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Life at a Distance: Archiving Disability Cultures of Remote Participation

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PLATFORMS & INFRASTRUCTURE

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In March 2020, the Covid-19 pandemic spread to the US, causing widespread lockdowns. Entire industries and workplaces shifted online, and nondisabled people struggled to adapt to these shifts. Many considered remote work and telehealth to be temporary solutions to a pandemic that (purportedly) would end after enough isolation. Others attempted “hybrid” solutions, such as when university classrooms divided their time between online learning and socially distanced, in-person learning. All of these options involved steep learning curves and investments made to facilitate safe, remote participation.

For one group of people, however, remote participation was a familiar, necessary, and still-contested part of daily life. Prior to the pandemic, many disabled people and disability communities relied on remote forms of accessibility, including email listservs; video streaming; and asynchronous participation through audio, video, and textual media. In the medical realm, practices such as telehealth and teletherapy date to early-twenty-first-century communication technologies (Zeavin 2021). In the social realm, people with chronic illnesses have long participated in events or even organized political protests and conferences from their beds (Piepzna-Samarasinha 2018). Autistic and neurodivergent people have used email listservs to communicate when in-person socializing is inaccessible or less desirable (Sinclair 2010). Some Deaf and hard-of-hearing people use video chats for communicating via sign language. And Alice Wong, founder of the Disability Visibility Project, famously visited the White House via a robot to meet President Barack Obama.

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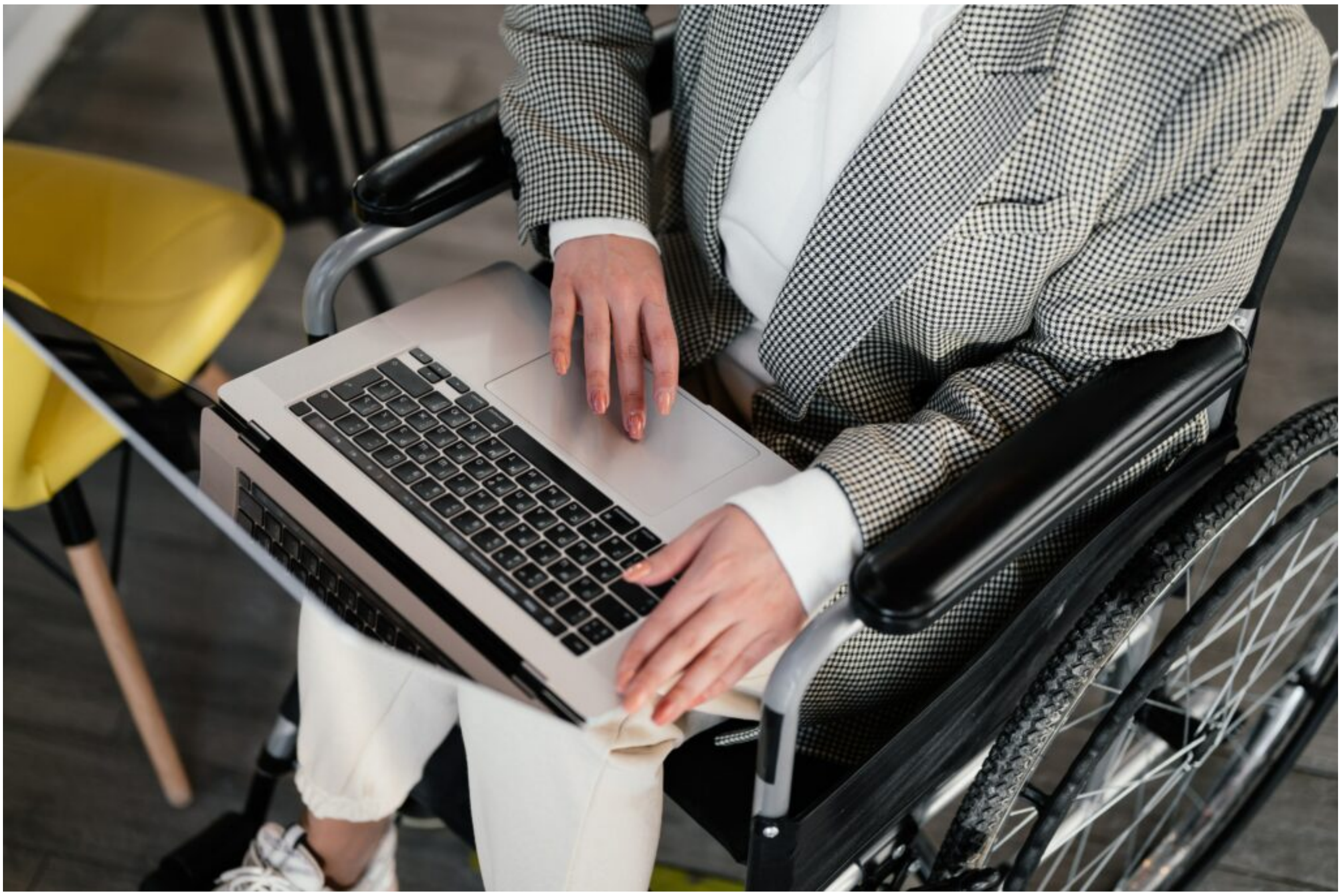
Although remote access precedes the pandemic, this phenomenon finds continuity with the forms of exclusion that disabled people face (and respond to) in our contemporary era. Prior to the pandemic, many disabled people requested—and were denied—access to remote learning, work, healthcare visits, conferences, and other opportunities. Frequently discussed within our own disability communities, albeit anecdotally, are the many requests for remote teaching, learning, and participation that were denied on the basis of perceived budgetary scarcity or technological unavailability. And as the pandemic-related restrictions were relaxed, remote options decreased. For example, in fall 2021, as campuses began to reopen, students at UCLA protested (both online and in person) to demand remote options. Remote access is thus precarious: even when it exists, it can easily be taken away. Put differently, while remote access is necessary for the participation of many people for many reasons, it is ultimately governed by forms of power dictating the allocation of resources, as well as by social values dictating that access for some is more important than access for others. The term *accessibility* usually describes efforts to make the public sphere (such as streets and buildings) more inclusive for disabled people, but within disability culture, in particular, remote access is a significant (though largely undocumented) dimension of social and vocational life. Thus, with funding from the SSRC’s Just Tech program, we set out to document the uses of remote access in disability communities, both before and during the pandemic, in the Remote Access Archive.

