So I like both of those elements of how you're thinking about tapestry here. Some of the textural language that I've noticed that I really, really loved, in -- this is in Paulina Abustan's piece on Animal Crossing, they use the language of gentleness and softness. And the comfy and cozy.
I love the idea of comfy and cozy as academic theoretical language, Right?" Gentle, soft, comfy, cozy." Like I love that that is a way you're talking about what access intimacy and care feels like on my body. And in my mind. And for my spirit.

>> THEODORA DANYLEVICH: Really briefly, this is Theodora. I did -- I was thinking of comfy and cozy preparing for this. And I am wearing sweatpants.

>> SANDIE YI: This is Sandie speaking, I think speaking of being comfy and cozy, one thing that I thought about after skimming through the overall content for this collection, I was really thinking about, wow, this is an amazing collection of recipes.
Because when I teach art therapy to my students, a lot of students are like, what materials do we use? How do we use them for, you know, treating specific communities or diagnosis? So it's really hard to tell students, well, there's no like one set of recipe. It's really all -- it really all depends.
And the flavors I'm tasting from this collection is that, wow, there's something for the mind. Something for the physical presence. Something for the invisible connections that we get to have with our crip siblings. And the collections gave me a lot of ideas like if -- I mean, hopefully God forbid another pandemic or some sort of crisis happens, like I could see that this is something that we can go back to and see like look at that, there were projects that people did in a small community where they practiced every day.
So there are a lot of survival skills that we can learn from. And so in a way that I feel like this is quite a [tool book], toolkit for us to imagine things that maybe we don't know
what the future will bring to us.
But think about like the collective wisdom and collective connection as, you know, how maybe how small or at the time you feel insignificant. They are actually creating more footprints for us to perhaps follow or perhaps to adapt. And also to have -- to fulfill the desire that we have for each other. And I'm thinking about the desire as the nutrients.

So what I want to say is like the tapestry, I love the visual metaphor of the tapestry and I would also like to add when I look at the collections, I feel like there's a visceral fulfillness like oh I'm getting some nutrients to -- for me to restore. And things will happen. Crisis will happen again. And perhaps that I will be able to utilize them or practice some of them.
Whenever crisis comes.

>> THEODORA DANYLEVICH: That is such an amazing way to put it, and I just so appreciate that, Sandie, thank you.

>> ALYSON PATSAVAS: Yeah, I'm struck.
This is Aly, I'm struck by the emotionality of hearing you all talk about the issue and what gratitude I have to the contributors for giving us such rich material. Like the generosity with which folks submitted like just really beautiful, really personal, really intensive, really grief filled material. I think it's sort of rising back up as we're talking about it and having such care for it in this space of just feeling so much gratitude both for your reflections but for the -- like the pieces of soul that I think people sent in to this collection.

>> MARGARET FINK: This is Margaret, I don't want to speculate on behalf of the contributors. But I do think the leaving evidence piece animated a lot of the contributions. And I think I'm trying to approach a way to talk about how the work of documenting what happened . . . is important. I'll just say that. I'm not sure how to talk about that yet.
But yeah, it does -- I was thinking -- I was reflecting a lot about how I talked about just trying to lean into crip versions of value. Even though I'm very aware of the Disability Cultural Center's context in the larger university that might measure success differently, and I was noticing that a lot of my sense of failure but maybe that queer version of failure that I think the Queer Art of Failure piece brought to the surface, a lot of my sense of failure had to do with the ephemerality the fact that we tried this and it was really neat and then it kind of went away and it lived on my phone and your phone. Or it lives kind of in the ether. Nobody recorded it. So I just I do appreciate that level of the issue. And that level of the contributions.
I mean, this is the whole point. Like weaving evidence . But I'm just trying to take some time to slow down and notice how generative that is or some other language. Maybe somebody else is thinking of a way to talk about it.

>> THEODORA DANYLEVICH: This is Theodora. As Sandie was talking, I don't know if this is like a bad translation. But when you were saying recipes, I was thinking of like, okay, a care recipe, is that like you know a prescription or medicine in a non-like negative connotation type of way?

>> SANDIE YI: This is Sandie speaking. I was really thinking about how -- yeah, I mean, one interpretation could be that, like, oh, yeah, we want to kind of go from the opposite of like purely medical model to like, hey, how about we twist the meanings of a recipe, a prescription, and add our flavors on disability culture. But for me like when I refer to recipe, I was really thinking about

how, you know, hey, this is my grandma's recipe. And -- but I don't have the same ingredients from you know, her generation or the technique. But I'm going to adapt something that I have. And I feel like because of disability isn't -- it doesn't really only happen within the family. And sometimes that our disability culture as a family, it's so big. And then I feel like we -- most of us weren't taught that this is your crip family. And so I like to think that we are creating a family together. And there could be our family recipes. And this recipe will be -- will have all sorts of flavors and practices.
Yeah. But I really like your question about is that like a prescription. Because I do work with students and other colleagues of mine who are thinking about disability from more like we have a medical model perspective. Yeah. But I like to think that, you know, we can have like our cousin's recipe focusing on autistic experience. Or another tribe's disability recipe for us to really piece out the flavors, based on how you see yourself -- the space in which how you see yourself in your crip body and mind fit. And also we can model after each other. It's like, oh, yeah, when I think about how I am going to dress, I may get some ideas from an article. That's just one other example.

