



VALERIE NOVACK

Interview Date: April 3, 2023

Image Description: Text reads “The Remote Access Archive” 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 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

2017, 2020, access failure, Americans with Disabilities Act (ADA), COVID-19 pandemic era, emergency management, emergency notification registries, hashtags, hybrid access, inclusive disaster response, local government, pandemic disinformation, policy, pre-COVID remote access, public health, remote work, social media, systemic ableism, telephone hotlines, Twitter

IDENTITIES GIVEN

biracial Afro Latina, she/her pronouns, disabled person

LOCATION

United States

Introductions

Aimi Hamraie:

This is Aimi Hamraie on April 3, 2023 and I'm here speaking to Valerie Novack. Valerie, could you please tell us your name, age, and where you currently call home?

Valerie Novack:

My name is Valerie Novack. I am 34 and I currently live just outside of Cleveland, Ohio.

Aimi Hamraie:

Great. And what words do you use to describe your race and gender?

Valerie Novack:

Afro Latina. I sort of avoid describing my gender. I use she/her pronouns for simplicity's sake.

Aimi Hamraie:

And FYI this is for if someone is referring to you [inaudible]. And do you identify as a disabled person or person with disability?

Valerie Novack:

Yes. Oh, and I think you asked about race and I forgot, I am biracial, Afro Latina.

Aimi Hamraie:

Great. And do you have preferred language around disability? Is there specific language that you want?

Valerie Novack:

If I have to, I usually use identity first language. I tend to use language interchangeably, so I don't have a hard preference, I guess.

Aimi Hamraie:

Okay. And do you consider yourself to be part of disability community or disability culture?

Valerie Novack:

Yes.

The Partnership for Inclusive Disaster Strategies: Remote Strategies and Hurricanes

Aimi Hamraie:

So we'll divide this up into talking about your experiences with remote access before the pandemic, and then during the pandemic, so about March 2020. And although we are going to talk quite a bit about this in the context of disaster planning, I would encourage you to talk about any experiences you have with remote access.

So let's start with before the pandemic. What were forms of remote participation that were significant for you before March of 2020?

Valerie Novack:

So before – I am part of that privileged class of people who was already on some kind of hybrid schedule because I have chronic illness. So from day to day whether or not I'm going to be able to get into an office to work was just not predictable. I was lucky enough to work for an organization that understood that and allowed me to work partially from home. And then on top of that, part of my work was looking at the emergency planning and disaster response, and I was doing that from Ohio for the broader area of the US [United States] as part of a larger organization called The Partnership for Inclusive Disaster Strategies. When we would help support, you know, the hurricanes, I think I started with them shortly after Harvey in 2017. I reached out to them, I really – I had gotten my masters in emergency management, or was getting my masters in emergency management. And I had done some work when I was in college with our city, looking at their ADA [Americans with Disabilities Act] plan for emergency for the city, which was like non-existent, and found out that it was pretty much non-existent across the country, when I was told to look for some best practices to implement in our city, I found lawsuits instead of best practices. So I knew that was something I wanted to work on.

So I believe it was after Harvey, I had reached out and I got connected to some people to try to work with disabled people. Getting stuff they needed, getting power if they needed that, getting into the temporary shelters if they needed. But all of that was done pretty much with a google sheet and a

google phone number and voicemail. And to this day they still run – I'm no longer part of the organization – but they still run a hotline which is their primary source of getting information to and from people with disabilities after disasters. And so my first experience was just being able to work back and forth, but as far as disaster management from the very beginning it was much more hybrid focused which allowed it to be run by and supported by people with disabilities, who didn't need to hop on a plane and fly 5,000 miles to go help, but was able to connect with people on the ground from wherever they were.

Aimi Hamraie:

Great. So it sounds like the people running the hotline were also disabled people, is that true?

Valerie Novack:

Yeah. So at the time there was just a very small group of people. It is still a pretty small group of people. I think it was 2 at the time we started the hotline, then it went to 5 briefly. I was running that organization, then left. And so it's always been led by and pretty much completely volunteer-based of people with disabilities.

Aimi Hamraie:

And this is the hotline for the Partnership for Inclusive Disaster Strategies?

Valerie Novack:

For Inclusive Disaster Strategies, yeah.

Aimi Hamraie:

Do you have any interesting stories about how resources were shared or how people got in touch or benefited from using this hotline?

