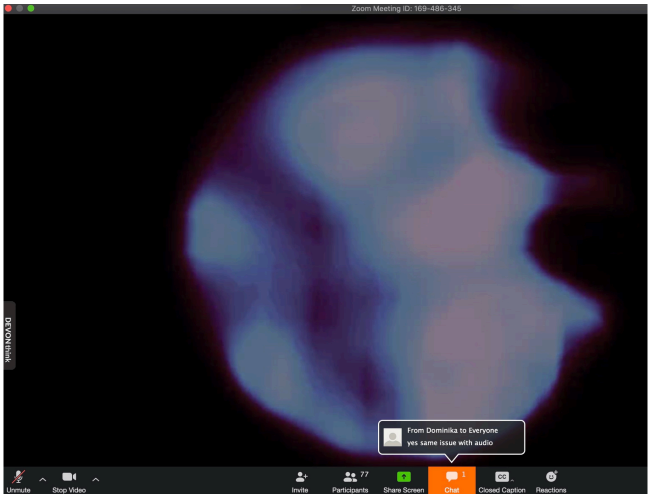

From Dominika to Everyone
yes same issue with audio

LAURA MAULDIN

Interview Date: March 15, 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

adaptive living, caregiving, COVID-19 pandemic era, disability knowledge, joy, online participant recruitment, systemic ableism, web design, websites

IDENTITIES GIVEN

white, cis woman

LOCATION

United States

Introductions

Kelsie Acton:
Okay, thanks so much for agreeing to do this interview. Can you tell us your name? And where you currently call home?

Laura Mauldin:
Sure, I'm Laura Mauldin, and I'm live from Brooklyn, New York.

Kelsie Acton:
Amazing, what words do you use to describe your race and gender?

Laura Mauldin:
I'm a white ciswoman.

Kelsie Acton:
Just because we're doing video, do you feel comfy doing a short visual description?

Laura Mauldin:
Sure, I am apparently middle aged now. I have very dark brown hair, dark eyes, dark eyebrows, and it's about chin length and curly, and a little wild, and I'm wearing a turquoise top with white polka dots.

Kelsie Acton:
Brilliant, and this is Kelsie conducting this interview. I'm a late thirties white woman, clear glasses, long brown hair that's pulled back today. I’m wearing a black puffer vest, and you can see the sort of magnolia yellow of the walls of the room I'm in.

So can you tell me if you identify as a disabled person or a person with a disability?

Laura Mauldin:
I'm not sure at the moment I'm working through that right now.

Kelsie Acton:
Thank you. But do you consider yourself to be part of disability culture?

Laura Mauldin:
Absolutely.

Kelsie Acton:
Do you mind saying more about that?

Laura Mauldin:
Oh, gosh! Sure! Well, I grew up with a lot of Deaf students in my school district, and I learned sign language early on. So I've been a fluent signer for most of my life, and I eventually went to Gallaudet University and lived on campus and just became really rooted– throughout both my undergraduate and graduate school when I went to Gallaudet– in the Deaf community for so long.

When I got to New York I became a caregiver to my late partner. I really started meshing myself in disability communities in New York City, both from an intellectual sort of you know, this was what I was studying was disability, but also from being enmeshed in disability systems and navigating those systems and getting care and arranging for, you know, community care. And it's just where I feel at home.

Introducing the “Disability at Home” Project

Kelsie Acton:
Thank you. So I'd love to hear a little bit about Disability at Home. Can you say a little bit about what it is?

Laura Mauldin:
Disability at Home is really intended to be both a lot of fun in terms of seeing the things that you do on a day-to-day basis that you think, “Oh, this is just me getting through”. But Disability at Home is meant to cast it in a new light, as this is actually so creative and so fantastic that you start to appreciate these sort of day-to-day, just getting through, in a new way. I think a lot of people find kind of fun and intriguing to see, to see it in that light.