>> MIMI KHUC: This is Mimi. I want to actually run with both of your metaphors of recipe A little bit, Just something sparked for me.
Thinking about, okay, if this is a recipe or a prescription or some kind of resource for thinking about how to move in the world, how to survive, how to create care, I love that there is deep grief in the issue, In that context. Because for me, it makes so much sense that care and survival involve feeling and expressing that grief as fully as possible. I'm thinking of the poem August 2020 by Jennifer -- I think it's Scuro. I was really struck by that poem. In its smallness. Like it's describing a very small moment Quiet moment, That is devastating, Right? And that for me, that affective place or register makes a lot of sense for what unwellness and pain has looked like. And the necessity of sitting with that And witnessing that. And feeling that. And not pretending that it's not there or that everything is going to be okay. So I love that that can be -- we can think of that, too, as a process of care, as well. Or as a model for care.

>> AIMI HAMRAIE: This is Aimi. As I've been listening to you all talk about recipes, I've just been thinking so much about the form of this -- I don't know if you're calling it like an issue or an archive or maybe tapestry is the right word. And the now kind of evolving practice of creating these like you know not typical academic texts and things related. And also thinking about Mimi's "Open in Emergency". And the sort of -- like the practice of giving someone a box that is full of care and knowledge and history. And all of these things. And so I wonder if maybe we could just like talk about form and design a little bit, too.
And one of the things I'm wondering because, you know, like I'm always talking about Disability Studies to people who are in fields where the form of knowledge production is usually purely textual. Maybe a little bit diagrammatic or visual.
And -- in some way, Is there a sort of Disability Studies norm do you think that is emerging in which our academic contributions also like necessarily take on these many different forms and also embody practices of care? And is that something that we could like pinpoint and say its part

of what it means to do Disability Studies? so if someone is like evaluating the work, let's say for a tenure file or something like that, that that could be like a metric for saying, like, yes, this belongs there with all of this other stuff. Or maybe even not that form of evaluation.

>> MIMI KHUC: This is Mimi, Aimi, I love that so much thinking about form and I love your framing of like is this a Disability Studies, Disability Community, necessity. To have more capacious understanding of what does it mean to do those kinds of works on the ground in the community. And like I think about -- you brought up tenure, boo tenure–You brought up tenure and evaluation. And it makes me think there are Disability Studies books and articles, right, that are super smart and investigate all kinds of things in disability theory, And even you know history and community But don't enact care themselves.
And that's a question I've been thinking a lot about. How are the things we create, even at the level of the academy, not just studied care as object, right, but think about the form so that we're actually practicing the things that we're trying to study, as well. That the form can reflect or can enact those commitments, as well.

>> ALYSON PATSAVAS: I hope so. I guess I was waiting for other people to jump in. But this is Aly. And I just want to say that I hope this is the world we're entering. And I feel like so much of Disability Studies work is about this like dreaming and imagining and sort of declaring a future that we want as we're building it. And as we're sort of demanding it. And so I love -- and thank you so much for bringing that into the space as we think about like how to intentionally name this as part of the project of Disability Studies work. to sit and you know certainly this collection has been modelled from folks who have done this very similar work, Putting poetry and art practice together. Those of you on this call are here precisely for leading the way to this kind of -- for this kind of work.
Yes and thank you.
And more, please.

>> MARGARET FINK: This is Margaret, I'm thinking about how this question of form and the idea that I think is kind of coming to me out of the submissions to the special issue that there are forms of knowledge that aren't really commensurate with a sentence that says words and yeah. I think a lot of what I have thought about in the now distant past was when I was thinking about image and text is really interested in that question of what can different media say that other media cannot really express.
So I think I'm trying to -- I think we're talking about – what I'm trying to talk about is just actually we would as a discipline need to accept other forms of knowledge-making in order to support that insight that I think it is -- I think is present in some of the work that's been coming out of the field that -- and definitely out of this volume that, you know, there -- we do need to proliferate the ways that we share understanding. Yeah, Yeah, there's other ways to talk about this.

I'm just going to go, you should cut this part out. But there's even I think people who talk about different forms of thought, constative thought. Where it's like you make a statement. It is true. And then there's other versions of even knowing. So I'm excited about some of those questions and what kinds of form would support even sharing that.

>> MIMI KHUC: This is Mimi, I just want to offer a phrase that I have found really meaningful for -- as a possible way of approaching some of the things we're talking about. This is from a dear friend and colleague Jim Lee. And he writes in his new book Pedagogies of Woundedness that rigor must be tender.
Right?(Chuckles).
Like what does it mean to -- we ideal ize and value rigor so much in academia. What does it mean to inject tenderness in there Or use tenderness as a frame for it Or have tenderness as the goal of that rigorous work? And for me that leads us to possibilities of care in, through our work ..Rigor is tender.

>> ALYSON PATSAVAS: I can think of no better way to end this conversation than that.
I just have like one line that I have to say before we send the captioners and CART off. But thank you, everyone, for your thoughtful and really generous insights on the issue's themes and content of the collection.
As a way of wrapping up I was hoping we could collectively invite folks to linger on, meander through, grieve alongside and find solace within the words, images and theorizing within the Crip Pandemic Life collection.
Thank you.

Faith, Michelle, Cindy, thank you so much for the access work today.

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