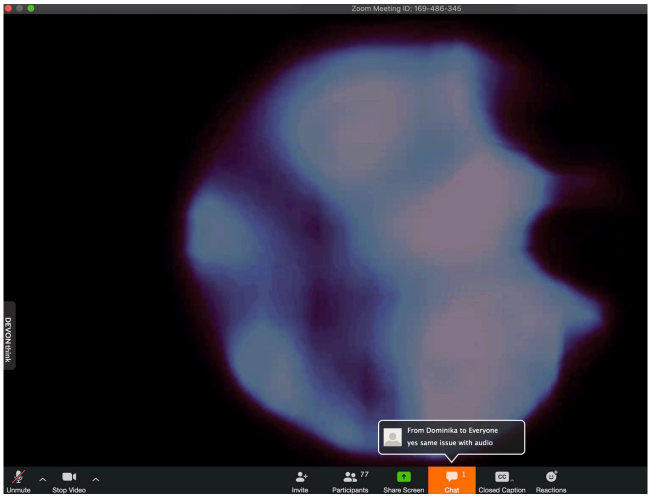

From Dominika to Everyone
yes same issue with audio

HECTOR RAMIREZ

Interview Date: March 20, 2023

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

KEYWORDS

2023, 2020, 2015, advocacy, autism, COVID-19 pandemic era, disability advocacy, disability rights, hard of hearing, healthcare rationing, HIV/AIDS, Medicare, mental health, policy, queer, recorded meetings, stakeholder, task forces, vaccination

IDENTITIES GIVEN

Chiricahua Apache, Mexican, bicultural, they/them pronouns, person with a disability, disabled person, autistic person, hard of hearing person, mental health disability/psychiatry disability, Two Spirit, nonbinary

LOCATION

United States

Introductions

Aimi Hamraie:
So I'm going to record. This is Aimi Hamraie, speaking on March 20, 2023, and I'm here with Hector Ramirez for an oral history for the Remote Access Archive. Hello, Hector!

Hector Ramirez:
Hi, I mean, how are you doing today?

Aimi Hamraie:
I'm doing well, I'm excited to talk to you. So to begin, please tell us your name, age, and where you currently call home.

Hector Ramirez:
Yeah. My name is Hector Ramirez. I am – actually my birthday was just a couple of days ago, I just realized that. So I'm not the same age that I'd normally say. I'm 48 years old. I am Chiricahua Apache and Mexican. And I live with my family, in the unceded lands of the Tongva people, here in what they call Los Angeles in Chatsworth. And my pronouns are they/them. I'm a person with a disability. I have autism. I am hard of hearing, and I also have a mental health disability – psychiatry disability. And I am a disability rights advocate.

Aimi Hamraie:
Great. Thank you so much. And, so the next thing that we'll do is we can both do a brief image description for the video. If you would like to keep the video on. So I am an olive skinned Iranian transmasculine person. I have short, dark, curly hair and blue aviator glasses, and I'm in a yellow room with a plant behind me. Would you like to do an image description?

Hector Ramirez:
Well, absolutely. Absolutely. And here's an interesting thing about visual descriptions. I love them because they're a great accessibility thing for a lot of folks, but I've actually been told by many of my blind friends that they don't like visual descriptions. But I do it as an accessibility feature for those people that really appreciate it like myself. So, just in consideration from those people that don't find them useful. So I'm actually sitting in my – in

my bedroom. But I'm using a Zoom background, and it has a picture of Los Angeles County's skyline. And we recently had snow. So the mountains in the back have snow, and you can see the contrast of the downtown city. You can’t see it in the picture, but the beach is right next door, so we kind of have it all. And, and so I like using that as my screen background.

I'm wearing an orange shirt because orange is my favorite color. And I have long hair, which I pull back in a ponytail. And clean shaven – I think I have a little bit of goatee that's been growing for the past month and a half. And I am a very good looking, sexy, smiling guy all the time.

Aimi Hamraie:
Excellent. Thank you. So you started to answer some of this before, but, what are the words that you would use to describe your race and gender?

Hector Ramirez:
I'm Two Spirit, and so I am part of the nonbinary community. I'm both male and female or neither. And so I previously had used “gay” to identify my sexual orientation. But I really connect to more of the bi community. So I really use Two Spirit both for gender and sexual education orientation. And I have been using they/them pronouns for quite awhile. And it's part of my community and my family expression.

I have a very intersectional background. So I was born in Mexico. My family is both Mexican, and Native American, both in the Apache community in the United States and the Apache community or Indigenous community in Mexico. So we're bicultural that way. But my family and I live here in Los Angeles County, and to the tradition of relocation. So we have a large community here in Los Angeles County. And for me, that really allows me to really both have a large Native community – because we have the largest Native American/Alaska Native community in the whole United States here in Los Angeles County. And we have a significant representation of tribal communities, and with that also allows me to also have my disability identity.