Valerie Novack:

Yeah. And I will also – I can connect you with Germán and Shaylin, I'm sure they have so many more stories. When we start talking about post-2020, COVID kind of broke me and so I have not done a lot of emergency management stuff in the last couple of years because of the experience with COVID.

But during pre-2020 we had several very bad hurricane years – as far as the South – and stories from – there is this a amazing, not the typical story

of being able to work with Cajun Navy in Louisiana and helicoptering somebody medicine from one person's house who had a kid that had this same disability who had extra medicine. And they were able to give it to these people, who in their helicopter came and did an airdrop into somebody else's backyard, because this kid absolutely needed their medication. So you had stories that were completely unbelievable like *that* to the really everyday. I remember talking to an older gentleman that had put his name on his county's registry in Florida. Was told if a situation like this happens there will be a bus that comes and gets you to evacuate. So when his family was like, do you want us to try to take you, he's like, no they're going to come get me. Well they never showed up. And he's on the hotline with us saying, my house is flooded, I don't have electricity, and I'm stuck here. What do I do? And so from the basic everyday calls, to these sort of extravagant type calls.

We ran a weekly call where we would connect with people like the Red Cross so that in these emergency situations we would have direct access to the people that were on the ground, so that we were able to answer the questions that were coming into the hotlines or connect them with somebody that was already there to get them briefs or what have you. We were also able to actually send a group to Puerto Rico to go and help people with disabilities. We were able to send shipments of things like chairs, briefs, different durable medical equipment that was kind of wiped out when Puerto Rico was just really really devastated. It kind of varied based on the people that were calling in and the disaster, whether it was more, okay I'm gonna give you this number to call this shelter that is in your zip code, or if it was like, I'm gonna connect with this organization and get you stuff that you need. We would just get calls from people with all myriad of different needs. Sometimes it was children, sometimes it was older adults, sometimes it was somebody who was a caregiver and was trying to figure out, my mom is stuck at home, how do I support her when I've left? Or different things like that. So it really ran the gambit of experiences.

Badly Prepared Local Governments: Registries and Lack of Action

Valerie Novack:

I was always somehow surprised at how badly prepared, no matter how often we had had these problems, how badly prepared the city or the county or the state was, to think about people with disabilities. Or just people in general who didn't have a car to jump into and money to buy a full tank of gas to evacuate an area. And it was just like there was very, very little thought on that.

Aimi Hamraie:

Yeah, so one thing I'm wondering about is, are there differences between – given what you just said, the difficulties with evacuation – are there differences between disaster planning protocols or even having hotlines like this when the intention is to help people with disabilities versus a majority non-disabled community?

Valerie Novack:

I think that's a tricky question to answer. I think the basic answer is yes. So on a more compliance/legal side, a lot of cities that have a plan should technically have something in there that says, this is what we're doing for populations with disabilities or that can or cannot do xyz. I have looked at so many of those and a lot of times it's like half a page that says something to the effect of, consider people with disabilities in this plan. But doesn't actually give you any details on how to do that. And so there is at least some awareness floating around with the people who are doing this work that, oh yeah that ADA thing, we gotta remember those wheelchair people, or whatever it is that they're thinking in their brain. But they don't really do anything with that information. And so then what you end up getting is this very general plan. Often it's, okay this is the place that we're going to have people evacuate to, it's a stadium or a big mall or church or something like that, and they'll maybe make sure that they – oh, we're going to cut off this part of the parking lot for accessible parking. And it's very, very basic level kind of compliance, accessibility stuff.

The other thing you will see a lot of times for older adults, for people with disabilities, that they kind of sell as a solution or as a help is these registries. Sign up for our notification registry, and then we'll let you know. That is created under this mindset that us disabled people are just sitting at home and we don't go anywhere. Like they're asking you for a phone number and an address that it's your responsibility to keep updated. If you moved someplace 6 years ago and you change your phone number or your address and then this disaster is coming, they're trying to get a hold of you

at a place you don't live anymore, if they're trying to get a hold of you at all. Right? And so you have two very different experiences, even if you're supposed to have a plan that fits for everybody. Particularly with these registries, the way that they are sold is, if you sign up for this registry, we will help you if a disaster comes. And time after time after time I have seen people stranded at home because they thought the city was gonna take care of them because they signed up for some registry, and they never got help. So that seems to be the band-aid answer, we'll just make a list of all the disabled people, and I guess do nothing with that list. But yeah, it's very, very much an afterthought. People with disabilities are just very much an after thought. Maybe we should make sure we have an accessible bathroom, simple things like that. Sometimes we have problems even getting accessible evacuation shelters. And then you do and they don't have accessible bathrooms for example. And it's like, well I can't go to the shelter because I can't use the restroom if I go to that shelter. It's very obviously not thought through when these plans are being put together.

