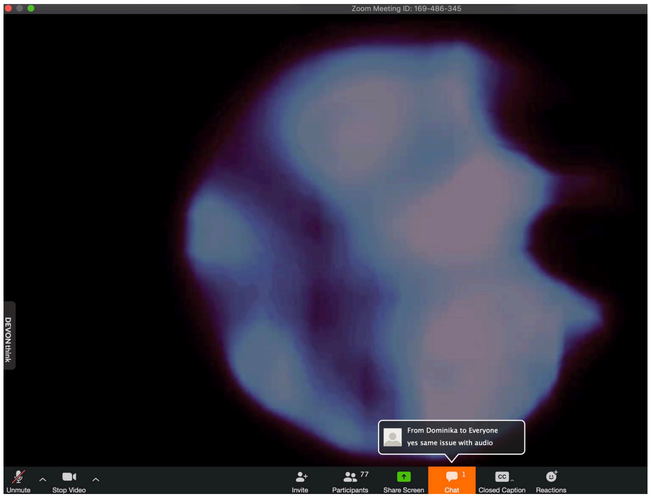

From Dominika to Everyone
yes same issue with audio

CORBETT O'TOOLE

Interview Date: February 14, 2023

Image Description: Text reads "The Remote Access rchive" atop a screenshot of a Zoom shared screen, which shows a work of art by Yo-Yo Lin. The art is a white and grey blob on a black background. The ottom shows a series of grey buttons, along with an orange chat button that is lit up. A speech bubble ove it "From Dominika to everyone" says "yes same issue with audio."

KEYWORDS

2020, 1990s, 1960s, 1970s, 1980s, America Online (AOL), collaborative access, disability justice, email organizing, in-person, long COVID, nomadic digital access, organizing, polio, pre-COVID remote access, recovery communities, remote socializing, skill sharing, technological equity, telephone

IDENTITIES GIVEN

white, woman, Irish, cis female, person with multiple disabilities

LOCATION

United States

Introductions

Aimi Hamraie:
My name is Aimi Hamraie. I appear on the screen as an olive skinned transmasculine person with glasses and short, dark, curly hair. I'm in a yellow room with plants and a dry erase board in the background. I'm here today on February 22, 2023, with Corbett O’Toole. Would you please tell us your name, age, and where you currently call home?

Corbett O’Toole:
My name is Corbett Joan O'Toole. I'm currently 71 years old, and the home questions are little confusing, because I live full time in a van. So, my legal address is in California, in the Bay Area of California.

Aimi Hamraie:
Okay. And where are you calling in from today?

Corbett O’Toole:
Today, I'm in the middle of the Central Valley. So I'm calling in from Button Willow, California, which is on Highway 5.

Aimi Hamraie:
Awesome. And how — What words do you use to describe your race and gender?

Corbett O'Toole:
I'm a white woman, just race and gender. Okay. So I'm white and fairly pale skinned, because my heritage is Irish, and I identify as a cis female.

Aimi Hamraie:
And do you wanna do an image description for the purposes of the video?

Corbett O’Toole:
Sure, I'm a white woman with salt and pepper hair, really short. I'm wearing bone conduction earphones, I have no teeth, and I'm wearing a purple top

with sheep wearing hats and scarves that says “baaaa humbug” and a blue knitted ascot thing. I'm in my van, but the background is blurred.

Aimi Hamraie:
Do you identify as a disabled person?

Corbett O’Toole:
I do. I identify as a person with multiple disabilities. Is this the time to say that or not? Okay. So I have physical disabilities. I use a wheelchair. I have Long COVID, so for me, what that means is, I have chronic fatigue pretty extensively. I've lost all my teeth to Long COVID. I also have psychiatric disabilities and….Lots of itises, arthritis, bursitis, all of the itises. But my primary mobility is that I use a wheelchair to get around, and I'm also a fat woman.

Aimi Hamraie:
Do you consider yourself to be part of disability community or disability culture?

Corbett O’Toole:
Yes, I do. I've been connected — I've been disabled since I was 12 months old with polio, and I've been… I attended disabled kids camps as a child. So that was my first encounter with disability community, and then as an adult, I moved to Berkeley, California, and became involved in the disability rights movement, and then have been part of a whole bunch of, you know, disabled and queer disabled and parents with disabilities and all kinds of parents of disabled kids, and lots of disabled communities over the years.

Aimi Hamraie:
Yeah. And these are thankfully documented in other archives as well, including the Bancroft Library and your personal papers, in the, is it the San Francisco public?

Corbett O’Toole:
San Francisco Public Library history archives.

Aimi Hamraie:
Yeah, so today, we're going to be talking about remote access, which is a term that we use to describe the ways that disabled people and disability communities have done different kinds of participation at a distance. And so I'm gonna ask you some questions about your experiences with this, both before and during the pandemic. So I want to see with before the pandemic. Did you have any experiences of remote access and participation that you can recall?

Remote Organizing Through Email and Listservs

Corbett O'Toole:
So I'm gonna use the term remote access to mean organizing via email.

Aimi Hamraie:
Yeah. Great.

Corbett O'Toole:
Okay, so prior to their being video options that were available to me, basically from 1993 to 95, I was working with a group of disabled women across the United States and Canada, and we were putting together a group of women, disabled women to go to the Fourth International Forum on Women for the United Nations in Beijing, China, and we did all of that work completely on email. It was all just email connections and stuff. And then in, from '98 to 2000, I was working with a group of people spread across the United States. There were like 10 of us, and we were organizing the first International Queer Disability Conference. So those were the big ways I was having social connections, but those were specifically things where remote access created opportunities and created events that wouldn't have been possible without having those remote access options.

Aimi Hamraie:
Hmm! Great! I'd like to ask you some follow-up questions about that. So the

organizing for going to the UN Meeting in Beijing was from ‘93 to ‘95, which, to me those dates stand out, as also kind of around the time that personal email was becoming available to people outside of government and things like that. So, do you have any recollection of how is the availability of technology affecting you at that time in terms of being able to make these connections? And what were you and other people doing over email, like where they're lists or discussion boards, or like, how did you find each other? Those kinds of things.