I was diagnosed when I was four. I come from pre-ADA [American Disability Act] law. And so for me that has also been a journey. I originally was originally diagnosed with child schizophrenia, which was the original autism diagnosis, and my mom was the typical “refrigerator mom”. And so you know those diagnoses were not just for you. They were for your family, your community as a Native community person as a single mother, you know. I ended up being removed from the family because of that, that was the law. And I didn't come back to my family until later on.

I got to go to high school right when special education integration was happening. And so I've been very active in the disability rights community and the LGBTQIS2 community and the Native American community, the immigrant community, definitely the Hispanic/Latinx community. Because those are…kind of like part of where I live, but also what iI looked like, or what others see.

Aimi Hamraie:
Great. Thank you so much for that. And so just to get a little bit more into disability. I'm curious when–when people refer to you, how do you want them to describe your disability or your relationship to disability? So, for example, do you use terms like “person with a disability”, or “disabled person”, or “autistic person” or “person with autism”? What is your usage?

Hector Ramirez:
Oh, yeah, it's progressive, you know. And so right now I really am centered as a disabled person. It's more of my social-cultural. But I tend to use “person with a disability” primarily because it emphasizes – when I use it I use it in spaces where I'm trying to really use ah – take up space as a disabled person. But also to really point out and ask for disability rights under state and federal laws, and where we are a protected group of people as “people with disabilities”. And so I use it primarily–that term in that [indistinct]. But in general I'm a disabled person. I'm an autistic person. I'm a hard of hearing person. I'm a person with lived experience, a person with a psychiatric disability, I’m a, you know, bipolar individual. So it's really more as a “disabled person”. It feels more in solidarity with everybody else.

Aimi Hamraie:
Great. Yeah, thank you. And it sounds like–like because you mentioned that “disabled person” is a social and cultural identity, do you consider yourself to be part of disability community or disability culture?

Hector Ramirez:

I did. Well, yeah, I don't think you really can't. Especially if you're from an equity-seeking population, or like a community of color or queer person. You know, because it's one of the things that's kind of intertwined with disability culture is just, you know, the continual fight for survival? And so, you know, I grew up around people with disabilities, I went to school with disabilities. I've lived on the streets with people with disabilities. I've been locked up and institutionalized. And so it's family, it's community. You know, people with disabilities have a shared culture. I have friends that do similar work that I've connected over the years. But we just lost, you know, definitely one of our leading forces in the disability rights movement with Judy Heumann’s death. And she was somebody that I got to know. And I think…yeah, I think I would like to believe that I'm part of the disability community.

Aimi Hamraie:
Yeah, great. Thank you for that.

Hector Ramirez:
Actually – yeah, what am I saying?! Yes, I am. That was kind of an, I don't know, are you like, “Am I, really?” I've never really thought about it, you know. But I don't have a membership card, I'm still waiting for it in the mail.

Remote Access Before COVID-19

Aimi Hamraie:
Right. I love your response because it also just like, has so much thoughtfulness and nuance in it, so thank you. So, now we'll shift gears to talking about remote access, and I'm curious. First, we're gonna talk about the period before the COVID-19 pandemic, which is a pretty long period of time. But can you think of times in your whole life when you participated in things remotely as a form of disability access? And if it's helpful, I can give some examples, but you can really take this prompt and be as creative and expansive with it as you would like to be.

Hector Ramirez:
Well, yeah. So one of the things that I do is I do policy work, you know at the at [indistinct] Los Angeles, so I do a lot of policy work at the city and county level. And then I was – I also do it at the state and national level. I

sit on the board of directors for the National Disability Rights Network up in Washington, D.C. And…we are a membership organization, that – this comprises protection and advocacy agencies from every single US state and territory. And so they all do disability rights work. And so before the pandemic, I would be doing a lot of traveling. Both, you know, downtown, I was – which was hard, because the traveling was something that's just long just getting there for like, half an hour meeting, you know, or something that could be taken care of in an email. It was a lot of that.

And so I did a lot of that. A lot of that. Not as much as I've done since the pandemic. I thought I did a lot but I was actually just doing a lot of traveling. I did it often – I did it because there weren't accommodations for me to do it remotely. Everything that I could do was typically over the phone, and there were times when I would just do it over the phone, and I would utilize some of my accessibility features that I had back then. And they have improved since the pandemic. But, before, the only option that I would have was to use a TTY [Teletypewriter] service or an ASL [American Sign Language] service, to be able to join by phone which was very, very challenging and very expensive. You know, even to, like, join like county board meetings or mental health meetings. And so I would have to, you know, do traveling. And that was before the pandemic.

But accessibility. I did have it because I come from academia. I have a background in communication, psychology, and even chemistry. And so…I had used it in classes before Zoom was there before, and I loved it. You know, cause it had that option of having better sound, first of all. It had that particular feature, and it was able to add other elements, because I could have, you know the CART [Communication Access Real-Time Transcription], or that's how I was able to interpret remotely as well, and they could add this additional thing. And so that was, that was happening in academia. And you know, before.

