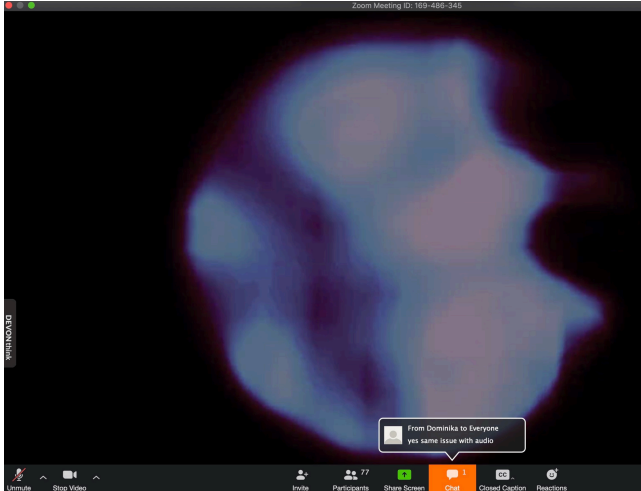




EI WELLSPRING EDITOR

Interview Date: November 2, 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

adapted home,
analog access,
chemical sensitivities,
electrical sensitivities,
environmental illness,
in-person, isolation,
mail, newsletters,
personal assistance,
planned
obsolescence,
telephone

IDENTITIES GIVEN

disabled, severe
multiple chemical
sensitivity, electrical
hypersensitivity,
photosensitivity,
environmental illness

LOCATION

United States

Interview for Disability Culture and Technology Study at Vanderbilt University
November 2, 2023

Biographical Information:

I am “El Wellspring Editor,” I prefer my real name to be withheld. I am 62 years old, male, living in rural Arizona. I am disabled by severe multiple chemical sensitivity, electrical hypersensitivity, and photosensitivity. This I collectively refer to as environmental illness (EI).

I have not held a job since the year 2000.

I am a part of a disability community, both in a broad sense and locally as well, as I live in an area where many people with environmental disabilities have settled. We live here as the air pollution and electrosmog is very low, and cost of living is low as well. It also allows us a social life.

Questions about remote access before the COVID-19 Pandemic:

The COVID-19 Pandemic has no effect on my use of technology. I already lived rather isolated from the rest of society due to mainstream people’s chemical and electronic lifestyles, which are harmful to me. I have practiced “social distancing” for decades before that name was invented, to avoid the chemical plume surrounding nearly all people created by their choices of personal care and laundry products — a plume most people are not even aware of themselves.

The only break in this imposed social isolation is through remote access, and interaction with other people with EI in the local community. Other people with severe EI also live without noxious chemicals and electronics, thus are safe to visit and have visit my home.

My remote access to other people, and any media, is mainly on paper. I receive personal letters and newsletters through the postal service. I subscribe to several magazines. I hire people to manage an email account with incoming emails printed on paper for me. They also find information on websites, based on specific questions or document names I request. This is also printed on paper.

I receive about a hundred sheets of printouts per week. As the fumes from the ink and the paper itself are a problem, each sheet is aired out for 24 hours on a clothesline inside an outbuilding.

Outgoing communication is also on paper on my end. I handwrite letters sent by the postal service. Where needed, I have the letter scanned as an image and stored in a PDF file and emailed to the recipient. This method is called "scanmail." I was introduced to scanmail 5-7 years ago, when our local copy shop upgraded their photocopiers. The new machines were Kyocera digital copies, connected to the store's wired network, and the internet. They had a button on the front panels to do scanmail. Very simple: enter the email address (or select one pre-stored), put the document in the feeder, press START, and it is done. The store offered this service for one dollar, along with other services, such as sending faxes.

A helper does this for me, instead of the store. This is simpler, and the return address is then mine instead of the store's.

It allows me faster transmission of messages, and the recipients intuitively understand they can reply electronically. If people receive a postal letter, that seems intimidating these days, as they may feel obligated to respond the same way, which many people are no longer comfortable with. Thus, they may not respond at all.