Aimi Hamraie:

Yeah, it sounds like it, I think the example you gave of accessible parking is really interesting given what you were also saying about how it's very difficult for people to just get into their car and go.

Valerie Novack:

Yeah. Yeah.

Twitter as Real-Time Remote Solution

Aimi Hamraie:

I'm curious, how does remote access fit into – possibly, I don't know – but how does that fit into efforts to go beyond these basic compliance measures in the context of disaster planning? Are there things that become possible through technology, that hotlines and registries and things like that are covering?

Valerie Novack:

Yeah. One of the biggest things I think in general that you see most with things like Twitter is the ability to real-time reach somebody who is close and available. Not having to wait for, this will probably sound bad, but the appropriate channels to get to somebody, because you can call somebody

who has an aunt in Florida who happens to live in that city and has a vehicle or some kind of resource like that. Because you know that organization that is in Louisiana that does durable medical equipment and has somebody who can run somebody something they need. Rather than trying to go through the Red Cross channels, or go through the city's EMS [Emergency Medical System]. And because we are acting individually, we're not beholden to those people so we're able to use that phone, email, social media, whatever it is, to collect the resources people need and get them what they need. In a way that isn't bogged down by the bureaucracy that you often have. Or even just the wait lists that you have to go through to get some of this stuff. I think it also – sometimes it's just opening up the communication when you've lost your power, you've lost maybe access to the internet, things like that, people honestly just don't even know what's going on. We've talked to people who just want to know, okay, do we have any idea when my power might come back on? Where *can* I go?

One thing that a lot of people that aren't in those situations aren't aware of is, often because of the way disasters land, shelter areas aren't picked way in advance, right? And so it's not like a person can go and see if a building is accessible months before a disaster happens because they know that's where the shelter's going to be. If you go to the American Red Cross website and try to look up shelters in your area, there's no list of what that would be, until an imminent disaster is coming. So sometimes it's as simple as, where am I even supposed to go? I have no power. I don't know where I'm supposed to go.

A big thing we've done is signed people up for food delivery. So a lot of times after these disaster events, churches, things like that will pull together food pantries and things. People's food goes bad because their power's out, things like that. So much stuff is online nowadays, if you don't have access or you're not very good at online, sometimes people just have anxiety trying to deal with stuff like that. And they would call us and be like, I don't have any food. And we would be able to fill out a form for them or make a phone call for them to someplace local that's providing food. Different things like that, without me ever having to leave my home, a 1,000 miles away, or whatever. So I think it is massively opened up our ability to help people.

Aimi Hamraie

So it would be the kind of thing where you are, where you're located, because you have internet access and other people possibly have internet access, you're coordinating resources on the ground for them to get delivered. Whereas otherwise you would have to physically go there to do that. And that might have other access barriers for you. That's super interesting.

I'm curious to hear more about Twitter and social media. It hadn't occurred to me before, but of course it's true and I think we've seen during the pandemic that people coordinate resources using social media. So what's your sense of how long that has been going on in the context of disaster? And I wonder if you have any stories about that too, ways that disabled people use Twitter for accessing resources or getting information.

Valerie Novack:

I think it definitely blew up after COVID. I know a lot – I don't know about the US - I know I've seen a lot or remember first seeing it around some international incidences. But my first experience with that was actually very, very early in Twitter. I remember having just downloaded the app and not really, I think like a lot of people at that time, not really sure what it was or what it was for. And this is before I identified as disabled, I wasn't even part of the disability community. I was sitting at work in a call center and suddenly we heard a noise. It was just this very big noise. And within minutes my phone was blowing up from Twitter. And probably a good 20 min, maybe longer, before we heard anything from the news Twitter had already explained everything that happened. You didn't need to be worried. It was a sound barrier thing. And then a little bit later something similar happened with an earthquake. Way before we heard anything about the news, Twitter was telling me, what you just experienced was an earthquake. And so even way before this became a thought, my introduction into Twitter and thinking, oh this is kind of cool, was two instances where we were like, oh what was that? And random strangers on the internet were able to tell us what it was before the news was able to tell us what it was.