And so I had a familiarity with it which was really good. Because when the pandemic hit, I had just been appointed to our state governor, Governor Newsom's, behavioral task force. We were going to be redoing Medicare, Medi-Cal for our systems, and I had the opportunity to be appointed as a stakeholder of a senator. Because I was also on the board of directors for Disability Rights California. I do a lot of disability rights advocacy work. And so I get appointed to this, and I remember I flew to Sacramento on the day that we had confirmation on our first community transmission case for the whole country. And he was there, and we had been following it along, thinking of possible scenarios, and we already knew how it was going to hit our disability community. We already knew, because this is not our first pandemic, you know? We've had the AIDS pandemic, H1N1. We've had multiple pandemics, especially like I said, if you're part of equity seeking populations, disabled, Native American, queer. You know. We've been dealing with AIDS epidemic as Native people. We're dealing with continuous epidemics. And so we already knew patterns of lack of access.

And so I remember, I think that was my last in-person meeting, being in Sacramento, and I flew back to Los Angeles, and I mean I used to fly at least twice a week. I mean I was like a road warrior. I was like flying twice a week, and you know something else. And I remember on the sixteenth of March, everything stopped. Everything stopped. And we had already been pushing for certain things to be able to be done remotely.

Whoa! - Hold on just a minute. My praying mantises just hatched!
So I have praying mantis hatches all over my – can you pause – I literally have –

Aimi Hamraie:
Yes, yeah, please! Please deal with that!

Hector Ramirez:
Okay, well, how did they get out?

[Aimi Hamraie is laughing in the background]

Hector Ramirez:
Okay, I have hundreds of praying mantises. I'll take care of this in a minute. I was like, why is this moving here? And I just got it. How weird. It pre-hatched! Beautiful moment!

Aimi Hamraie:
That is so beautiful. Also, it's like the spring equinox today, and…

Hector Ramirez:

I know!! It's – okay this is gonna be interesting. Yeah. So I'm in my bedroom, and I have my desk, and it's now covered in praying mantises, so let’s see. [Audio becomes more broken as Hector switches to moving camera and moves away from the microphone.] I’m gonna turn off my…it is absolutely bizarre. I don’t know if you can see them?

Aimi Hamraie:
Let's see, where should I be looking?

Hector Ramirez:
The white box.

Aimi Hamraie:
Oh, like, okay, yeah. Yeah. Oh! I definitely see some things moving around they’re little praying mantises.

Hector Ramirez:
Oh my goodness gracious I can’t handle it.

[crosstalk]

Hector Ramirez:
[indistinct] I’m going to fix my camera. [Hector comes back on screen and audio becomes clearer.]

Aimi Hamraie:
That's extremely exciting, congratulations!

COVID’s Impacts on Disabled Lifestyles

Hector Ramirez:
Thank you! Oh, thank you. Okay. They didn’t close this tight enough so they got out a lot of content at this. Okay. But anyways. So, you know, the pandemic hit. And. You know it was. It was a reality. It was – I was working literally every day? Around issues of access. You know the civil rights. We were inundated with, with work. The first thing right away was the stay at home order. No, the first one was like the space. And I was also volunteering at the weekend, so I used to volunteer at a food pantry you

know, and it was like a once a week thing. The thing that I knew was, food was gonna be an issue for folks. Particularly people with disabilities. And so I remember, I started working at the state level to work in food pantry work. And so I did that. Then we…we realized that every single issue impacting – every every little thing around people with disabilities was going to be impacted and none of it was in a good way.

And so it was…really weird, because it was – I knew just how difficult it was gonna be, but I was stuck at home. And that was all hard as a person with a disability, with autism. As an autistic person I had worked really hard on my socialization skills. I would force myself to go out and just be around people. And now I didn't have people around me, and for a little bit it felt good. But then it felt like I was back in an institution and that was the weirdest thing, because, you know…it felt like the community had been taken away. You know, “you can't go there”, “you can't go there”, “you have to stay here”. And even though I knew it was for safety, and I would tell myself, it really felt, almost like I was back in an institution. And that was a really difficult thing.

And I remember that's when I started volunteering at my food pantry more and then making masks. I started connecting with other activists, disability activists across my county who were feeling the same way. And they realized that they had forgotten all about us. And so we were making, you know, YouTube and Facebook groups on how to make, you know, hand sanitizers. I learned how to make hand sanitizers and teaching people to do that. Masks, how to make masks. We started with socks, and you know, because we didn't have access to PPE [personal protective equipment]. And you know those sorts of things and trying to do groups.

And so remote access…became a tool of survival? And…those of us that had access to it because we did have an additional divide from a lot of folks, that space for privacy or to do that. So those of us that were really doing it, we just started supporting each other. Twitter was how we found out how things, where things were happening, what things needed.
And you know so when I would go to my meetings and I was able to really provide about, provide a lot of that information. But having had experience using Zoom before or Skype, I knew how to better manage this. And so when I was having these meetings with other people, not only was I better able to communicate the needs because I wasn't struggling like a lot of

folks, I could also really use it more of a tool, to really advocate. And so I noticed that a lot of other folks, the similar folks were doing, Alice Wong, you know, and I really…I don't know, I just echoed, and we follow each other, and you know, and we knew, because we started to see family and friends dying of COVID right away.