Corbett O’Toole:
For the most part the people that I knew, we were shifting from having sometimes met up occasionally at conferences, and then intermittently having phone conversations, but this is when long distance was a separate charge from local calls, so, in the old days for me it was AOL as an option when AOL and emails became available. We started to use that, and we did some listservs, but I'm not really remembering that very well about exactly how we used listservs. I remember a whole bunch of us were on AOL, and we would have communication there. This is a ‘93 to ‘95 stuff, and we were spurred on because Laura Hershey, who is significantly disabled, had gone to the Third International Forum on Women in Nairobi, the United Nations one, and had come back and talked about how organized the disabled women in Africa were. Basically she went to Nairobi because she's like, the US women who were organizing women to get to the Forum in Nairobi are saying, “don't bother we don't care about disabled women coming in.” She said we have to change that conversation. So we made a commitment to get disabled women to Beijing, even though the US women’s official group, the NGO group, had said to us, it’s still inaccessible, we’re not gonna make any access for you, and we’re not gonna help you, so please don’t come. They literally said to our face, please don't come.

Aimi Hamraie:
Wow!

Corbett O’Toole:

Well, actually, they didn't. They actually didn't say please, they just said don't come. And we were like, you know, yeah, this is kind of the way it is sometimes with white feminism, and disabled women, white disabled women. So we're like, well, we're going, so we were on our own for fundraising, and made T-shirts, that kind of stuff just kinda and brought 50 women from mostly from the US, a few women from Canada and a couple of women from Mexico.

Aimi Hamraie:
Hmm! So it sounds like you met people at conferences and you exchanged email addresses. And then you have some correspondence with the organizers of this event, and then had to organize your own funds and travel, and all that kind of stuff. And so how did email help you do those things like, what were some of the kinds of conversations you were having?

Corbett O'Toole:
Well, email saved us a lot of money. For one thing, we didn't have to make long distance phone calls and budget for that. Another thing is email allowed us to have communication across disabilities. Because you know, typically getting something together in person, if we had print stuff we had to figure out how to make it accessible to the women with vision disabilities. And if people were talking, we had to make it accessible to the women with hearing disabilities…And also, you know, people with environmental illness at that point didn't have a lot of options for any kind of in-person meetings for lots of different reasons, for you know, the planes were inaccessible from from a chemical point of view, and the gatherings were inaccessible. So it allowed a lot of women, I mean, certainly not all women, but a lot of women, to have a space that provided access in a way that we hadn't had before. People didn’t have to go anywhere, women with mobility disabilities didn’t have to deal with transit. So it kind of created this sense of, for the first time, we were having conversations across disabilities in a way that allowed us to, if you will, share space.

Aimi Hamraie:
Hmm! That's great. So like the digital and tech space format. And then, like

you were saying, the cost of phone calls is too high, and so email got around that because, you would dial into the local AOL number from your computer as opposed to calling long distance.

Corbett O’Toole:
And just one more thing is, it didn't matter where people were located. We didn't have to deal with any time zone issues.

Aimi Hamraie:
So it was like asynchronous participation. Basically that was the language we would use today. Were there any access barriers that came up around email that you can remember?

Corbett O’Toole:
Not everybody could afford it. You know, there were financial costs. There wasn't much in the way of training, so those of us that lived in urban areas that had access to people who are more tech savvy, or had more money, or were in or connected to organizations that could provide…so much of the access to email was about someone, one person teaching another person how to do, which sounds silly now, given the ubiquitousness of email. But there was a time when it was a whole learning curve in addition to the financial costs, so some of the barriers were money, people couldn't afford an AOL account. Some of the barriers were people couldn't figure out the technology on their own, and also it really prioritized people for whom typing cause there wasn't a lot of like…Dragon Dictation so an equivalent didn't exist, so somebody who couldn't type for themselves had to dictate, it also really excluded people that were not primarily text-based. It really excluded the whole self-advocacy, developmental disability community that's primarily an oral tradition community, not a written-based community. So there were definitely people that weren't part of the conversations.

Aimi Hamraie:
Do you remember if people had their own personal computers back then, or where people using Internet cafes that in your experience, or that you knew of from other people?

Corbett O’Toole:
Well, you know I'm a white woman with a physical disability, who got State Department of Rehabilitation to send me to college. So there was a whole bunch of folks in my generation like, so I'm seventy-one now, so in the sixties who got their college education paid for, and so that gave me access to stuff like people that had, you know, hand me down computers or ways of knowing. I was working at the Center for Independent Living in the early seventies, and then at the Disability Rights Education and Defense Fund. So I had access to people that had access to stuff. And so I could say to somebody, What do I buy, or how do I get a deal on this, or do you have to hand me down? So I was able to have a personal computer, and for people that had to go to public spaces…I don't know if libraries had computers then, but certainly some agencies did. A lot of people just did it, like at the Center for Independent Living, if they had a job or something. And I just want to qualify, job didn’t always mean you got a full salary, sometimes a job was giving you enough money to work with your benefit package so you didn’t lose government benefits like healthcare. But anyway, it was all about…there was a privilege to being networked that made the likelihood of having a personal email account and a personal device greater.

Aimi Hamraie:
And it sounds like networks of disabled people and disability community organizations were facilitating access to technology in certain ways.

Corbett O’Toole:
Within the constraints of the disability rights movement, yes, within the constraints of if you're white and physically disabled, you had the greatest access to resources. And then, if you were blind and white, you had a bunch of resources primarily through blind networks and then pretty much everybody else was “good luck, you're on your own, figure it out,” in terms of the access to resources that I knew about.

Remote Access Before the Nineties

Aimi Hamraie:
I wonder if you can think of the remote access that you may have used or seen other people use earlier than the nineties. So, for example, in the lead up to or like the way that you talk to people after going to camp when you're a kid or when you are working at the center for independent living, or you know, in those kind of like pre-internet times.

Corbett O'Toole:
Can you give me an example? I'm just trying to get on the same page with you.

Aimi Hamraie:
Yeah, some of the things that we've been really curious about are things like newsletters, phone trees, telegrams, radio. Like all these, you know, technologies that existed before the Internet, that people may have used.

Corbett O’Toole:
So I was aware, and the polio community something that later be called later became G. I. N. I., and it was a whole post-polio network and a newsletter and also letter writing between members. I think part of it was attached to people that were using iron lungs, or using respirators of various kinds. It seemed very old fashioned to me, and slow, so that was never of much interest to me, but I was aware of it. I knew that the blind folks always had radios in their houses, and had kind of, if you will, “blind radios” and “blind stations” that they would allude to, but I wasn't particularly privy to that.