Distance and Proximity

Struggles for disability rights have often emphasized the right to public presence and participation. Since the early twentieth century, disability activists have demanded the closure of institutions and nursing homes that kept disabled people out of public life (Ben-Moshe 2020). They agitated against eugenic-era “ugly laws” dictating that people with physical differences should be unseen on the street (Schweik 2010). Yet, the absence of broad, public accessibility has often necessitated that some disability communities operate across long distances, whether through the use of the internet by chronically ill and neurodivergent people or through the uses of earlier analog technologies such as newsletters (Williamson 2012).



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Anecdotally, histories of remote access are part of the origin stories of various disability communities and movements. Autistic self-advocacy, for instance, famously emerged in the 1990s from internet discussion boards, which allowed autistic adults to connect and form communities without having to socialize in person (Sinclair 2010). Even earlier, in the 1940s and 50s, institutionalized disabled people used technologies such as sending quilt patches to their families (as forms of storytelling), while disabled people living at home with families shared tips and tricks in print newsletters for making houses more accessible (Burch 2019).

Digital forms of remote access for work and social life have been important within disability communities, but they were less available within the mainstream prior to the Covid-19 pandemic. Kate McWilliams's hashtag #AccessibilityForAbleds points out the irony that the forms of accessibility that disabled people developed (and that were often denied by employers, universities, and other institutions) were now becoming widely available due to the needs of nondisabled people to work and socialize from home. Others pointed out that the relative ease and creativity with which disability communities shifted online was possible because many were already participating through remote, digital tools, such as livestreaming events with real-time captioning and American Sign Language interpretation.

Disabled people are increasingly using the internet and social media to shape approaches to technology informed by disability culture, with specific attention to intersectionality. These approaches include the creation of new hashtags, the reappropriation of technologies such as Zoom and Google Docs, and experimentation with artificial intelligence–generated captioning. It is undeniable that remote forms of access have been significant to the formation and continuation of *disability culture*, a term that encompasses the myriad technologies, protocols, and social practices that emerge when disabled people engage with one another, whether in person or across long distances.

Yet the frictions surrounding remote access are evident through the framework of inclusion, such as when “inclusive design” is understood as “design for all.” These frameworks suggest that designing for some disabilities is inclusive of all disabilities and access needs or that what benefits some disabled people ought to be the preference of all disabled people. Historically, the concept of “design for all” has also represented disability as a homogeneous category that is not intersected by race and gender (Hamraie 2017). For example, architectural accessibility focuses on technical standards for wheelchair ramps but rarely takes account of how race, class, and geography shape access to buildings used for housing or employment.

> *Online platforms have enabled Black disabled content creators, in particular, to shape cultural narratives about disability*

By contrast, contemporary forms of remote access, particularly social media, complicate disability as a singular identity. As Vilissa Thompson argues, online platforms have enabled Black disabled content creators, in particular, to shape cultural narratives about disability. “Technology,” she writes, “gives us the ability to find the community we desperately seek, particularly those of us who live in areas that are not very diverse or where we cannot venture out safely or independently in our communities due to systemic and/or architectural barriers” (Thompson 2019). As the *New York Times* reported, young Black Deaf people have sought out TikTok and other social media platforms to both use and draw attention to the importance of Black American Sign Language. Social media has thus provided a public face for the forms of disability culture that have been growing for decades.