And you know my family earlier on we lost our aunt right at the beginning in April. And we saw the isolation of the hospitals, the lack of oversight of disability rights, both to be able to go to meetings and complain and say “this is happening to us” was just astonishing. You know, we couldn't really look out for ourselves in hospitals. And so, it really not only became an opportunity to like what we're doing, but also to really point out how we were being left behind. You know, when, things like the vaccine came out or was being developed, I actually volunteered to be one of the test subjects of one of the vaccines earlier on, because I wanted to make sure that when it came out, that people with disabilities wouldn't be left out, because that always happens. You know? I wanted to make sure that autistic people wouldn't, because that's always, you know, “vaccines cause autism!” And I was like, “no!”, you know.

It's…I don't know it really…It really became a necessary tool and sometimes I feel like I'm – yeah I'm still doing it, you know. And so it, it – went from traveling every day to, you know, being in front of the computer almost all day, from meeting to meeting, reading, reading, writing, writing, communicating, you know, and I did it at home around my family. Well, we were happy. But we were sad. But we were sick, you know, my brother, I had a brother who was younger than I was. He was also with his parents, and he had lived with – he was living with HIV/AIDS. And you know he knew, he knew that he wasn’t gonna make it. He knew that the vaccine wasn't gonna come out in time.

And you know he lived independently – he had been homeless for like over a decade, he had just managed to be able to get off the streets, and, you know, live the way he wanted to, and – but he couldn't go out to buy groceries. The nurse couldn't come in to see him, and so he started developing opportunistic illnesses that we hadn't seen since the eighties. And we knew what that meant. Our whole family had lived it. And so he came, and he stayed with us, and he would do advocacy with me. You know, when he was sick, and he did it literally in this room where I am at. I guess I'm actually in my room, you know. And he did it until the day he died from COVID. While using Zoom, you know.

Digital Access as Documented Testimony

Hector Ramirez:
But I think that was the thing that allowed us to really, perhaps fight for things, because we were able to really get our governor to change policy, because in California we were, we were pushed back in the priority list from January until March. Even though we were part of the COVID task force and advising, and you know, they didn’t listen to our recommendations. But I think that's one of the things that we have been able to really hold our leaders accountable, because these meetings are recorded.

Aimi Hamraie:
Yeah.

Hector Ramirez:
And so…I think that's perhaps one of the other things about a lot of the meetings that we've been able to do remotely is that we have testimony. Pleas, recommendations from people that use this as an advocacy tool until the day they die. You know we have this pandemic documented in ways that we weren't really aware was gonna happen. And I think that's one of the ways in which the disability experience has really been documented like never before, because of COVID.

Aimi Hamraie:
Well, first I want to say I'm so sorry for all of your losses and your family, and I'm also just…so sorry for our whole disability community and the ways that people have been excluded and left behind in this whole process, it’s so painful and awful. And I'm curious to hear you talk more about that documentation you were just talking about. So where…like, who is doing that documenting and like, where is it?

Hector Ramirez:
Well, you know I'll – the localities, so localities that have been utilizing, you know, Zoom, Microsoft Teams – what other platforms – Skype, many of them, have kept them. Have kept the actual copies of it, either because of

the Brown Act, state or city coast. So I know here in California, we actually – I started to keep them all, the actual copies of them with the video inside. Before that was done we have audio recordings of them as well, because they were kept for accessibility purposes, but also for notekeeping purposes, to assist.

And then we also have for a lot of meetings, CART transcripts. Which are like full text of the meetings, and for some you have all of them. And that has really been the push, not necessarily to keep a record, but for accessibility purposes. Which has been one of the biggest fights that has really leveraged a lot of never before seen progress as far as accessibility. Which is one of the things that I am currently working both at the county and state level, to be able to ensure that accessibility is maintained, as you know the emergency right now recedes, and people go back to meetings.

I think one of the things that people have both realized the value, definitely. You know how difficult sometimes it could be to join certain meetings? Some platforms are more accessible than others, some meetings are easier to join definitely than others. But I think a lot of first – for government stakeholder purposes, like there's some funding streams that require…agencies to have stakeholder participation. And so, Medicare, MediCal, Affordable Healthcare Act, SAMHSA [Substance Abuse and Mental Health Services Administration], you know. Those are some of the big funding sources that require that people engage with the departments and definitely engage with their city officials. And so that documentation is there. And I use it a lot, because, you know I use it as examples of how, you know, public meetings that are open to the public, and before the pandemic had significant amounts of disability access needs that was never really met.

And I used to be a commissioner here in Los Angeles County, for the Department of Mental Health, which is the largest public mental health system in the world. And I could only do it for a couple of months, and I stopped because, as a hard of hearing person, in Los Angeles County back in 2015, I couldn't get captions. I couldn't get CART, as a commissioner. And I couldn't hear what people were telling me.

And as a person with a disability, I'm telling you, in the biggest county I couldn't get that. But there was no documentation oftentimes to prove it.

Now, when we have our public meetings done remotely, we – the ADA, and you know, disability meeting guidelines were never rescinded during the pandemic.