At that point in Berkeley, the School for the Deaf was still there, and it was run by Deaf people, and it was a huge center of Deaf community and Ella Mae Lentz was one of the early documenters of American Sign Language as a language was based in Berkeley. So I was aware of a lot of ways that Deaf communities had networks… people would jokingly talk about going to somebody's house and just waiting for hours till they came home, because they had no way to tell them they were coming. The Center for Independent Living, early on, there was a Deaf man named Dale Dahl, who was a multi-generation Deaf ASL signer, and he became a hemiplegic, and so he just wandered into the center one day, and then just kinda never left and taught all of us sign language. So there were these very informal ways of kind of connecting people that we saw that happened in different kinds of communities. I recently talked to Susan Molloy who is very early on in creating communities for people with multiple chemical sensitivity. And she has an entire, shed of newsletters, because that community did a lot of newsletters and letter writing as ways of organizing themselves. So I was aware that they were these other kinds of networks. I wasn't personally participating in them, but it was like I knew enough to say, oh if you need this resource, that's where you go.

Aimi Hamraie:
Yeah, that makes a lot of sense. Were there ways that you kept in touch with people that you went to camp with?

Corbett O’Toole:
I didn't. One of the things about my camp was, unlike a lot of camps…the director of the camp was a disabled man. He had had polio, and his daughter had had polio, and he ended up permanently disabled from the polio, and he started the camp for his kid. He was also the Director of Special Education for the city of Somerville, Massachusetts. So he made the camp be like, really broad range, 90 kids for a month at a time. No parent visits. And all kinds of disabilities. It was a pretty unusual arrangement, but there wasn't any attempt by him or by us to stay in touch between summers, and I'm not really quite sure why but it just wasn't part of the culture and all the staff, except for him, were non-disabled. They're mostly college kids. So yeah, I didn't do that.

Aimi Hamraie:
Earlier you mentioned when we were talking about email, you were talking about the cost comparison between email and phones. And at first I didn't

even think to ask this, because the phone continues to be such a ubiquitous way for people to communicate. But you know, for the purposes of this archive, what are some ways that phone communication was part of disability, culture, and community and organizing that you can remember?

Corbett O’Toole:
Well, for both the Beijing Conference and the Queer Disability Conference, Laura Hershey was involved, and by the time we got to 1993 Laura couldn't use her hands anymore. So any kind of typed communication required her, in those days, basically to have someone else typing for her. Later in time, things like Dragon Dictate became available, so it's just so much faster. They just call her and say, hey, you know, what about this? What about this? What about this? So some things were much easier by phone. But her partner, Robin Stevens, who has significant cerebral palsy speech, is much more challenging to understand on the phone did much better via email. So it would be interesting, like when we call the house, if Robin was talking. Laura was literally translating voice, voice interpreting. So in some ways we used the tools interchangeably. It's kind of like whatever access, whoever you needed to talk to you, did the access that made the most sense for them. You know, if you were into different time zones and they were a night person, you were a morning person. You did asynchronous email if they like text. It was somebody like me, where my communication is pretty direct, so my voice allows more nuance than typing and communicates my message more clearly and less offensively. So it just kinda…we just kinda did both.

Aimi Hamraie:
Hmm, that's really interesting, that navigation of text and phone. Do you remember where Laura and Robin lived?

Corbett O'Toole:
They always lived in Denver, Laura never left Denver, I mean, for housing, she never left Denver.

Aimi Hamraie:

And were you in California at the time?

Corbett O’Toole:
Yeah, I was. I moved to California in 1973, and I stayed there till two and a half years ago.

Aimi Hamraie:
And where were some of the other people who are involved with organizing those conferences?

Remote Organizing Around Conferences

Corbett O’Toole:
So the Beijing Conference…it would be Russo in New York City, Marsha Saxton at that point was in Boston, Tanis Doe and the Disabled Women’s Network (DAWN) in Canada. I think Meenu was in Toronto at the time. Alicia Contreras was in San Luis Potos, Mexico, Eleanor Smith was in Atlanta… cause a bunch of us in the eighties, there was a little bit of money right at the end of the seventies and early eighties for disabled women's work, so a whole bunch of us got networked through those efforts, so that was kind of the backbone for the Beijing network. And then we knew different people. Sometimes we knew the sign language interpreter. Sometimes we knew the deaf person. So there was a whole bunch of people in the Bay area. It was a little gathering in Denver, and then kind of people were just all over the place for that one, and then for the queer disability conference, the primary organizers were Laura and Robin and Carrie Lucas, all of them were based in Denver…and then most of the next people I'm gonna mention… well, Eli Clare was working at a university, but he was not an academic. There, his partner, Samuel Laurie, was involved. They’re not disabled. And then it was Ellen Samuel who, I believe, was in graduate school at the time. Alison Kafer, who, I believe, was in graduate school at the time. Jay Williams, who was an undergrad at San Francisco, State. I'm forgetting where… I think Alison went to school in Southern California. I guess Ellen was at Berkeley at that point. I'm not sure. Who

else was the organizers? I'm spacing. It's pretty well documented. I know I'm missing somebody else. That was pivotal, though. Yeah, there were like 6 of us that we're doing kind of programming stuff, and then Laura Robin and Carrie in Denver. I think I have it as Eli and Samuel and me, and Alison and Jay and Ellen. Yeah, that was it. That was the core group. And then different people came along, closer to the conference, in different ways.

Aimi Hamraie:
And that was an international conference.

Corbett O'Toole:
That was an international conference. We held it. I used to organize the day before SDS, the Society for Disability Studies, gathering. So I would piggyback on other people's money, because then we could get the interpreter contracts like an extra day or two, and San Francisco State agreed to host us. Paul Longmore was still alive then, so we had the conference at San Francisco State, like Monday and Tuesday, and then SDS, Wednesday was the Board meeting, and Thursday the conference started, and that way we had a week where there are no students, and access to the dorms. Basically, the whole campus was ours, nobody else was there, which was pretty amazing.

Oh, we did it all in terms of digital access. We had one in-person meeting in the entire organizing year and a half. We only met once, and the rest of the time it was all emails and phone calls.