But going further out, we've seen after earthquakes, whether that's finding people, locating – we've seen stuff go out like, does anybody have access to somebody who lives in xyz area, we have somebody that's stuck there. It's not suggested, it's not always the safest, but post-disaster a lot of times

you're just doing what you can do to make sure the people you love are okay, that people who are stranded or hurt have somebody, right.

Financial support is also a thing that seems to come in differently on Twitter than it does other places. I don't know if that's the potential reach or how that changes hands, I'm not sure what it is about that mechanism that seems to support that, but it does.

I've been connected – this was more so during COVID – where something gets tweeted out and before you know it, next thing you know you're talking to the head of a nonprofit who happens to be in that city who's like, hey we have space to do this or we have storage for that. Or things like that. It facilitates unexpected conversations. It connects you with people that you wouldn't even know to call. Right? And usually quite quickly.

I think it's an underutilized, or at least was – I don't know how well it would work now – but I think it's an underutilized resource when you're trying to get to people on the ground right away. I think we've seen this – I mean people talk about how many historical events we watched in real time on Twitter. And I think disasters are one of those that historians and such will be able to go and look back at for some of these events and see very real back and forth between people trying to help each other.

Aimi Hamraie:

I think you're totally right. One of the things we've been trying to do for the archive is actually document certain disability hashtags, especially when it looked like Twitter might –

Valerie Novack:

Yeah!

Aimi Hamraie:

You know, we were like oh no. It seems like it's doing okay. I'm curious, were people using any hashtags that you think are significant? Or was it more just finding people based on location or some other way?

Valerie Novack:

You know, I don't really remember. I don't know that I paid enough attention. I think a lot of big events like this end up with hashtags, so there probably was hashtags, but it wouldn't have – it probably wasn't specific to

like disability support. But being able to piggyback on those and get the attention of people. The only one I can really think of is a lot of the mutual aid hashtags that came up after COVID. But I would imagine probably so, I'm just not thinking of any right now.

Other Social Media Platforms

Aimi Hamraie:

That's fair. Are there any other social media platforms besides Twitter that were useful for disaster stuff?

Valerie Novack:

I think that's really the most useful. I don't know what sort of changed the mindset, but it did seem like for a little while people were starting to realize that was a potential power. Because I know Facebook launched their "marked safe" feature or whatever, so that if you were in a disaster area you could mark that you were safe from that disaster. That's really the other thing that comes to mind. But I vaguely recall when that was happening, that there were conversations where it sounded like maybe we were going to start harnessing the immediate communication of social media in our disaster response. But never really saw that turn into anything.

Aimi Hamraie:

Yeah. And I can understand why certain platforms wouldn't really be amenable to it, like TikTok or Instagram. Maybe Instagram kind of, but it's really just not set up in the same way that Twitter is.

Valerie Novack:

And it's possible something like Tiktok might – I didn't even really – I thought Tiktok was for 12 year olds until the pandemic. So that was honestly not a social media site I ever looked at before 2020. So I really have no idea what was going on there. I do think there was some usage of Instagram kind of in a similar way to Twitter though.

Aimi Hamraie:

Interesting. Are there any other ways that you can think of that remote access was significant for those pre-pandemic disasters?

Valerie Novack:

I think the big way in blue-sky-times was also organizing. Because of the internet and the phone, we were able to be in pretty regular contact with a significant number of what are called the FEMA [Federal Emergency Management Agency] regions of the US, so that we were able to maintain those contacts before an emergency happened. Even with a team of 4 or 5 people in not the same place, we were able to have a listserv of hundreds of people and have access to a large number of people that we could reach out to if we needed to, solely because we were able to keep everything virtual. I don't know that the network would have even existed as it did, if we didn't have the remote access portion, if it wasn't this in the cloud kind of thing.

March 2020

Aimi Hamraie:

Yeah, that totally makes sense. So I wonder if we could shift to talking about the pandemic era? And I know you said that you were moving out of disaster by then. So what has remote access been like for you since March of 2020?