In fact, in my mindset, and many others, it was actually mentioned that during the pandemic, those requirements were not only maintained, but they needed to be monitored. California was one of those, and so, you know, when that meeting didn't have captions, when a meeting didn't have sign language interpreters, linguistic accessibility has become a new thing as well, priority for us, ensuring that non-Spanish speaking folks have access to that. Plain language has been one of the other things that we have been requesting. That's often times in these meetings we get materials that are very complex to read. And because, you know, this needs to be accessible to the general public, that means also that anybody, regardless [indistinct].

So that’s a big thing, it's almost getting to my spiel, because it's my elevator pitch. But you know, things like that, and definitely, highlighting the need to access, you know, traditional platforms, but also to equipment and broadband as an accessibility need for folks. Because we know that more people have been able to utilize remote platforms for medical services than before. It's more cost effective for a lot of communities. For some individuals this has facilitated a variety of other services, but in the government sector this has really facilitated and increased the public engagement. Sectors that are elected officials and government officials need, you know, to make those necessary decisions, especially during the pandemic, when decisions need to be made fast, and you need to have that input from the community. This was like a really good thing. You know. People being able to join remotely by phone or by zoom and being able to actually listen or participate.

It has allowed people, and our elected officials to hear from folks like never before. Like, here in California we're tackling homelessness as a state of emergency crisis declaration. Because, you know, I think folks finally listen. There's a difference between listening and hearing. And I think accessibility in platforms allows our elected officials and government officials not only to listen, but to hear us better. And I mean definitely does. But since the pandemic I’ve been able to travel less. And join more space than ever before.

And I mean I'm part of a lot of different task forces. And I think part of it was for my mental health, but I think you are so out of survival, but I think more than anything it’s because I could do it. I was able to do it. I had access. And you know I fought like hell for my captions. I fought like hell for ASL in every space that I would go in. And I was surprised in how many spaces I would go in that were not accessible, and they didn't think that they were accessible. And I hated the fact that as a disabled person I had to go into these public or government spaces all the time and fight for that, when that was not the purpose of me being there. And oh, my gosh!
It was just – that was like the worst thing for my mental health and my physical health. But it was just – everywhere that I was going, you know. People didn't understand that.

Aimi Hamraie:
Hmm, so I wanna just summarize, or what I heard a few of the things that you said that were interesting and I've never heard anyone say before. One is that there were – because accessibility was built into these meetings, and so there were recordings and transcripts – it better enabled people like you, disability activists and advocates, to actually advocate with, you know, local and state governments and possibly other entities, because you had these conversations documented. Did I get that right?

Hector Ramirez:
Oh, no, that's quite true. I – you know, and we actually – like I’ll give you an example of the impact. We did secure the Department of Mental Health. We just got a new director of mental health. The first woman ever, Asian woman. Before that we had a director who didn't really understand the disability community, and oftentimes…

But one of the things is like, in public meetings sometimes people would say things that like, “Did I hear you say that?” And they're like, “Oh, no, no, I didn't say that!” Or like, “I heard you say this in your testimony, and I’m really concerned because it contradicts something” and you know that would always…but with these meetings, not only was it more clear and it's like, “Wait a minute. I just looked at the recording, and you said something else”. Or…we some…a lot of like blatant examples of discrimination in both statements and practices. And…there were other people in the meetings that could see it.

So it wasn't an over exaggeration, and I think more than anything, other people when they were coming into these meetings, they learn about accessibility, or making sure that spaces were accessible. And really considering that, I guess a lot of folks, you know, they’re just coming from home, and I think a lot of people don't realize that we were also coming from home. And many of our homes were in crisis. Many of our homes, you know, were in the streets. And we were – we were literally coming where we were. There were a lot of people in institutions. We had people joining in from state hospitals, you know. We had people literally calling house lists on the streets, on rainy days for our meetings. And in their cars. And you know, it allowed to not only see people, but disabled people where they were, but also it allowed the general community to see us in a way that perhaps others have never seen.

They saw our abilities like they've never – they saw our ability to not only engage, but to really contribute and be a significant asset, like we've always said – than ever before, because we were right there in their faces, you know, we were so close. And you know, that has had that particular impact. And it has helped a lot of folks with disabilities get hired like never before. I've like, wow! These past two years I've seen like a lot of…a lot of opportunities for folks that I had never really seen. And I think this has helped to highlight that. But I think it has also helped to highlight the inequities we're facing.

Aimi Hamraie:
Yeah that’s really–that’s so interesting to hear. And it sounds like to…something that you said that I've heard other people talk about is that the ability to participate remotely meant, for you and other people, that you could even do all of these things, go to these meetings, etc, because you didn't have that transit time, and –

Hector Ramirez:
The car. You know there –

Aimi Hamraie:
Yeah.