Aimi Hamraie:
Do you happen to remember if any of the conference itself added remote parts, like were people calling in or participating by sending the paper for someone else to read, or anything like that?

Corbett O’Toole:
Alison Kafer and Eli Claire were the program people, so they would be better to answer that question. I was doing on-site logistics, so I knew more about what was happening in terms of the on the ground stuff.

Aimi Hamraie:
Okay, yeah, just curious, like, alright. Do you remember any disability conferences where people were maybe doing kind of like a hybrid or entirely remote format.

Corbett O’Toole:
In pre-COVID? No, and, in fact, lots and lots and lots of disabled people would ask for it, and it was always no. I mean, I remember going to conferences or going mostly to SDS, and I would remember people reading papers for each other. Like sometimes that would happen, but I don't remember any ability for people to call in or answer questions from the audience, or even do their paper that way.

I think there were a few SDS where there was a video recording. I seem to have a memory early on of Carol Gill, up on a screen, but it was like a prerecorded, not a live presentation. So there were a few of those. Sometimes it was performance. I remember one time there was a Neil Marcus film, and I think a Mark O’Brian film got shown. So sometimes it was like, packaged stuff, but I don't remember anything live or interactive, that was remote.

Aimi Hamraie:
Do you have a sense of why people maybe were asking for remote options in those states?

Corbett O'Toole:
Yeah, I mean, yeah, it was all kinds of stuff. It was, you know, almost none of the people with multiple chemical sensitivities could ever attend those conferences. They were always in hotels, they were never accessible for that. That was one reason, another was economics. it was $1,000 to go to SDS, you know, even if you shared a room 17 ways, there was still food, there was still conference fees, there was still an airplane, so it was a very expensive thing to do, and particularly for people like me, who are community scholars. It was really hard on fixed income, on your social

security income, it was really hard to find that kind of money. So lots of people wanted access remotely for economic reasons, not for just disability reasons. It's not just about accommodating people with chemical sensitivities, but also for energy level, for transportation issues. People didn't have money to pay an attendant to drive them to the conference and work extra hours. That was all out of pocket, and the conferences never had budgets…if they had a budget for an interpreter, they didn't have a budget to help people with attendant costs, or the cost of an extra room, or whatever. And also there was an issue that things started at 9 in the morning, and I don't know about you, but everybody I know that's a quad, you know anything much before noon is pretty much not gonna happen because their attendant morning schedule. If they wanna have to be something at 9 in the morning, they have to be up at 4 in the morning.

It was always interesting to me about… SDS is the one I know best… there were lots of barriers that seem like they could have been negotiable, like, for instance, if someone could be watching a presentation while they were doing their morning attendant routine, they could be participating later in discussions about it: “Hey? When you said this, at this panel, I thought that, you know…” So it isn't necessarily that they had to be in the room, but the fact that there was no way for them to know what happened in the room was really a big problem. And also stuff was never recorded, you know, if you were lucky, there was a paper a year or two later, but there was nothing like you had no way. If you missed it in person, you missed it completely.

Remote Access 2000 - 2020

Aimi Hamraie:
So between the late nineties, and when the pandemic started in 2020 in the US, do you have any recollections of remote access during that time, and that could include all the stuff I said before, it could also be things like live streams, Skype, Zoom calls, you know, talks online and things like that.

Corbett O’Toole:

So, I have brain fog from COVID. So this is part of my brain: this is today, there was yesterday, and there was some time in the past. So, and then kind of it's like, after my daughter was born in 1993. So I know it was since my daughter was born but you know, like I'm just telling you that the events I remember better because they had very specific time markers. But prior to COVID, I was using zoom. I was attending some things on zoom, mostly like a webinar or two. I would see stuff mostly by big institutions, mostly with no actual access, like no interpreters know, live captioning, or even actual transcription. This is pre-FaceTime. I don't even remember when Facetime started. Mostly with Zoom, what I'm remembering is some Zoom pre Zoom captioning and pre-COVID. And I remember lots of people posting…I was using Facebook a lot. I wasn't on Twitter yet. And people would post they wanted remote access and the best you could get, sometimes, was that they would have been a panel that was videoed, and sometime later it might end up on Youtube or an institution's channel, usually without captions or any audio description. Yeah, that's what I'm remembering. I mean for me, you know, I always want remote access with my economics. As the US poverty line went higher in dollars, my income hasn’t changed. I've been on Social Security since 1990. I think I've had about maybe a $100 cost a living increase in whatever that's been, 30 years. So the economics for me, plus my increasing fatigue, even pre-COVID, meant that I was always on the lookout for remote access options.

Remote Access to Archives

I mean, remote access options are hugely important to me, and not just to events, but also to things like archives. One of the things that I'm very unhappy about, actually, is that for my own archive, people can only get the catalog, the guide to the collection, online. They can't actually see anything. And according to the library, they're never gonna be able to see anything without physically going to San Francisco, and that wasn't my understanding. And that's probably just on my part. That's certainly not what I wish.

Aimi Hamraie:
That's really interesting. So you put your papers and probably other forms of documentation and an archive. And only people who can physically get there and afford to do that can access the materials in the formats that are there and first created are gonna be able to use it.

Corbett O'Toole:
So, I know this is inappropriate, and I want to stick it in anyway. When I first approached archives. Nobody wanted my archive. They said, “we'll send a student over and we'll pick one piece of paper”. I know that if you give them a spreadsheet, they love it, so Emily Nussbaum and I went through all my stuff and literally created a master spreadsheet with subcategories, and basically boxed everything up in baggies by the subcategories, and said, Would you like this? And they took it all, and so the guide is actually developed by me, with Emily's help, and it's pretty thorough. So it says, why is this picture related to this book or related to this thing?

There were so many barriers to getting any of our history archivally collected. And it was a workaround that I think gives remote access. At least someone could go online and say, here's the breadth of what's in the collection, as opposed to some…I don't mean to be offensive to archivists…but people that don't know anything about disability or queer life, or whatever, categorizing stuff in a way that wouldn't make sense from my perspective.

Aimi Hamraie:
Yeah, that totally makes sense. It's kind of like a community archive approach that we're like, do you know about what Fat Rose is doing?

Corbett O'Toole:
Yes.