Valerie Novack:

So I think the first thing I would kind of mention is because of access to broader internet we actually started working on COVID stuff at the end of February. So we started having daily calls to try to figure out what was going on in different areas, what the response was in different areas, towards the end of February. So a couple of weeks before we even wanted to acknowledge that covid was a thing. Then as things started moving forward, it was a lot of looking into continuum of care in hospitals. There was some support for some of the potential lawsuits that we thought were gonna have to happen. And then because the first big outbreak was in a nursing home, we knew that this was going to be – I mean from the rhetoric at the beginning about, it's only old and disabled people – we knew that this was going to be a mess for people with disabilities. And so our hands were in everything. We were trying to help people who were working on nursing home stuff. We were working on legislation. We were trying to get much more into the bills that we were being worked on at that time to try to get support. And then also just keeping people safe. Whether that was getting people masks or being able to make sure people were getting food delivery. And then everything went remote, or a lot of things went remote, and there

was very much a feeling of both of relief for that but also this huge – which you probably felt this as well – but this huge wave of frustration from people who for years and years of years have needed this and been told, that's not something we can do. And I think that pushed a wave forward, we got a lot of influx of people trying to help. I don't know, I think it's just invigorated something in people. Because it became very obvious that this kind of support and access was always possible. People just didn't want to pay to do it. And I think it lit some fires.

But yeah, I feel like at that point there was almost no – it felt like there was almost no direction we weren't finding that people with disabilities were being harmed. And trying to figure out how to respond. Probably the most overwhelmed I've ever felt in a disaster situation. Because it was just – it was everywhere. And it seemed like no matter what direction we tried to turn for help or support, it was like, oh they don't care about us there either. It was very difficult. But the reason we were even able to do that much, especially during a pandemic, is because we didn't have to be in the same room together.

Aimi Hamraie:

That makes sense. Right. Because being in the same room would have [inaudible]. Just to clarify, when you say “we” are you talking about the Partnership for Inclusive Disaster Strategies?

Valerie Novack:

Yeah, so mostly the partnership at that point, though I was also working in DC [District of Columbia] doing policy work. So I was working on emergency management policy at that time as well. It was a little bit of both work and personal volunteer or whatever you want to call it.

Aimi Hamraie:

Were you working for an organization or federal agency?

Valerie Novack:

Yeah, I was working for a think tank.

Aimi Hamraie:

Okay, gotcha. Do you want to tell me what they're called?

Valerie Novack:

No, because I don't like to be associated with them.

Aimi Hamraie:

That's fine. Yeah, that's fine. This all makes a lot of sense.

Differences Between Disaster Planning Strategies and Pandemic Strategies

Aimi Hamraie:

So you are putting together the pieces that this pandemic is about disability in all of these different ways. It's circulating a disability space. People are using all of this rhetoric about who's likely to get sick and what the risks are, and things like that. I'm curious, since you also studied disaster planning, I'm curious if there's something that's different about a pandemic as a disaster versus a hurricane or something else as a disaster, in terms of the types of strategies that you have to use.

Valerie Novack

Yeah, I mean, I think the first thing, of course, is the – sorry my phone is ringing – the covered area. Usually when we're looking at earthquakes, tornadoes, hurricanes, things like that, you're looking, you have a boundary of some sort right? And sometimes that boundary is a problem, because states and counties and stuff don't want to work together. But you know you have an area that is contained that you are trying to help people in, to get certain kinds of resources or certain kinds of supports. Whereas really any kind of viral illness you have a much harder time predicting and containing where that's going to be. With COVID, and I would imagine other pandemics that were like it, although I wasn't – I was too young last time something like this happened – it also just hits so many facets. When you have something like a hurricane you know certain things are gonna happen. You know you're probably gonna lose power, you know people are gonna lose their shelter. There might be some job loss or loss of work because of things like building's getting destroyed, or things like that. You know people are going to be hungry. They might have problems with an accessible shelter.

But with COVID it was all of those things plus a bunch of stuff that we had never had to deal with before. Suddenly it's not just oh, you're gonna be out

of work for one week while they're waiting to get the power on. Or this week's groceries went bad because of the power. It was, I lost my job. I can't get out of bed because I have Long COVID and I can't pay my bills. Indefinitely, right? It was just a very, very different time frame that you were looking at. So you were looking at a much larger area that was not predictable, an indefinite timeline. And the timeline I think also made the support of helping newly disabled people heavier. With a lot of disasters, they are creators of disability. But when you look at these numbers, a lot of times they're considered what people would say 'small', right? I don't think anybody dying is ever small, but when you look at say, the recent tornadoes that have happened, I think the last number I saw was 32, which compared to one and a half million is – right? So because of the amount of new disability you're experiencing, sometimes we're not even talking to those people. Within months. I mean the first person I knew that had Long COVID had COVID like March 20th of 2020, or something like that, and has never fully recovered. The amount of newly disabled people that were suddenly like, well what do I do if I can no longer walk very long? What do I do? Suddenly – so we also had this group of people new to disability who were also seeking resources, which I think was a very, very different thing. And it was happening simultaneously with the disaster and not something a little bit after. So you have all these new kinds of supports, then you have the supports we're used to but for people who have never had to deal with them before. It was a very, very different atmosphere.