Hector Ramirez:

It's, you know, especially when you're doing like state or federal level advocacy. The cost is significant to do it. If it's, if an agency doesn't sponsor or reimburse, it is significant. Before the pandemic, like in Los Angeles County my peers and I we’re like, I kid you not myself included, we would collect our aluminum and we would collectively, like, save it so we could pay for our bus pass, you know, to go to meetings. Or we would share lunches with each other. Because the travel time between here and there could take like three hours, and there was no water or food there, or a bathroom on the way. You know? It made it physically, mentally, really inaccessible for disabled folks to really participate in these spaces where decisions are being made about our lives. And hold on. But “nothing about us without us” means that we need to be wherever those conversations are happening.

And these platforms allowed that to really happen. Like I was able to be in meetings with my governor, with my mayor, you know, with my board of supervisors. You know, I was able to jump in and on task forces around the state. You know, one meeting after another – that means it's a lot, a lot of accessibility, you know, and it was also very exhausting. As you didn't know sometimes what hat you were wearing. Or you would go from one meeting to the other one, and you would be in one mood, because you're always fighting for accessibility, you're starting another one, and you're like, AHHH! You can't even take a break. So while I had these benefits, it also had those particular kinds of things. Sometimes I feel like I'm just watching the longest television show, on Netflix, on my computer. You know. And – but I'm in it for some reason.

COVID, Access Trauma, and Ongoing Frustrations

Aimi Hamraie:
Yeah, yeah, so that's so interesting. And it's like, it's helpful to hear about these really tangible, you know, like resources that were required to do these things, that then having remote access, made possible to do with a different set of resources and technologies. So one more thing that I wanna talk about that you said that was really interesting to me, and I was kind of piecing it together from, you know, the life history that you shared earlier in our interview and then something you said a little later was that it sounds like as a child, or as a young person you were institutionalized. And then,

when the pandemic started, and this isolation came back, you felt like that kind of institutionalization and social isolation. Again. And so I wonder, do you – is there anything that you wanna share about remote access from the time of your life when you were institutionalized? Was there anything that was happening or not happening during that time?

Hector Ramirez:
You know, being institutionalized earlier on really meant a complete shutdown. Or being – that was the – it was being warehoused away. And…I always used to dream about what life was outside. I had, you know.
I would see some TV or magazines, and I thought that I had no idea what that was like. And I would…I think I did disassociate myself, and just think that I was dreaming that I wasn't there, and I think that came back a lot, and I still struggle with it. That I feel that I'm still back there, and this is all just a dream. Because it has – it felt…it felt that isolating, even though I wasn't alone. But it's just because it was just such a…it was just such a major shift in routines. Big, big big major.

And…my life was all about routines. I – still is – routines that feel good. Routines that I had to have. Routines that I forced myself to do, routines that I really enjoyed. And all of that disappeared. And the last time that I felt that was when I was institutionalized back then. And so...that, perhaps, for me, is one of the reasons that I tried to do, whenever I can, anything in person? Which I still struggle – you know I'm still high risk, I got COVID and…I'm afraid. That's reality. I'm still afraid, I have every reason to be afraid. You know. We had a significant number of people in the family get Covid, and we also had a significant number die. They were all disabled, every single one of them that died. And…it makes me mad when I leave, and I don't see people now. You know by this, like, I have to…I don't know. [Long pause.] What was the question?

Aimi Hamraie:
I think I was just wondering about like… So, when you were institutionalized, were there forms of remote access?

Hector Ramirez:
Oh, no, no, no! People visited you when they could. You would go out on an outing every once in a while. Local area. But it was an outing really.

Aimi Hamraie:
Yeah, that makes sense. Yeah, I thought –

Hector Ramirez:
Yeah.

Aimi Hamraie:
And then it sounds like – you know, something that you described with COVID was that like – because that feeling came back, you and other disabled people were actively creating all of these spaces in order to connect over Twitter and Facebook and Youtube and things like that.

Hector Ramirez:
When I was in the hospital – not only was that disconnection there, from the like society, but something else. When…my peers would get hurt or they would get sick. They would disappear. You know, and that was it. Little by little, they were all disappearing. You know. And that's what COVID felt like. And you knew it was only a matter of time before it was you. You knew it was a matter of time before it was a person that was sleeping in the bunk next to you. It happened to a lot, and…there was nobody there. That's what Covid felt like as people started, you know, dying, disabled people. That's…what it felt like. I think, if I have to put it into words.

And that’s, why…joining remotely perhaps as many meetings as I could, felt like an emergency. I still did, and you know, I think this is where my autism – my autism kicked in, you know. Cause I was able to really create a lot of routines and really manage or think that I could manage a lot of these meetings. In a way, it felt like I was back at school and why I've learned so much about COVID, I learned so much about government. I also learned a lot about loss, you know. I – every day. I literally have whiteboards around me, where I take notes. I have notebooks and notebooks. You know, I stopped printing because it's just not good to print stuff. But you know, because I was doing a report looking at data and stuff like that. It has a purpose to be able to do this remotely, and to be able to engage from this type of activity.