Once communication has been established, I may send letters through the postal service while they continue to send me emails. That is simpler for me than the scanmail. I do wonder if people think of such a different approach as strange, too beyond their comfort zone.

There is also the problem that people often expect their message to be received and responded to within hours. I operate on the timescale of days and weeks. It usually takes a week from I write [sic] something to it is actually sent. And it can take a week or two before I receive their message on paper, and the stack I get can take a week to air out (the line holds twenty sheets at a time).

The scanmail system saves a bit of money when communicating with people in other countries, especially if I include attached documents. Of course, I can't present my text as nicely as on a computer, with italics, fonts, etc. Nor can I do much editing — that's pretty much limited to using the eraser, or rewriting the page.

I use a reading box for books and magazines, as they are not realistic to air out. The reading box encapsulates the reading material and keeps the fumes at bay. I move the pages with two sticks and read through the glass top of the box. This technology is at least forty years old, I've used it for about twenty years.

I do not use social media or Zoom, as they require direct interaction with a computer. Computers hurt.

I use the phone sparingly, as it hurts, too. Nearly all phone communications is [sic] by leaving voicemails. It takes five minutes on the phone to say interactively what you can say in one minute on a voicemail. We've experimented with trying to eliminate the pleasantries on interactive phonecalls, but it is not possible, the social conventions are simply too strong.

I receive postal mail once a week. Every other week I also get the email prints. I always look forward to these days, it's like the "mail call" in the Army of old.

I am the editor and main writer for the website EI Wellspring. I started it in 2007, i.e. 16 years ago, to put the kind of information out that I wished I had when I needed it. I trusted I would be finished in a couple of years! I didn't plan on it being ongoing, but there seem to be endless topics to cover. The mainstay is various ways [sic] to cope with EI. Much I've learned from others, some I've figured out myself. Severe EI is daunting in the start [sic], this is a place people can seek out comprehensive answers that are thought through[.]

I write and edit the website almost entirely on paper. Most computer use is copying files between flash drives, which are then handed over to someone who sends them by email to the webmaster, typists, authors, etc. They respond back by email, which I receive on paper. That includes updated webpages, typed documents, etc. I instruct the webmaster by marking up prints of the webpages, with instructions where [sic] to place new documents, etc.

My part is very slow and very labor intensive. It would be much faster and simpler if I could just do it myself on the computer. My rule of thumb is that what a regular person can do in one hour on a computer will take me at least [emphasis in original] two weeks. It can be four weeks.

I compensate by being very organized, and running a sort of assembly line. From [when] I finish writing a new document, it takes three months before it appears on the website. It can sometimes take six months. I mostly hire people with disabilities, their work capacities can fluctuate, some get sicker over time, I've had one die on me.

I have many adaptations in my home: how it is built, how it is heated, how I get electricity, my phone, my car, how I cook. It is a very long list. The website is pretty much the list, almost all of it involves personal experience.

Much I learned from others, personally. That is inefficient and unavailable to most people, hence the need to put it on the web.

I have helped several others with their adaptations, such as when building a house or buying an air purifier. Their questions inspired me to write about the problem, or update articles I already had. We do a lot of updates, as we learn more.

I don't really recall many questions on remote access issues, other than basic stuff about telephones and computers. Most people give up when they become that severely disabled. It took many years to get from "all I can do is sit and stare at the wall" stage to overcoming enough barriers that I can do something again. I've never been the kind of person to spend a day on the beach, I need interesting things to do, I've found it [sic] with the website.

Question: Were you ever denied access to remote participation or accommodation...

Not in any malicious way. People have been pretty good, as long as they are not inconvenienced. Businesses require you to use a computer for most communication. They ignore any letter sent to them. Calling on the phone is impossible. So I pay someone to access their websites for me, at my cost.

I file my annual tax return on paper. They now delay sending out the forms beyond the filing date, perhaps to force people to file online. I get someone to download and print the forms for me, to circumvent that. But in a couple of years the IRS will not longer accept filings on paper. We'll see how that'll go with someone doing the filing without my presence. I can't go to HR Block or such places.