And the other thing that it is a repository or a resource for other people who may benefit from these really creative and ingenious ways of repurposing everyday household objects, in a way they weren't intended to be used, but if you use them in a different way, it allows you to do something more, and it gives access in a way that perhaps is surprising, And if you hadn't thought of it, well, somebody else did and so this is a way to share it, so it's both, I think, fun and also a resource.

Why is “Disability at Home” a Website?

Kelsie Acton:
Amazing. So Disability at Home is, or at least in the form, I stumbled upon it, is a website. Can you talk about a little bit about why you chose a website?

Laura Mauldin:
Yeah, so should I talk about how it, how the material, how I got the material, and then I can talk about why?

Kelsie Acton:
Yeah, that would be lovely.

Laura Mauldin:
Okay. So I had planned for months leading up to the arrival of the pandemic and March 2020, I had planned for months to be launching, around that same time, a new study in which I was going to do home visits with people local in New York and Connecticut, New Jersey, to talk to them about their lives where one person in the couple – so it was all couples – was a caregiver to their partner that person may or may not be disabled themselves, but one of them identified as a caregiver.

And, of course, the pandemic happened, and I was certainly not going to be going to people's homes and traveling throughout the city or the tri-state area, and so I had to switch my project to a remote project where I was then recruiting online. I ended up posting in different groups and things, and so I recruited from a national sample rather than my local connections, although, to be sure, there are a few New Yorkers in the study that I talked to remotely.

But what ended up happening for me was, I felt unable to see people's environments, because I was just looking at them on a screen. I could get a sense of what was behind them. But it's not like I got a sense of how they moved through that space, how they used their space in caregiving and in co-creating access at home with their disabled partner. I would have been able to see that if I could go in-person, but because the in-person visits got scrapped, I was sort of scrambling a little bit to figure out well, what are ways, then, that I can see how people are using and making their space accessible, using things to make their space accessible.

And so, to solve that problem during the work, I had about 44 participants across 22 States, and not only did I interview them like we are interviewing now, but I interviewed everyone twice. For the second interview, in the intervening time, I ask them to send me photos of everything and anything that they used in care or creating access at home so that I could get a sense of what their space looked like, and the objects that they use, and the ways that they use them. So that ended up giving me over 500 photos. I got such a huge batch of photos that I then went through and pared down because some of them were duplicates, some of them were pictures of the same thing in a different space, but I also had a lot of fun going, “Oh, I have 20 different pill boxes here, like people have shown me their pill box”, or I have, you know, 20 different shower chairs or commodes, right? Or things like that. And so it ranged from sort of quote, unquote “standard medical equipment” at home to using, for example, painters tape. Like, one person held down paper because he had a stroke and only one side of his body works so he couldn't hold down a piece of paper and sign it with his other hand, so he would tape the paper down with painters tape, and then sign it, and did a variety of things this way. Actually anything that required 2 hands. He just used painters tape for everything, and so painters tape came up.

So those are some of the things that I got pictures of. So, standard medical equipment to repurposing different things. But basically, I ended up with this huge amount of photos. And I thought about, well, what should I do with them? And I don't use Instagram, so there was no sort of infrastructure for me to even know how to even begin with that, because I just don't know how it works. I don't use it and it seems to me that a website would be the most expedient way of collating all of these, and also being able to filter them by type, so that you can look through different categories. And so I wrote a grant for a web designer and worked with a web designer on how best to present that information. So that's how it ended up being a website. So that was a very long, roundabout answer.

Kelsie Acton:
No!

Laura Mauldin:
So it's a product of both my limitations with social media and needing to sort and filter in these different ways, and so a website seemed the best way to do that.

Coding Access-making and Adaptations

Kelsie Acton:
Yeah, can I circle back? One of the beautiful things about the website is that you can click on the adaptations button and sort of choose what category you want to look at. How did you go about determining the categories?