Aimi Hamraie:

Like that, and it does make a difference when you say, “here are the categories.” That's something I feel like we could have a whole very interesting conversation about. So, okay, maybe this is a good time to shift into talking about the pandemic era. Have you participated in remote access or used remote access since March of 2020? And if so, what does that look like?

Remote Access Since March 2020

Corbett O’Toole:
So, because I had long COVID so early, and because for me it was a debilitating situation — I had pneumonia for the first 7 months — I switched pretty much exclusively. Like, I don't go in public spaces. I don't go into any buildings. I don't meet people indoors. So remote access has been literally my lifeline to the world, and everything from friendships like everything other than sex, is remote access for me. So I use it a lot, and I pay attention a lot to what is and isn't available. For me, the big shift happened when, in March of 2020, when the Longmore Institute started doing webinars with access baked in. That was a huge game changer, because now when I would see something online, I could post it on public social media spaces and say, there will be captioning, or there will be live transcription, professional transcription, live captioning, or it will be recorded, and the captions will be cleaned up.

That way of being accessible in a way that makes sense to broader disability communities was really important to me. I've been in recovery now eight years, and I do all of my recovery meetings in Zoom or online 100% of the time. I do a meeting everyday, so I've seen the kind of ways that different spaces have and have not embraced accessibility in relation to remote access, which systems have embedded certain kinds of remote access and which systems have made it optional. It’s surprisingly not related, in my experience, to resources. So, for instance, the Massachusetts Historical Society, which has a very large institutional budget, held a series of eight seminars on disability history topics, and only four of them had any captioning or access for people that couldn't hear. So, you know. Whereas other organizations will just build in either real time captioning or a professional sign language interpreter, or something else. So it seems to be kind of a matter of consciousness and commitment to disability, rather than necessarily institutional budget. But yeah, my life is a 100% remote at this point.

Aimi Hamraie:
Yeah, that makes sense. And when did you go on the road with your van? I can't remember, or the bus first?
.
Corbett O’Toole:
I went on the road, November 15, 2020. I got COVID in February 2020, Longmore Institute made their stuff accessible in webinar form and discussions in March 2020, a bunch of the world opened up in terms of, like, the recovery community primarily went online at that point as well because of lockdowns…so a whole world of information and work that I wouldn't have access to that had formerly been just: you have to go to this conference, you have to go to this place, suddenly became available. It was like it was a feast. It was such a lovely feast of just…I got to see speakers, hear panels, that I would never have seen or heard otherwise, and I say that as a person with the privilege to be able to access something that has no accessibility other than just being onscreen. A lot of it did not have access for people that needed audio description. There was almost never audio description, and very little captioning, or even turning it on, when they would later become available, the live captions.

Aimi Hamraie:
Yeah, so like the possibility of zooming in or doing a live stream gave you access, even though you were on the road and traveling and recovering, or like, I don't know, what the right word is for long COVID.

Corbett O'Toole:
Yeah, I don't either.

Aimi Hamraie:
But the process of, you know, experiencing your symptoms and hopefully getting care for long COVID, and it sounds like the volume of available opportunities increase, like there's a greater number of things and somewhere accessible or more thoughtful about what types of accessibility might be needed.

Corbett O’Toole:
Yeah. And the Internet, the Internet got cheaper, just being able to use an email or whatever got cheaper, having access to a Wi-fi signal became more available. Part of my journey in the nomad community is that I have 2 forms of online access, basically a hot spot on my phone and a hot spot that's separate from my phone on 2 different networks so I pretty much always have some kind of Wi-fi access, at least good enough for zoom. But I do my social life on Zoom, I do my work life on Zoom, I do my scholarship research on Zoom, I mean on the Internet, I am completely connected. Everything for me is only remote access. I don't go into libraries anymore. I do it 100% remote.

Aimi Hamraie:
In figuring out how to do that, did you figure that out yourself? Was anybody helping you figure it out like, were there other disabled people that you knew who were like, here's the best way to get Internet and your van, or anything like that?

Corbett O’Toole:
So it's kind of two separate questions for me. Because the nomad community is not location-specific, I needed people that knew how to think about Internet access in a non-location specific way. There's a thing called the Mobile Internet Resource Center. A couple of nomads started it, and they keep track of, what are the best deals? What are the best ways to go? And they have a network of providing very concrete advice. If you want this kind of access, here are the best resources. If you want that kind of access here, the best resource. So I depended on them in terms of which way to

go. They said, have two different provider systems. And here's the cheapest way to get this provider with the most amount of data and separate from a phone, so that for remote access. They were the most useful thing with disability access.

It’s been interesting, when I post something on — I still use Facebook primarily — when I post something on Facebook, I always say you know, because I'm pretty much only posting virtual events, I always try to say I'll find out what's the access level of the event. Is there going to be professional transcription? Is there going to be a sign language interpreter available? Is there going to be audio description? And I make a special access note, so people can know what the level of access is going to be provided before they sign up for the EventBrite webinar, whatever. One of the things I've become increasingly aware of, mostly through Cal Montgomery, is ways in which the ubiquitousness of Zoom as the panacea for everything is, in fact, very problematic for a lot of people. I recently encountered this in the recovery community. I was telling a friend about a meeting. I go to when they came to the meeting and I wasn't there that day, and they said to the host of the meeting, you know, “can you toggle the switch to turn on so close caption so that live transcription would be engaged?” and the host is like “I don't know how to do that,” and then just ignored them. And it was pretty, you know. It's pretty tacky, but because recovery communities are…it's a completely decentralized model, and each group is autonomous, accessibility in that community has been hugely problematic. I mean, hugely problematic. You can almost never get a sign language interpreter at any of the meetings. Access of any kind is not really built into the structure, so it's a place that has enormous barriers.

But even within disability events hosted by disability organizations, I mean a classic thing that Cal talks about, which I think is really, I swear to God one of us should do it. Maybe somebody in your world would do this, like they turn on the live captions for a Zoom Meeting and it's the usual, some good, some gobbledygook, and then they post that video with the gobbledygook transcription as the permanent record on Youtube or on the institutional website. And Cal’s like, “somebody should go through quoting the webinar and say, here's what was said, and literally just use the actual official record transcription.” So there's still a lot of barriers, and other people that use transcription like Google meet say it's a lot more accurate than Zoom, but everybody is kind of just,”Oh, I'm a Zoom person.” And then, of course, now, what's happening is, and I'm air quoting and being extremely ironic here, you know, “the pandemic is over, hahaha, and so we don’t need any of that stuff anymore, hahaha, and so we’re just not gonna have access.” And so what I've been experiencing is things I would want to go to have pulled back.