And then because COVID got oddly political, there was this whole other layer of not really having an authority to point to. Right? In a lot of these – when a hurricane or an earthquake hits you don't really have a whole lot of people telling you it's not happening and so they don't need to help anybody or they're fine to do whatever they wanna do. That was a unique experience that I have not experienced with any other kind of emergency situation, is trying to support people when you have a not insignificant portion of people that just don't believe anything is happening at all. And that was just a whole other area of complexity. Because when you're looking at such a large area and you're trying to advocate for change that's going to help the most amount of people and you don't have even base-level support. Or people are too scared to do things because they're worried about the way the politics look. That's what made me throw my hands up and say I can't do this anymore. It was trying to walk up a never ending hill, right. And having to watch people die all the time because people did not want to do anything. Whereas people love to pull out their

checkbooks and things when the Red Cross says there's an ad for an earthquake or they're showing pictures of flooded towns. But COVID was just different on every level. But pandemics are different in a general sense as well.

Nuances of Remoteness: Online Connection, Disinformation, Apathy, and Failure to Use Available Technology

Aimi Hamraie:

Right, yeah. It's very interesting to me this thing about COVID denial. And you're pointing out that there's a visual optics to certain types of things. So showing people, showing places that have been affected by disaster. With all of these things there's this simultaneous remoteness. And the remoteness in some cases seems to bring up feelings of sympathy and wanting to help and in other cases it brings up this denial. And I wonder, do you have any stories about having to navigate that, given that you – it sounds like you were working remotely, I mean as remotely as we can be in a pandemic right? But how did the distance or the fact that people were mediated by screens and stuff like that, affect this part of your work?

Valerie Novack:

We've already talked a little bit about the ability to do work that we couldn't do otherwise, but I think on the other side there were, on one hand, things we were able to expect because we were able to see what was going on in other places. One thing that I've noticed has been really useful in the now-time, where we are still very much in a pandemic but nobody seems to be acting like it, is figuring out our own resources and solutions. Getting recommendations from people on air purifiers and figuring out what masks fit best and work best. And learning from each other how to keep ourselves safe. Even at the beginning of the pandemic before we even really started wearing masks. And I remember conversations on social media about people trying to take grocery shopping trips and talking about waiting in line for toilet paper. And there was a lot of MacGyver-type solutions for people going around from person to person that was available on the internet. When the people that were supposed to be giving us this kind of information weren't saying anything or weren't doing anything.

On the other hand, it was extremely frustrating to have so much access to information and not be able to do anything with it. I remember a particular story where I was working for a think tank that has a lot of influence. And I wrote an email sometime in March, it was still early, to the head of that organization. Saying this is what is being predicted for this pandemic. We are supposed to be an example kind of organization. We should not be functioning the way we're functioning right now, we should be giving people time, we should be sending people home. And I was told – well we know at that time Imperial College in the UK [United Kingdom] was predicting that if the US went on its path we would have 200,000 people dead at the end of the year. And the response I got was something to the effect of, well we know what those estimates are but they don't take account for American science productivity, or something like that. And were like, oh I'm sure we'll be fine by July. And that kind of blasé attitude towards information that we were *able* to gather was pretty infuriating. Because it was almost like there was so much information available that nobody believed anything. And you could access information from anywhere from anybody who wanted to say anything. And it just created a lot of confusion for people and a major lack of action where there should have been action. And that information just spread so fast, even at a time when people weren't necessarily being together. And I think that was a weird – it's really great when that's good information that can happen. It's really bad when it's not good information. And so for every housing situation we were able to help or something like that because of these remote networks, there was another disinformation campaign that was making people – it was a battle for access to people almost. Everybody was online it seemed like, but whether or not you could reach those people with the information they needed when everybody was being so inundated was a little bit more difficult.