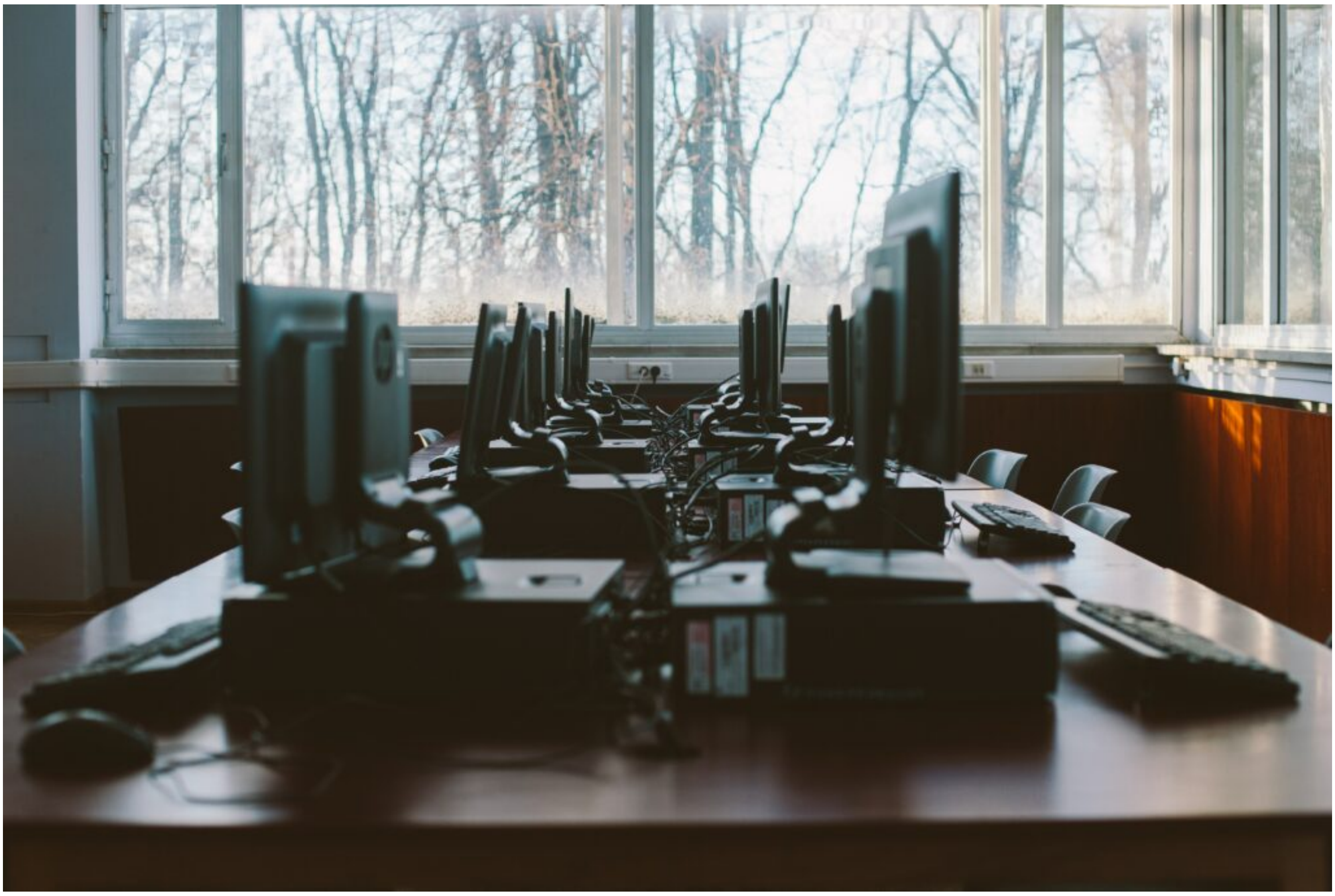
Digital platforms and resources can also create access barriers for some disabled people, including blind people, for whom images on the internet may not be discernible by screen reader technologies. In response, cultural practices of image and audio description have emerged to embed data about image content in photos and videos. Remote projects devoted to image description have yielded important community resources. People’s Image Descriptions, a Facebook group moderated by disabled people, adopts a crowdsourcing model, which simultaneously teaches the skill of image description and provides a resource for those for whom producing such descriptions is difficult. Bojana Coklyat and Shannon Finnegan’s Alt-Text as Poetry project invites participants into creative, iterative, and aesthetic approaches to accessibility. The pair host events such as Alt-Text “Potlucks” to invite others into this practice.