I consider hybrid hell. I've seen descriptions of how hybrid could be good, but I've never experienced a hybrid meeting of any kind that was actually well done. And more and more, it's just like, “we don't have to bother with zoom anymore, because if you really cared you'd come in person to this thing that's inaccessible to you as a person who can't be in a room with other people. As well as, we're not gonna provide any other accessibility, anyway.” So, from a cost analysis point of view, it seems very counterintuitive to me. However, it seems that, you know, though the mainstream world has decided that you know the pandemic over and Zoom is no longer as needed, and it's only if it's convenient for them, do they bother doing it. So, my experience has been, in terms of access to the outer world, it has gotten a lot smaller. Particularly in the last year, in terms of accessing that world.

Aimi Hamraie:
Do you have a sense of what happened that made some people think that pandemic was over, or to do this shift away from remote access during the pandemic?

Corbett O’Toole:
I don't understand exactly why. But what I've seen is this, even throughout lockdowns and stuff, there was this narrative that quote unquote, “normal” means in-person, face to face. And disabled people have been fighting this forever, because face to face is often the most inaccessible form for us, or the most expensive way to connect. I've seen that happen. I've seen the

“oh, I'm gonna get COVID, anyway, it’s not that bad.” I've seen these narratives emerging and becoming more powerful, that have seemed to me have seemed to directly influence it. “Of course we can meet in person unmasked, because Covid is not that bad.” “Of course we can meet in person, because it's quote unquote, “real,” as if there's some intrinsic like absolute value that in-person is real and digital connection is fake and well, “you people always needed special stuff anyway,” as kind of the narrative I hear around just about any of us saying, you know, Zoom is accessible in-person is not. “Well, you people always want quote unquote ‘special’ things, and we can't really accommodate special.” So you know, “haven't you heard that the pandemic created economic problems for us? And we don't really have the time, money, resources,” when really, it's really like “we don't care.”

But you know my writing, I've been saying for years, it's easy when you start from the perspective that you know they want you dead, and the world is set up as if you didn't exist. It's part of the narrative, I mean, it's heartbreaking. Yeah.

I wanna say one thing on the positive, if I can. One of the questions I get a lot. I've been on the road two years and four months. One of the things people often say to me is, “Aren't you lonely?” And my experience has been that seeing somebody's facial expressions, sharing this digital space, fills my need for human connection with them, for the communication connection, without any of the downsides of my body has to be more exhausted. I just have to show up for the time that I'm on camera with someone, and for me I have more time and more energy and more to give to the connection when I don't have to spend all my time and energy on other things that aren't involved in actually showing up and being connected to someone. And for me it’s been like, you know, the whole “is digital real…” It's not even a question for me. And it's not just because I have COVID and it's dangerous for me to be in spaces with people. It's actually satisfying.

Aimi Hamraie:

Yeah, yeah, it sounds like for you, it's like a really meaningful way to have social life and other types of participation. Did you feel that way before the pandemic, or is it something that, like, you've come to realize over the course of the last couple of years?

Just Accommodating Each Other

Corbett O’Toole:
I think because I kind of have always accepted… I've been part of disability community my entire adult life as my primary, both social and emotional community, and it always just…you know, I grew up in a working class family. My dad was a firefighter. So you kinda just accommodated each other, you know, when you did family gatherings. You did it at whoever's house had the most space, and whoever was available to take care of the kids did. It was like, there was this kind of almost intuitive…I mean, it was gendered and stuff. But there was this kind of intuitive, “we're just gonna make it work. We're gonna eat when everybody's kind of hungry. We're gonna accommodate each other.” I think somebody on the Internet says something like, “we're gonna be gracious hosts.” I think they used another word. But you know, “we're gonna be welcoming hosts” and…I lost the question. I was going there, and I just lost the question. Tell me again!

Aimi Hamraie:
Yeah, I guess I'm just wondering, you're saying that you really like having remote participation. Did you feel that way before the pandemic too? Has this been part of your life in an ongoing way?

Corbett O’Toole:
Thank you. When we do the, when we did the organizing for Beijing, and then the organizing for the queer disability conference, we kind of did it that way, you know. We just kind of accommodated each other. We met whenever, we did phone calls whenever everybody could kind of gather. We just kinda adapted. And so the digital part of it for me is just kind of an

extension of that like, how does it work. So, Cal Montgomery? I would love to Zoom with him, and it's not accessible to him, so my relationship with him is on the phone. I mean, we text to check in. And then, you know, I'll say you know, “is this a good time for calling?” and he'll say yes or no, and we'll talk on. It's kinda like, you kinda do what needs to be done for whoever you're with, and that kind of just being a gracious friend or a gracious connection. So having done it already, it didn't feel like, you know, where we used email with some people and phone with other people and in-person with other people. It just kind of felt like it’s just another tool in the toolbox.

Aimi Hamraie:
Yeah, I've heard other people say similar things, and this makes me wonder something: if you have a sense or experiences of whether there's a difference in how remote access or participation shows up in disabled versus non-disabled communities and spaces. Are they different? Do they do different things, are they used differently?

Corbett O’Toole:
I feel like…If we could pretend for the moment that disabled spaces means people give a shit about each other and give a shit about each other's access. You know I'm not gonna say, you know, I'm not talking disability organizations here. I mean, like human commitment to, and also awareness of, needs beyond your own individual disability needs. And again, in absolute terms, that non-disabled in this context means, you know, people that don't have connections to disabled people don't have awareness even, you know, it's just not on their radar. I'm trying to be kind here. Okay, sorry about that. I thought I had that turned off, the noise.

In my experience, disabled people know what it’s like to need access, need something that’s not in the built environment. And then the negotiation becomes almost like an internal discussion becomes, what do I need? Do I have to have it? How do I? How could I possibly get it? And do I have to involve a non-disabled person to get it? You know, there's like these layers of…so I feel like when we approach each other, like again, with my friendship with Cal. For most people I’m zooming, you know, like, can we talk? As means can we like face to face, and but with Cal, that's not what works for him. So it just becomes, that's part of our friendship is that we just do that. And I feel like the fact that we do that without big deal or a judgment, or whatever, I mean, that's just one teeny, tiny example. But like that's kind of the way I approach disability.