One barrier is that some businesses want electronic authentication, especially by sending text messages to your cell phone. My phone is not a cell phone, it cannot receive text (SMS) messages. I've had to give up once. As the talk was optional, it was not worth the trouble. In another case, I talked to someone on the phone, who took care of the problem after many "control questions" such as the name of my first pet, etc.

I've had to ask friends to be the person holding the phone for the long waits though. Businesses really discourage people from calling them that way, which is another barrier to me who can't really use a computer. Another problem with businesses is that they really, really, really want your email address. They promise not to send junk emails, one phone operator was adamant they never did, but they still did. I have to pay for all that paper. So I have to instruct my helpers to NEVER give out my email address. They sometimes forget. Then I have to ask them to mark the sender as a spammer so their emails don't get printed. Asking a business to remove you takes more effort and doesn't always work anyway.

Questions about COVID-19 Impact on my remote access:

The pandemic did not cause any changes to my remote access, or how other people engage with me. Video tools such as Zoom and Teams are not accessible to me. I do fear that zoom will be required to access some services, such as healthcare now [that] the pandemic made them more "acceptable" to use. If I had just MCS, I would be thrilled to use Zoom, as doctor's offices are often a problem to enter, especially their waiting rooms (most do not allow you to wait outside).

General questions about novel ways the disability community use or modify technologies for remote access:

Many of us reduce the radiation from computers by running them on batteries instead of grid power, and then charge them when we are not near them. We disconnect the wireless part and use cables for internet and peripherals. A computer mouse radiates less than a touch pad. An external keyboard allows a little extra distance to the computer, compared to a built-in keyboard on a laptop.

A few people have spent serious money building a shielded rear-projection monitor setup. With the computer itself well away. Personally, I use a laptop computer placed on a high counter. I use it standing up. I step back and forth, so I'm only near it when I actually need to touch it. In between I get ready for the next task, all to minimize exposure time and maximize what I can accomplish in the combined five minutes of time I have available (which may be spread out over 30 minutes of clock time).

Some people use tube telephones. The technology was invented in Sweden in the 1990s for use with landline phones. There was a small cottage industry manufacturing these phones. The handset is totally non-electric. INstead there are two sound tubes that carry the sound to the ear, and to the microphone.

The phase-out of telephone landlines is a serious threat to us. Some people with EHS already live without any phone service, in particularly in Scandinavia where the dismantling is moving most aggressively. Some people use a cellphone they place on a table and then step back from, using the speaker phone option. Others use a headset with a long cord. Another option is a fixed wireless setup, with a transmitter that is connected to a traditional landline phone. These used to be available from both AT&T

and Verizon, now only Verizon offers it. We'll see if Verizon will come out with a 5G version, or [if] they'll let it die when 4G is phased out.

People who live in areas not serviced by Verizon are not able to use this system. That of course includes much of the world. These are people whose only option is using a cell phone. Some use them for texting only. They start it up so it connects with the tuner, while they stand back. They pick it up and set it to airplane mode while they read and respond to any text messages (also called SMS). Then they take it out of airplane mode and set it down so it can transmit. Then shut it down again.

The electronics itself [sic] radiate too much for me to use this method myself.

The traditional analog landline is still the safest for us, but unless the world wizens up about the health hazards, they will die out. In Scandinavia they [are] now actively dismantling the landline system.

On our website, eiwellspring.org, we put all articles in both HTML and PDF formats. The PDF formats print better, so people who can't use computers much can read the articles on paper. We also use a menu system listing the articles, so people can print the menus and mark which articles they want for a helper to print for them. Unfortunately, a lot of other websites do not print well, with text missing or poorly formatted, etc. A website is not accessible if it cannot be printed.

The EI community has adapted and developed a great many technologies in other areas, especially around healthy housing and indoor air quality.

"EI Wellspring Editor"