Remote participation provides an important means of connection but is also often imperfect and can even be exclusionary. Connecting remotely requires access to certain resources, such as the internet, a computer, or a smartphone. Zoom fatigue is a serious concern for many people with ADHD. In some cases, remote connection precludes other important forms of participation. Artist Joseph Grigley’s

“Inventory of Apologies” documents the lack of access for Deaf people in remote meetings and events during the Covid-19 pandemic (Grigley 2020). DeafBlind scholar John Lee Clark uses the term *distantism* to describe the bias of many forms of accessibility (including American Sign Language or audio) toward vision or hearing, two senses that for some can be felt at a distance, without direct and tactile touch. Clark advocates instead for the close proximity of tactility and touch, such as in the DeafBlind language ProTactile, which requires in-person participation and interaction (Clark 2017).

Archiving Remote Access

While remote access pervades disability history in the twentieth and twenty-first centuries, its forms and protocols are largely undocumented. In disability archives—such as the University of California Berkeley’s Disability Rights and Independent Living Project, the British Deaf Museum and Archive collections, and the Living Archives on Eugenics in Western Canada at the University of Alberta—disability communities are documented according to their geographic proximity and based on demands for access to public space. Less well documented are the methods of contact across long distances that have taken place throughout this historical span.



Funded by the SSRC’s Just Tech program, we created a new archive project in 2021 to document disabled remote access before and during the Covid-19 pandemic. The project grew out of the Critical Design Lab, a collaboration of disabled artists, designers, and researchers who apply disability culture methods to studying design and technology. The objective was to document the ways that disabled, Deaf, chronically ill, blind, and neurodivergent people have engaged in remote forms of participation. Specifically, the archive has sought to identify the specific technologies, social protocols, ways of relating, and ways of adapting or reconfiguring the world that shape and have been shaped by disability culture.

Submissions in the first six months of the project reveal the creative and political uses of technology that continue to shape disability culture, even during the pandemic. Some items document the role of remote access in shaping conferences, public events, and residencies. For example, in 2010–2011, disability scholars Sue Schweik and Cathy Kudlick organized a virtual critical disability studies residency conducted over Skype, before Zoom even existed (Kudlick and Schweik 2014). Accounting for the various interactions of assistive technologies with virtual platforms has been a focus since these virtual gatherings began. These negotiations of accessible technology have become well known within the knowledge base involved in planning disability gatherings, yet they have been largely illegible to nondisabled people shifting online during the pandemic. The archive contextualizes these disability community norms alongside other guides to accessibility developed during the pandemic, such as Danielle Lorenz and Hannah Sullivan Fackwitz's conference paper on cripping pandemic pedagogy, documenting these disabled graduate students' activism within the academy for their students' access as learning went remote.

Documenting the shift to remote working, learning, and connecting during the pandemic has also been an important part of the Remote Access Archive. Liam O'Dell's writing for the *Limping Chicken* blog documenting the #WhereIsTheInterpreter campaign is now part of the Remote Access Archive. This campaign, beginning in the early days of the pandemic, successfully pressured the UK government into including British Sign Language interpreters at Covid-19 press conferences, ensuring meaningful access for Great Britain's Deaf community to critical public health information. The archive also features artist M. Eifler's virtual gallery of their weekly paintings incorporating newsprint in response to the first year of the pandemic. These paintings exist in virtual space but are also deeply local, as headlines specific to the San Francisco Bay Area can be glimpsed through the bright whorls of paint.

The Remote Access Archive also documents the emergence of technologies for forms of access that go beyond more productive work or energetic social lives. Raquel Meseguer Zafe's Cloudspotting, an app and virtual performance developed before the pandemic, allows people who have to rest in public to log in and find solidarity and community with people around the world resting. Each time a member of the Cloudspotting community rests, they log on and appear in the app as light in a constellation; they can see the lights of everyone else who is resting. The collection also includes the Autistic Archive, which collects the blogs and websites through which autistic people around the world found each other and developed their culture.

> *Disability culture has been, and will continue to be, engaged in remote access, bringing people together to work, learn, connect, and create.*

These and many other interviews and documents attest to the prevalence of remote access within disability communities, particularly in social media and online digital spaces. But more importantly, they reveal that remote access continues to be a site of ingenuity, experimentation, and reinvention informed by disability experiences. More remains to be documented and explored, particularly in terms of the longer histories of remote access through predigital and analog technologies, including telegraphs, mail, phone trees, and print ephemera.

Remote access is an important yet underdocumented part of disability culture. Access to public spaces will always be a vital part of disability activism, particularly in this moment, when the rush to declare the pandemic over has forced some disabled people at particular risk from Covid-19 to return to isolation. But disability culture has been, and will continue to be, engaged in remote access, bringing people together to work, learn, connect, and create.

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