Laura Mauldin:
Yeah, that's a great question. So all 500 photos went into a qualitative coding software. And so much like you might code your interview transcripts, we coded – my research assistant and I – coded the photos. And as we did that the sort of they clumped together, in these different categories, so we kept coding “commode”, or kept coding, you know, the things related to wheelchairs or mobile other mobility devices so, and then “repurposing” was a code, because that was like, Well, where does that duct tape go? Right? So those kinds of things kind of got born out in the process of trying to code everything to collate. I'm just trying to get a picture of “What do we have? What's the range here? What kinds of categories does this span?”.

And then for the website, I thought, well, some people might be – it seemed to me that a lot of the adaptations clustered around rooms. So bathroom and kitchen in particular, because – and bathrooms are really really important, that's where the majority of falls happen. So, making your bathroom accessible means making your bathrooms safe, and so that's really important, and that was something that I think also as part of the project, is not just, “Oh, this is creative, like great, awesome, that you're doing this. This is super creative”, but also that,in creating access you’re creating safety, right? And that's really important. So that's why I kind of came up with the “rooms” situation, because a lot of people talked about being in the kitchen and like not wanting to burn themselves, ne person was an amputee, and they were trying to figure out safe ways to use an oven mitt on the one hand, but it wasn't safe for them to put their mouth on it to try and pull it onto their one hand. The trouble getting the mitt on was why they chose a trivet instead, like a silicone trivet that you could just grab with one hand without having to touch your mouth on the potentially hot things, that kind of thing.

So it seemed to me that a lot of the problems that we're trying to be solved were in these sort of activities around food and going to the bathroom or showering, you know, hygiene came up and I thought, “, “Let's think about this”. Creating access is creating safety.

Kelsie Acton:
Yeah. Can you also tell me more about the process of working with a web designer, once you sort of had a handle on what you had here?

Laura Mauldin:
Sure. So I'm so grateful to have had a web designer, Harris Kornstein, with a background in disability studies. It was really amazing to be able – and I learned of him through a friend and colleague, Mara Mills, – so this was a way that I felt I could have somebody who understood the technical side, but also the content,and to appreciate the content and how we might put that together.

I talked to him about, here's the pages I think we should have, you know, an introduction and description, something with more details about the project itself, and then a main page from which you can go through these different categories and bring up the category. He gave me a bit of a tutorial on how to fill in pre-designed spreadsheets that he made based on our desires, right? So, that I'm gonna call, I'm gonna use the word “axial” in the sense of like moving through these coded categories, but the spreadsheets included were sort of all-inclusive, so that it was the shorthand description of the adaptation, the alt text for the photo.

So it was done in this huge batch: the short description, the alt text for the photo – because everything on the website is described – and then the categories, and then the keywords, which are different. And then I added narrative that accompanies the photo or photos – in some cases there's multiple. I was able to learn how he needed that information in a very uniform way, and could do that in a huge batch. He basically took that information and uploaded the necessary pieces so that they would follow these categorical filters.

It was great, and I learned so much by being able to break down each piece and then put those pieces together in a way that made it as efficient and quick as possible for the designer. I took the 500 and narrowed down to about 80 photos. There's about 80 on the site, so that meant 80 alt texts, 80 narratives for all of these photos.

Penning Access Narratives: Capturing Cheerfulness and Creativity

Kelsie Acton:
Amazing. I love the tone of the narratives and, like, the way they're presented. Can you tell me a bit about your choices around that?

Laura Mauldin:
Do you wanna say more about what tone? I think I have a sense, but I wanna make sure I understand.

Kelsie Acton:
Yeah. I find it very conversational. You've got like these big chunks of often, like, quite lengthy quotes from your participants. Sorry I don't know what term you would choose in your field.

Laura Mauldin:
It's good. Yeah.

Kelsie Acton:
And yeah, and there's sort of – It feels helpful and warm to me when I read those narratives, like that was what you were going for.