Aimi Hamraie:

This is so interesting, and I don't think I've heard anybody talk about this. But it makes sense to me that it's like suddenly everybody is extremely online and so that also means that there has to be more discernment about the types of information that is taken to be true. I think that puts into perspective a lot of the things that have happened with the CDC [Centers for Disease Control and Prevention] being over the place with what is the risk, should you wear masks? But then also these sort of conspiratorial things and things about drugs that could possibly affect your symptoms versus getting vaccinated and that kind of stuff. So it seems like it's the other side of this extreme information economy.

Valerie Novack:

Yeah, you can look at – they're almost two sides of the same coin. For every good link I got or recommendation I got on an N95, someone else was giving an ivermectin link right? And one of those is a little bit more helpful than the other one. But that's the reality that it was at that time and what you're trying to prepare against or for in that kind of situation.

Aimi Hamraie:

Right totally. That makes a lot of sense. I wonder, are there any other things that come to mind that are like this, where it's like a friction or a tension that remoteness created during the pandemic? Or maybe ways that technology failed and didn't work as well as you would have wanted it to?

Valerie Novack:

It's hard to say if the technology failed or the policy that is behind the technology failed. Right. I think for example one of the things that immediately or more immediately comes to mind is our hospital networks. A big part of what we were trying to prepare for and head off and that a lot of work was done on continuums of care when ICUs [Intensive Care Units] were full. And they were talking about who is and isn't gonna get a ventilator. Who is and isn't gonna get health care. And having to worry if we're gonna come to those points where those kinds of decisions are having to be made. And – oh, I'm losing the word – like manufacturing systems – which is not the word I'm trying to think of – but that could have helped alleviate some of that should there have been enough of a push or a desire to do so. Partnerships that could have connected some of these hospital systems across state lines, that usually you're not able to do that. We saw examples of people using alternate forms of electricity, using buses or things like that to hold morgue spaces. Right. So there was – but all of that kind of stuff is handcuffed to a lot of bigger bureaucratic things. It wasn't as easy as a doctor just calling over to another hospital and saying, hey let's work together and fix this because people are dying. Right. And then there was lots of incentives. I will never understand how we did not have a massive overhaul of our air quality standards in May of 2020. That we weren't supplying massive amounts of money and incentives for people to switch over to better air filtration. That is a technology that could have saved who knows how many lives. And so I think there was a failure, but it was more of a failure to *use* some of that technology.

I think it's the same with remote access now. I feel like every couple of days I go online and see another article about some big corporation saying, we're going back to the office. That's not because suddenly we can't do remote work anymore, it's completely policy choices rather than a failure of the technology. I hope a power we now have though is that we can no longer say it's a failure of the technology. We know we have the technology to do this stuff. I don't know how many friends I have, pretty much everybody in my life is disabled in some way or another, that have been told, well we just can't do that. That we now know – I was telling some of my friends, you mark down every single one of these organizations that's going remote right now and did it in a week, so when you apply for them in the future they can't tell you something they can't do.

I will say I think schools, particularly colleges – I don't have kids, I don't know a whole lot about what happened under that – but I would say they showed maybe the biggest failure and lack of creative thinking when it came to technology. The idea that students, both children and adults, were in my opinion completely unnecessarily put in harm's way. When we absolutely have the type of technology, we have the computers that we could have provided students to not put them in that situation. That will never – sorry I'm getting emotional – but it will never not crush my heart. I mean we've been doing online schooling for I don't know how long. There's entire colleges that are online right now. And you know my spouse at the time was doing, he does IT [Information Technology] stuff for a college. And so I watched as he helped move this stuff online for a college that did not have a lot of money. So I knew this stuff could happen from a few different angles. And so I think if I had to pick a place where I saw it fail the most, I think it is failing our students and the teachers and professors that work at those colleges. Because there was just very little reason for it. I don't like to speak in absolutes, there's always going to be somebody who needs something else, but by and large there was just so many different ways of doing, well we must get everybody back to school. Which by itself if you ask me is BS [bullshit]. But even if we're gonna say that that's the requirement, right, I think that was probably the biggest failure and unnecessary risk to people.

Aimi Hamraie:

Yeah, I am right there with you.

Valerie Novack:

It was a tough pill to swallow.

Aimi Hamraie:

Yeah, it's interesting. There's something in it about how disaster is perceived and calculated. And that once it seems slow enough, certain kinds of risks become permissible, and that is very confusing.

Valerie Novack:

Sometimes I feel like it almost got so big it became invisible. It was so everywhere that people just stopped seeing it at all.