And as a disabled person who's autistic, I think for me this was a really good way to show my skills, but only when it was accessible. I cannot tell you just how hard it was to go to a meeting, and not be able to hear, and have folks start. They would go “Oh, oh, we'll just start without him, and you know we'll –” Oh, no, you're not gonna – you’re not starting without me. How dare you? And having to assert, you know, your humanity over and over, it’s exhausting. You know. And I wish there was some option – now I’m glad, you know when you can request the captions now, you can choose languages. Before you're like, ”Oh, well, Hector, you should know how to do this like I'm not getting paid for–” I've spent so many hours teaching people how to make meetings accessible. I have spent so much money like – I wanna get paid – well, actually no, because I didn't like doing that you know.

Aimi Hamraie:
Yeah, it sounds like, even though the – you know the – those meetings on Zoom provided some kinds of access. There are other kinds of access that it was other people's job to provide. And you really had to do a lot of advocacy, for – in order to get in those spaces. Like captions. [Longer pause.] Yeah.

Hector Ramirez:
Yeah, and you know, it was weird, because in some of those meetings, I played, like I had – in some of those meetings I had key roles where I was like leading them. And you know, when the person leading, or you know in charge of them, cannot even participate, it was like – we were like – okay. Or when they couldn't see them. That was the interesting thing: people got to experience what it's like not to have access. “Oh! Did it freeze?” or “Wait! How do I turn the volume on?” or – and I was like, hmm interesting. And you could see their frustrations. “Oh, I've been trying to raise my hand all morning!” You're like. Tell me about it, you know?

And…and so that has been kinda like the leveling of the playing field sort of? We sort of had a taste of what it – what it's like to have a level playing field? For all of us. Especially when we were joining remotely. We're – we’re on our own, and we had no technical assistance to help us and everybody's in their room trying to figure it out. Or somebody's not getting through. We, this platform has really established a level playing field for many folks. But it has also highlighted – how I mean it is for even other folks living in poverty, other people with disabilities.

But technology is one of our main tools as disabled folks. You know. We are – it's innovative, and we are, of course. Perhaps it's great as – practitioner.

Aimi Hamraie:
Yeah, that's – I think so, too. So one last question before we stop recording. I'm curious if you have encountered anything in terms of remote access during the pandemic that was surprising to you that you weren't expecting, based on your experiences.

Hector Ramirez:
You know I wasn't expecting Microsoft teams to be so inaccessible. It's such a highly utilized tool in the business setting. And if…well, first of all, it was highlighting just how many spaces we were not in. And I – cause I was always able to see, and how many people didn't know but I think…You know, one time I came into a meeting and...it had automatic captions. The window for the ASL interpreter was there. And it was – yeah, I came in one day, and somebody had a disability etiquette for the meeting, and this wasn't a disability meeting. And I was like, "What? What, who's the disabled person here?" And I was the only one there, and I was like, "Wait a minute. How'd you do that?" And they go, "Oh, we're just ensuring that all our meetings are inclusive, diverse, equitable, and accessible." And it was like, 2023. Okay?

Aimi Hamraie:
Interesting.

Hector Ramirez:
2023. And so, 2023 really has been the year when I'm really coming to these spaces and they are accessible. You know, not just like captions – like see captions in other languages, or they have, like they - the translator with, or multiple translators. That was a big one. CART in more than one language. That was a big one. You know, and so those are some of the things that I'm continuously being impressed. I saw a presentation of a remote meeting done with a virtual headset – that was really interesting, too.

And so, you know, I'm glad that people are really seeing the benefits of this.

And I know they want a break. Everybody wants a break from anything, and that means meetings. But you know, I don't know why people think the pandemic is over. It's so – I think all of us, many of us, will continue to do this, and that's why it's so important to have this continued access for stakeholders from a legal government point of view. But also from my community point of view, because you know, a lot of folks when they join in those meetings, and they're making those comments, so they're public statements. That is the last thing that remains of them. Especially people with disabilities.

Aimi Hamraie:
Yeah.

Hector Ramirez:
And they come, and they use this. They want somebody to hear them. They want somebody to know what's gonna happen. They want somebody to know that they were alive. And they were asking for help. And…there's this high poetry with the fact that although these meetings are recorded there – perhaps, like some of our most big five, but for a lot of folks, the last thing we have of them.

Aimi Hamraie:
Hmm, yeah, that's so powerful. Yeah, you're right. That is a sad poetry. Well, thank you so much, Hector. That might be a good place for us to wrap up. Is there anything else that you would like to share about remote access before we go?

Hector Ramirez:
No, you know, definitely, I appreciate what you're doing. I really, really, really do. I think you are…I haven't heard anybody really starting to do what you're doing, and so I'm really, really glad. I think you're onto something really big…and I think large here. And I think it reminds me…when – I have a praying mantis on my hair now – When state hospitals were closing and people were leaving, you know there was a lot of things that was left behind in state hospitals.

There was a woman – I can’t remember her name, New York, she just died – but she started going to some of these state hospitals, and she would find abandoned luggage. With some of the belongings to some of the folks. And that was like last things. And I think this is very similar to that in some aspects. Because it's still living, you know. This is more, it's still more active. But it – when I realized that their fullest, all these, like recorded meetings in our and all these different deposits, are some – I can only imagine what's in them.