Laura Mauldin:
Yeah, you know the big thing I was going for was, let's remove any hesitation, tension, stigma, embarrassment. We have bodies and we're just gonna talk about how we move through the world with these bodies. This doesn't need to be an antsy thing. We can just be very very nonchalant, to really model the acceptability of it, and to just treat it as the most routine thing in the world that our bodies have these needs. That's the routine thing. I wanted to make sure that I used a tone that conveyed cheerfulness and joy around the access part and the creativity part, right? I didn't wanna be cloying and like overwrought about it, but I also wanted to make sure that came through.

Kelsie Acton:
Yeah. Yeah, I love, love the idea of the cheerfulness, enjoy around access. That's really beautiful.

Laura Mauldin:
Yeah, and I think I talked about this a little bit on this, maybe I talked about this on the website, but it came out of my own experience with my late partner, when we would, for example, if we were traveling, and we needed to give an infusion because she had a port, and I would do infusions every week, and we would be out, we wouldn't have our IV pole because we were traveling, so I would take a shoestring and loop it through the saline bag and hang it and tie it to the shower curtain rod, and I never thought anything of that. It was just whatever, that was just what we did.

It wasn't until I was actually doing the project and started talking with people and asking for their photos and them telling me these stories like I thought to myself, oh, my partner and I have done the same thing like same kinds of things, and I had these flashes and memories of it, but I never thought to document it. I never thought it was anything special. And now, through this project and through talking with my participants, I was able to readjust the way that I looked back on things, and the way that I saw that what we had gotten through and how we'd gotten through, it was actually really quite clever so I wanted that to come through as well. That, hey, yeah, it sucks that you have to deal with some of this stuff, but this is so clever, and the world needs to know it, you know?

Online Participant Recruitment & Remote Research Practices

Kelsie Acton:
Yes. So you have a contact form on the website– there is a segue here, I promise– that says like, if you have questions or comments, or maybe your own adaptations to share, we'd love to hear from you without revealing anything that obviously you can't, have you heard from people?

Laura Mauldin:
You know surprisingly few, I would say less than 10. It's surprisingly few. I do get spam through that, so that's weird. But a couple of people. You know, what mostly comes through is people asking for help, and I can't help them. Like there are things that I can't help with, you know. I need a caregiver. I need help, you know, and I can't. It's a little bit devastating actually to receive those. And then, every now and then, I think I've gotten a couple where people have said, I bought this chair, and I really liked it, and we'll have a link to it. I'm just at this point kind of collating those and keeping my eye out. But yeah, sadly, that has not been as conducive to gathering information as I had thought. And you know probably it would do better if I was on Instagram and knew how to use social media, it might be more effective. So if there's anybody out there that's interested in doing that, that's fine, but I have my limitations.

Kelsie Acton:
Yeah, I mean, maybe this leads me to like one of the last questions that I wanted to ask, which will probably send us on a whole other tangent, but I feel like there's often a lot of talk about like contemporary disability culture being very online. By which people often mean social media. Clearly, this hasn't been your experience. Can you say anything about like? Oh, sorry! Where am I going with this? Yeah, like, what are some of– the you've talked a little bit about this earlier in the interview– but what are some of the things that the website and the online nature of your research has enabled?

Laura Mauldin:
Oh, yeah, I mean, I think, you know, I'm very online around Twitter. That's kind of it, which is its own thing. But I recognize it is not, as you know, visual, you know, it's not driven by photos like this website is.

But what I think is most amazing to me, doing this research remotely and getting to talk to people from 22 different states, that just feels amazing, first of all. Like there, in no context as a researcher, have I ever talked to people in 22 states, you know, in my life. And that was, I think, one of the biggest advantages to doing this project, because I don't think if I had been doing this locally, and my original plan, I was going to do a deep dive with like 5 people in New York because there's only so many people you can go to their house and spend time with them, but by shifting it online it became so expansive to me. And I could talk to so many, 10 times more people nearly, and see that people are being inventive across the U.S. That's amazing.