Aimi Hamraie:

Yeah, it's like the people who say that COVID is just endemic. It's been very interesting to watch what people's risk tolerance is like and how they calculate that. We're speaking in April now, so pretty soon the emergency authorization is going to expire. Or maybe it already did? Is it April fifteenth?

Valerie Novack:

Yeah, I think it's in a couple of weeks.

Aimi Hamraie:

Yeah, so access to testing and those kinds of things is going to get a lot more expensive. I completely agree with everything you're saying.

Leaving a PhD Program Because of Denied Remote Access

Valerie Novack:

I feel like I should – I'm just thinking I should probably caveat that I did leave a PhD [Doctor of Philosophy] program during COVID. So that might also have something to do with my feelings towards colleges. I should probably note that. I felt that much before, I think, and less about that. But I'm just processing that now and thinking, oh I might be also a little bitter because suddenly my college is like, you have to come back whether not you like it. And I was like, I'm not gonna teach and do that. And my husband's immunocompromised and I'm chronically ill, it's just not gonna happen. But yeah, it has been a ride.

Aimi Hamraie:

So you left your program because there weren't remote access accommodations, basically.

Valerie Novack:

Yeah. So I started my PhD program in 2020 thinking like a lot of people did, maybe I'll spend my first year of my PhD in a pandemic. I can do that. It's mostly classes, it's not a big deal. And then COVID was not over in a year. The second year we were still largely hybrid, and pretty much everything I could do online. And I had a closet for an office. So I was pretty isolated if I did have to go to campus for something.

Towards the end of that year though they removed accommodations for being remote. Most or many of the classes went back to being in person and it was just not a risk that I could take. Especially because I was already working, I've had my job for – the PhD was so that more people would listen to me I guess. I don't know. But it wasn't a thing of the heart, right, it wasn't a passion project, and it was just not a risk I was willing to take for some letters.

Aimi Hamraie:

Yeah, that makes sense. Yeah, wow. It seems like this issue really affects your ability to access things from here on out.

Valerie Novack:

Yeah.

Wrapping Up: Community

Aimi Hamraie:

Is there anything else that you can think of that we haven't touched on yet?

Valerie Novack:

I think you'll get this from a lot of people separately. But I don't think I can stress enough, when it comes to the community part, how important this has been. And I know that's a big part of the Remote Access [Archive] project, because I've been following it since it went up. But on the just person side of COVID and not as somebody who focuses on disaster, like I

said I have an autoimmune disorder, my husband has an autoimmune disorder and is on immunomodulators. We have been largely isolating for 3 years. Luckily we were both already remote at the time. But that has meant we go weeks and not leave the house. And this has been 3 years. And the amount of inner strength – that sounds so gross and mushy – but I have taken a lot from the community that I had cultivated online before the pandemic. And that has continued through. There's also been a tremendous amount of death which has been another thing, and it's very hard to mourn people you've never actually met. Or mourn people whose actual given names you don't even know. Right. They're letters and numbers on a computer but have deep impact in your life. And the fact that we have had things like Twitter, the fact that we have things like Switch where we have game nights with friends in different states and things like that has kept us being able to go day to day without it being so horrible, while being really isolated away from people. And I think there is a very very real trauma that we are collectively going through right now, even if a lot of people do not want to acknowledge it. And that, if it is not and hasn't been already, will in our very near future become very much a disability issue because of the way it is and has been affecting people. And I think the ability to have online community and to access real resources, things like telehealth, going online, has probably saved in an untold amount of lives in the last 3 years. In a way that I don't know that anybody is counting or that it's possible to count. By allowing us to stay connected, allowing us to see doctors, or go to therapists, or watch movies for hours because we need something to do with our brain. I think I've been more grateful for remote ability in the last couple of years than I ever would have imagined I would have been.

Aimi Hamraie:

Thank you so much for that. And such a powerful summary of how significant this has been, not just individually but for the whole population. And I totally agree with you that nobody's really calculating that. It would be so interesting to try to quantify it, if such a thing were even possible. To give us also something that is more tangible to hold onto in addition to all the statistics about the people who have died and gotten Long COVID. I wanna thank you so much Valerie, this is such a great interview.

Valerie Novack:

Oh, awesome. Great. Do you want me to send you names, additional names?

Aimi Hamraie:
Sure.

Valerie Novack:
Okay, yeah. I'll send you – I know a couple of people who I think would probably really love to share some stories.