Aimi Hamraie:
Yeah, that's so…that's so true. What a…what an apt comparison to those suitcases! I think I know exactly what you're talking about, like the collections of people's belongings from state hospitals. Yeah, you've definitely given me a lot to think about, too, in terms of intersections with institutionalization here so thank you so much for that.

Hector Ramirez:
Okay!

Aimi Hamraie:
Well, I'm gonna –

Hector Ramirez:
You know, it was also really good to show representation, you know. And that was, that was the thing, because…not only could you see disability, but you know, we were able to really highlight intersectional culture, intersectional disability community, because sometimes disability is so white. You know. And that the people in some of these meetings sometimes don't represent the diversity or the equity that we have. And so I think that has also been a significant benefit for the collective work that we all do in the disability justice community. Particularly for the trans community or nonbinary community, and our neurodiversity community. You know. So.

Aimi Hamraie:
Yeah.

Hector Ramirez:
That's – that, that was a little surprise. Like, I was in a meeting. I was in a meeting. Where was it? I think it was two months ago. And I was like fifty autistic people from all over the world. And it was really interesting because we were all having like pausing conversations, and everybody's stimming

or doing their things. And it was kind of interesting because I had my little Brady Bunch kind of screen. And everybody is like moving and doing their things, and I'm like, “Oh…” But it's like we have so much diverse representations like, I have never really…wow. And so I think that has been good. And you know it has a lot of opportunities to collaborate. I have collaborated like I've never before. I have so much writing. I don't even wanna do it, but it's like I have…Gosh! I have done so many research projects and stuff like that.

And I haven't had the opportunity to really do it. But it's been a lot of work, but like I said, it’s been survival. It's been survival. And – I just thought about – I don't know if it's correct, but. I feel like I've been working the corner. And that's not a bad thing.

Aimi Hamraie:
What do you mean by that?

Hector Ramirez:
Well…Because it was so personal, really. This type of advocacy, this past–since the pandemic – has been a very personal type of advocacy, like, I've never had – it’s in my home. It's literally in my home. You know. And so at times it was…the meetings were like, everything was happening, now, and so it felt so personal? Sometimes like prostitution, but done in a bad way. Like to try to survive.

Aimi Hamraie:
Hmm! I see.

Hector Ramirez:
Like I did whatever I had to even exposing myself.

Aimi Hamraie:
Yeah, it's like, an incredibly vulnerable thing. But it's helping you survive and your community. So.

Hector Ramirez:
I've never looked at people's faces so long! And it's weird, because sometimes I turn my camera and I just look at people's faces like, yes I never do that, you know, and they don't know that I'm looking. I'm like,

Hmm! And that was–that is the weird thing, because I'm like. You know, I look at how many times they blink, you know, their expression. That was the other part that has been like – that's why it's like school. I look at their backgrounds and everything, you know, cause that's what I think. It was like – I’m fascinated. But then, you know, their reactions while they're talking…I don't know a lot of other stuff I haven't really noticed before. And you know it's more…I don't do FaceTime like, I didn't know what FaceTiming was before, until you know. And I was like, what do you mean FaceTime? You know. I don't do that whole – do you think that people would do on Facebook before now? I do!

And that is so. It's weird. It has also sharpened my boundaries. And I wonder if I'm staring more when I'm in public now. I was doing it a lot already, and I wonder if I'm doing it more. And so.

Aimi Hamraie:
That's such a – yeah.

Hector Ramirez:
You know it's interesting to see how it has shaped some of my…uniqueness. Or what's – my mom calls my “behavior”, my weirdness. But anyways.

Aimi Hamraie:
Well, so do you have any – do you have any thoughts about where you would want remote access to go from here, in the future? Whether for community or advocacy, or anything else.

Hector Ramirez:
Well, you know, the accessibility element is a big one. The continuation of that. You know. It's, so, I think, really, having…and you have the documented, you're going in the direction. It really helps us to really fortify that argument for a community. And I hope it's not a…long term need that we have to continue fighting for that. But it probably usually is? But then also…I…Every meeting that I go to I feel like I have a chip on my shoulder. You know. I'm mad at how many people are dying, how many people have died, and how…How we were left behind, how many we have, how many – this really could be something to help us document and memorialize what has happened to us? Because this is a genocide. It’s not a genocide

it’s…Has felt…we were made expendable, and I literally saw…More than a quarter of my community die.

Aimi Hamraie:
Huh.

Hector Ramirez:
You know. And that's for my whole disability community. And people are acting like…I understand. You know they're tired, and they are still afraid, and they just want…to live…But I think the disability experience is always about reminding folks to keep going. But that doesn't mean they need to forget. And I think that's what you have the potential to do with your project.

Aimi Hamraie:
Thank you. I hope so. And it sounds like you are doing such important work. So I'm really glad that we're able to document this and to…to document how important remote access has been for advocacy as well. Because that's something that we’ll have to keep fighting for going forward.

Hector Ramirez:
[Hector signs “thank you” in ASL with two hands for emphasis]
Thank you. I hope you have a wonderful day.