And that also they have the same issues. People across so many different states have the same challenges and they're figuring those things out in different ways. That was incredible to me. And I'll say that my recruitment really happened through the caregiving angle, like caregiver support groups, and so I came to people through that, but was able to include the disabled partner through incorporating the collaborations with the day-to-day access-making, and to me that felt like I could be more expansive in who's participating rather than just centering caregivers, I could bring in that collaboration.

Later in the following year, after vaccines, I got to visit 4 different couples in 4 different states, and some of the photos on the site were taken by me on those site visits and with extensive, you know, conversations with disabled folks around how they're using these objects. So that was another way for me, and that's not being online, that's going in person, obviously. But I wouldn't have known those people to go visit them had it not been for that shift online and for those connections into different caregiving groups. So there were Facebook groups on spousal caregivers, and these were all spouses, but then those people posted in their MS [Multiple Sclerosis] group, and then those people posted in there, you know, whatever group and it just spiraled out. So I think it expanded in ways that I couldn't have, I could never have planned for in my recruitment, because it was online like that.

Kelsie Acton:

Yeah, did you find any barriers associated with, like, recruiting and initially conducting the research online?

Laura Mauldin:
I mean. The barriers were from the IRB [Institutional Review Board]. That's where the barriers were.

Kelsie Acton:
Okay.

Laura Mauldin:
My university, put me through the wringer on this project and I was elevated to their general counsel's office because I was “asking about health”. I mean to my mind, I wasn't asking about health, but to their mind I was. So this was sent to the HIPAA [Health Insurance Portability and Accountability Act] person. Those are definitely research barriers you have to deal with.

Trying to get things posted in different places when there are gatekeepers around who can post in groups. And it's okay with me that there are gatekeepers. It's just that it sometimes didn't work out, because there's one organization that will not let any researchers post anything, and that was tough because they're a big, big organization and that was a barrier for me. The explanation I heard was that they don't want researchers to know more about their members than they do. That was how someone explained it to me, which I thought was very interesting.

So they have a blanket no research rule, and I found that to be a big barrier, because again, that was a really big organization and would have been incredible to be able to recruit through.

Kelsie Acton:
Hmm, yeah, that's very fascinating. It also has me thinking about like organizational resources on social media versus like, sometimes support groups are just run by like 2 or 3 people moderating.

Laura Mauldin:
Oh, yeah.

Kelsie Acton:

Yeah. And then different approaches.

Laura Mauldin:
Yeah, the more shoestring ones were the most open and the most giving. It was incredible to be in collaboration with those folks, and now I'm friends with them, you know. I gained a lot of friends. It was really an incredible process.

Disability Experiences, Caregiving, and Access Resources

Kelsie Acton:
Amazing. I just want to open it up broadly, is there anything I haven't asked about Disability at Home that I should have asked you for anything you want to say about it?

Laura Mauldin:
Just that I'm really proud of it, and I hope that people use it. I want to tell a quick story, and that is, I have a very good friend, and her father started needing more assistance at home, and her mother was sort of talking with her about this, and my friend said, “Oh, well, if you need some ideas, you can go to my friend's website called Disability at Home”. And her mom said, “Oh, that's really nice of you, but he's not disabled”. So I think there's a real barrier for folks who have impairments and need to get creative about access, but can't bring themselves to identify as disabled so that they might find something like this, or be open to looking at it. Yet, on my end it was really important to me to have disability in the name of it. So that I, because I want to signal a certain creativity and a certain ethos about what disability is. And yet this was the very thing that prevented some people from exploring it who would need it.

Kelsie Acton:
Yeah.

Laura Mauldin:
And that's a bit of a conundrum. That's a conundrum, and that's why again, to go back to the language and the sort of tone that's used throughout is precisely to kind of meet people where they're at around that, and to model,

we don't need to get upset, we can just talk about it. You know, and that if we just talk about it, then we can solve a=problem, and then there we go, you know, and then we're fine! So for me it was a bit of an experiment in, like, psychosocial kind of “How do I meet people where they're at? How do I make them comfortable in reading about this?” Because it may be that the people who are reading it are uncomfortable with the fact that they are. So that's an issue.