So I recently had a conversation — and since this is being recorded, I'm gonna speak somewhat in code, and you will know what I'm talking about — about somebody who was preparing for a gathering in the future, and they are inviting people to apply, and the application says you have to be available from nine to five, Monday through Friday, and some weekends, and I contacted them and said, “I find this extremely problematic and I'm not gonna share this invitation for applications, because I think there's another way to do it that would be more inviting.” And I think more inviting is, you're only gonna have a very small number of people actually coming together. Why don't you say, here's the meetings that have to happen during your time together, here's the resources that are available…And this group of you, there's a small enough group, figure out what your access needs are, and how you’re going to accomplish this. That seems doable to me when you have a finite group of people and a specific amount of time, and you want them to develop relationships and leadership skills anyway. That's my belief of how people in disability spaces can do things. And I think that the reason that the job was written as nine to five Monday - Friday, was because a non-disabled person was writing it, and they're sort of trying to say this is the expectation. But they didn't have the lived disability community experience, even though they have lots of other experience to kind of think and believe that you could say to a group of disabled people, here's what you got for space and time and resources, how do you wanna do it? I believe that that's easy to do, and completely doable. And if you say what the deliverables are, people will get it done.

That to me is like one example of thinking about remote access and resources in a way that's disabled versus a way that's not disabled. Not disabled feels like, here's the white man business structure, fit into it. So right now, if the white man business structure narrative is in-person meetings, we have to figure out how our bodyminds can fit into that. Whereas I feel like the disabled model is, what are our bodyminds bringing to this space at this time? And how can we accomplish what we need to accomplish with the bodymind we have in the virtual space at this time, the asynchronous virtual space, if that makes sense. I don't know if I was too rambly.

Aimi Hamraie:
Yeah, this is something I would love to talk to you more about in application to something else that I'm planning, too, because I what I hear and what you're saying is that there's an idea of like a normal or typical way of, doing things that's very standardized, and it sounds like what you're saying is that disabled people tend to approach the same objective or deliverables through flexible, or maybe, like, creative process, or something like that. I mean, am I summarizing that accurately?

Corbett O’Toole:
Yeah, It’s really a more organic process. It's like, the able-bodied model presumes that the bodyminds have to fit into a plan, and the disabled model is, the bodymind is where we start from, and how do we accomplish the plan with the bodyminds in the room? And I mean virtual, I don't mean room as a physical space, but as an in the available bodyminds.

Aimi Hamraie:
It reminds me of, you know, adrienne maree brown, who wrote that book, *Emergent Strategy*. There's a line in there that says, “there's something that only the people in this room can do. Figure out what it is, and do it.” And so that idea of like, yeah, it's emergent. It's not a free, given thing.

Corbett O’Toole:
Before you go on, I just wanna make one more point. When I saw the nine to five model, I literally thought, oh, this application is asking for the people with the least impairing handicaps. I saw that once on a job application, you know we don't discriminate on the basis of race, gender, or unimpairing

handicap, and I feel like you know, nine to five, Monday through Friday, is saying the people who can accommodate and for extended period of time, five days a week, every week, the most normative schedule, get to participate. And if you don't have a bodymind that can accommodate that kind of schedule, you're not welcome. And I'm like, no, if the plan is to develop disabled people's community and leadership, we need to have a model that says we start from where we are and believe that we can accomplish, and it doesn't have to be in a normative way, you know. Kind of the basic Disability Justice type principles when Disability Justice meant the real thing, you know, like Sins Invalid stuff, and not, “let's take all the race and gender and queers out of it.”

Aimi Hamraie:
I'm wondering if there's something that you might say about exactly this thing that you're talking about in terms of, like, the hierarchy of disabled people, and how it shows up around remote access or the denial of remote access. Is there something about a willingness to provide or facilitate remote access that intersects with that in some way, or does remote access create those hierarchies in some way? I don't know if there's an answer to this. I'm just kind of wondering.

Corbett O’Toole:
Well, I feel like nobody wants to tell me the truth about what they are providing, and everybody wants to pretend that what they're providing is what's quote unquote “right and acceptable.” So whether it's a disability organization that maybe provides a sign language interpreter, but no audio description and no live transcription, they're like, that's enough. And so if someone comes along and says, “can I please have facilitation for this meeting, or can I please have something else that someone might need to participate?” Or, “can we take breaks longer than five min to go to the bathroom, or can it start in the afternoon instead of the morning?” They're like, “No, no, no, that's not really…” There's a minimizing of…it's like, the schedule is set, and the bodymind has to fit it, and remote access embeds it in way that it's being used. We bring a lot of privileges with us. So people like me who can see and hear, we create Zoom Rooms where for people

that can see and hear and can do a certain kind of schedule in the day, and that means that people that don't see or hear well and can't do that schedule in a day or that amount of time, info load, or participation load, don't get to participate. And we don’t start with, “how can we, as a group…let's gather and let's talk about how we need the space to be, and then proceed.” We basically say, “this is what's being offered, end of discussion, kind of like school, you know, or the business meeting; show up, this is the way it's gonna be, and there's no access for anybody that can't do it that way.”

So it's a new form of it's a whole form of privilege and discrimination that does not get named, and does not get owned and has no accountability. It's almost like when we had in-person meetings. If you were very lucky, the poster might say, “if you have access needs, contact so and so.” But remote access meetings don't say, “if you have access needs, contact so-and-so,” it's just like, we're pretending as if it's accessible when it's not. It’s always, access for whom?

Aimi Hamraie:
Yeah, I've noticed, and conversations that I've had, and I think this is part of what shape this project for me was that I talked to a lot of people who assumed providing any kinds of remote access because of COVID meant that it was accessible, and the critiques that Deaf people have brought forward about online conferences, for example, were just ignored as kind of like “Oh, well. That's just going too far.” And that's usually coming from non disabled people. So I've been really interested to just learn from people who are in disability culture about why those additional considerations are not actually additional. Like, they have to be built in and part of it in a similar way that we would talk about, you know, accessible buildings. Like, a retrofit is not as beneficial as something that is built-in, for example, and it seems like you're pointing to differences in what people think to do or know how to do, in addition to some of the inaccessibilities of the technology itself, and the ways that it has to be adapted.