I find that disability communities are often separate from and siloed out from caregiving communities. And I think that overall I'm trying to tell these stories in different ways. So what this is, is a visual way that sort of highlights one aspect of it. The book is a different way, and highlights other aspects of it. But all of it together, I see this as coalition building work or coalitional work, so that we can break down some of these silos between caregiving communities and disability communities. Because, to me, there is such a powerful connection that is often split and siloed politically, socially, in the way that support groups are run, organizations are run, so that's another kind of barrier I think that I ran into.

Kelsie Acton:
Just wondering if you can like, just say a little bit more cause I've actually never thought about this. I think a lot about how different disability communities siloed themselves off.

Laura Mauldin:
Yeah.

Kelsie Acton:
But just say a little bit more about like, how caregiving –

Laura Mauldin:
For example, yeah, for example, I think a lot of the caregiving organizations - there's organizations that support family caregivers, for example, family caregivers usually - not always, but usually - don't see their problems as a product of structural abandonment of disabled people. They see their problems more individually, just like folks that may not identify as politically disabled, see their problems as, “Oh, this is my individual problem that I have to figure out and I'm, you know, worthless to become it because of it, or something”, right? Individual caregivers are going, “I just need a tool to

get me through this day” They're not thinking that there's this huge, like, that there's design issues, or that there's systemic ableism.

That means disabled people, who have been largely abandoned by the state, have to then be reliant upon caregivers, unpaid family caregivers at home. This is not sustainable or safe or thriving for anyone. But generally, I think the politics of disability and disability communities play out in one arena, while the politics of caregiving often play out in another. In other words, I don't think the politics of disability, the systemic nature of ableism is often on the radar, if that makes sense, of caregiving-related movements. That I didn't do on the website is say, this is what ableism means, I didn't do any of that.

What I did do was model what it might look like to talk frankly about these things, and to model a space where it's simply our bodies. And it's totally acceptable, and it's fine. And to me that is modeling a radical departure from systemic, structural, internalized ableism, and instead offering up this more freeing option of all needs are acceptable, all bodies are good bodies. Let's just problem-solve and think about all the amazing, beautiful things that you're doing to do to get through the day and recognizing that as creative and ingenious and innovative, and all these things.

I'm very much inspired by Aimi [Hamraie]’s work and their co-author Kelly [Fritsch], and you know, very much inspired by some of that, but also not wanting to be heavy-handed at all, or academic, on the site.

Kelsie Acton:
Yeah, once you see it, I can totally see it in the way you’re like, it's not pointing out the massive design issues with any of these things are the built environment. It's just saying, here's some solutions, and in some ways just providing the solution points to the initial issue. But not in the same way that like ADAPT would have.

Laura Mauldin:
Right, right? Yeah. So it's sort of a careful balance of being helpful, hopefully, but also again emphasizing the joy and the creativity, and frankly, the ordinariness of it, like. We live in these bodies, and it's utterly ordinary to encounter impairment. And so we need not be fussy about it. People

tend to get so pent up and full of shame around it. So yeah, it's sort of an anti-shame ethos. I hope that comes through.

Kelsie Acton:
Very much so, I think, we went on a tangent, of course, so I'll ask like one more time. Is there anything else I should have asked, or any last stories you wanna share?

Laura Mauldin:
No, that was just the one story I wanted to mention. Yeah.

Kelsie Acton:
Yeah, it's an important one for sure. Thank you so much for your time. I so appreciate it.

Laura Mauldin:
You're welcome.

Kelsie Acton:
And also your website is a delight, it was great to spend some time with it.

Laura Mauldin:
I'm so glad, I'm so glad. Share it with whomever.