Corbett O’Toole:

And also that any request for access in remote access situations is considered like bitching and disrespectful, and “you're being ungrateful” and “don't you know that we've met the standard” as opposed to, “oh, I never thought about that! I wonder how we could accomplish that. Do you know how to accomplish it? Who might know how to accomplish it?” You know, there's no welcoming of difference. There's a way in which remote access is like Zoom is God. God is good. End of discussion.

And you know, we have to have space, you know, all bodyminds are not gonna fit into one mold, and we have to have space to have those conversations. And right now, whether it's the disabled community organizing a zoom or non-disabled community, there are enormous barriers, and nobody wants to talk about it. And talking about it is like, I’m thinking about Sara Ahmed’s, “the complainer is the problem.”

Aimi Hamraie:
Hmm, yeah, that's a really good connection there, too. Are there any other interesting things about remote access that you want to make sure that we talk about or get on the historical record?

Corbett O’Toole:
I feel like framing remote access as only for disabled people, is very problematic in terms of this, in terms of how the future moves forward. We always know that this is disability access is always viewed in the non-disabled world as extraneous and special and not needed, so by making remote access be an accommodation as opposed to a form of communication, the way that telephone and the cell phone and the Internet become vehicles for communication, we kind of reify the idea that it's optional. I think that that framing has not been challenged very well, and in fact, lots of disability groups kind of feed into, “we need it, we need it, we need it,” as opposed to, “how can all of us benefit? Like, why does the telephone provide a different kind of access than the Internet?” And I feel like that kind of framing is not in the public discourse, and it ignores…all the people that, you know.

I have these conversations with people all the time of, if you have a little bit of money, provide live transcription, like professional, for $125 an hour, because more people can read texts that need audio help than can read American Sign Language. So if you're gonna do one thing for a broad audience, having live transcription in English is a really useful tool to consider in your toolbox depending on who your audience is gonna be.

And people are like, “huh,” but they get like goody points in their head, like, “I'm a goody-point person because I hired an interpreter, even though I did no Deaf outreach, I have no connection to Deaf community, and nobody is here,” whereas a lot of people can lose their hearing as they age, and lots of people could really use that transcription support.

Aimi Hamraie:
Yeah, that makes sense. Things that you might know from being in disability community that people wouldn’t know if they’re just checking the boxes.

Corbett O’Toole:
Quite frankly, that's something I know from recovery community, where lots of people are like, “What? Huh? Can you say that again? Huh?” Because there are people that are not part of disability community, but need access, that we typically have siloed into disability discussions when really they're just kind of gracious host things: Does everybody have access to, in this case, what's being said?

Aimi Hamraie:
This reminds me, I wanted to ask earlier: do you have a sense, or can you describe what has happened with remote access in recovery communities? Like, was there remote access before the pandemic, what has been happening during the pandemic?

Remote Access in Recovery Communities

Corbett O'Toole:
So, I'm trying to figure out how to navigate this within the…Okay, so the recovery community, I'm most familiar with is one that started in the US in the 1930s. So within that community, from the beginning people were having recovery experiences through the mail, and later through the telephone, and later through email, and all that's easily available online. You can look it up from the perspective of that community, and those things have been there literally since the very beginning of the organization, in part because people were really spread out, and in part because some people were not able to go to physical meetings because they were so few and they were so far away. So that trajectory has always been there. In the more, if you will, modern digital age, there's been a community of people who were in technology outside of their recovery communities that have started to explore, how could recovery communities reach more people, particularly in rural areas, or for people for whom going to in person meetings wasn't useful. And there's an entire group, an entire listserv and annual conference on technology within that specific community, and more recently, one of the things that happened with the pandemic was, in a lot of locations…according to the CDC, The Centers for Disease Control, recovery meetings because they are not professionally-run are “social gatherings” and did not meet the criteria for the exemption to in-person, so they had to shut down. And some groups did, and some groups didn’t, and that’s a whole other story.

So a lot of recovery meetings went online, and went online specifically on Zoom, and almost none of them provided any accessibility. It's extremely rare to find to find any accessibility in that community, and as the framing of the pandemic and the need for remote versus in-person gatherings has shifted, so has it shifted in the in-person community, and people that had always gone to in person meetings have literally used phrases like, “I want a real meeting.” I'm saying that in quotes, they mean an in-person meeting. And so there's been a lot of that — no masking mandate, no, whatever. But one of the things that's interesting that emerged from this is that some meetings went on Zoom and have stayed on Zoom, and there's an entire national network. In fact, a woman from Australia, and a woman from the US started a 24/7 women's meeting that has been going now for over 2 years. 24/7, around the world, in English for over 2 years. So there are meetings like that, that are just virtual meetings. They always have, and they're built around Zoom, and they do use Zoom as a platform.

So more recently, that recovery community has created… because the structure is bottom heavy, every group is independent and information feeds upwards. So decisions that get made are kind of inverted; decisions get made at the national level completely based on input from the local level. But people who were Zoom-based had no geographic location. So they recently created an entire… they call them intergroups, an entire intergroup that is literally just for Zoom-based meetings. So they would have representation and decision-making throughout the organization, throughout the organizational structure without being a location-based service.

Aimi Hamraie:
Very interesting.

Corbett O’Toole:
So, there's still a lot of tension. The online meetings have diminished greatly in scope, but many, many people who, completely unrelated to disability, would never have thought of remote access, but have discovered they can take care of the kids and stay at home. They don't have to worry about public transportation and stay at home. They don't have to worry about a snow day and stay at home, and can still participate in a regular basis in their own recovery communities, and they all do it online.

Aimi Hamraie:
Oh, interesting, definitely, gonna follow up on this and try to learn more about what's going on. And it sounds like there are maybe some privacy considerations around…

Corbett O’Toole:
Well, the fellowship, the group I'm talking about has an anonymity requirement, but I'm happy to talk about it not on camera with you.

Aimi Hamraie:
Yeah, great. Thank you so much, Corbett. This is all so helpful and wonderful to learn about. I really appreciate the thoroughness of all of your comments and what you shared, and also all of the kind of historical range of this, I think, is really interesting to get your perspective on all of it together. So really appreciate talking to you.

Corbett O’Toole:
I always love your work, Aimi. I'm always happy to participate in whatever you're doing. So, thanks for asking me!