# **High-Touch Media**

Caring Practices at the Deaf AIDS Information Center

ABSTRACT Disabled activists in the United States brought unique expertise to HIV/AIDS in the 1980s and '90s, including understanding social stigma and health as social justice issues and approaching information as a complex access problem. Disproportionately affected Deaf communities mounted a response that carefully blended face-to-face caring practices with mediated information by and for deaf people grappling with HIV. San Francisco's Deaf AIDS Information Center (DAIC) advocated for wider access to Telecommunications Device for the Deaf (TDD) in the AIDS service sector while also marking this text and modem-based machine's inadequacies as a substitute for the high-touch, one-to-one interpretive work needed by many ASL users. Crossovers among media, AIDS, and disability justice histories are underdocumented and risk seeming minor. Through our analysis of the DAIC, we argue that this intersection is key to advancing knowledge of how HIV left an imprint on emerging communication technologies and how sexuality and disability factor in technological cultures. KEYWORDS Activism, ASL, Deaf, Disability, HIV/AIDS, Information, Scrapbooks, Telecommunications Device for the Deaf

# INTRODUCTION

The HIV/AIDS crisis that exploded in the United States in the 1980s generated many responses. Stigma, silence, and government abandonment of the sick, the dying, and the vulnerable was met by vital activism aimed at meeting basic material needs and sharing good information about prevention and treatment. As the crisis most profoundly affected gay men, IV drug users, and Black and brown communities, activists knew information about HIV/AIDS needed to be culturally specific and peer-delivered to be meaningful. Within this context, disabled activists brought unique expertise and experience with social stigma and health as social justice issues, approaching information as a complex access problem. Deaf communities in particular were disproportionately affected by HIV/AIDS and mounted a response to the crisis that carefully blended high-touch, face-to-face caring practices with

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information by and for deaf people grappling with HIV.<sup>1</sup> In this article, we draw on archival research to surface and document the crossovers between media, AIDS, and disability justice histories, focusing on the San Francisco Bay area as a geographic crossroads and a site of intense interchange between AIDS activists and disability justice advocates in the late 1980s. Exchanges between these movements are underdocumented and so risk seeming minor. We argue that this intersection is key to advancing knowledge of how HIV left an imprint on emerging communication technologies and how sexuality and disability factor in technological cultures.

We focus on a specific organization called the Deaf AIDS Information Center (DAIC) and how those working at the center advocated for access to HIV-related information for deaf people. This organization campaigned for the provision of Telecommunications Device for the Deaf (TDD),<sup>2</sup> a technology that used teletype machines and modems to facilitate telephone communication using text. The DAIC advocated for wider access to TDD in the AIDS service sector while also marking its inadequacies as a substitute to the high-touch, caring, one-to-one interpretive work needed by many ASL users (TDD relies on written English, a second language to most ASL signers). Much of the work of the DAIC was based on ASL interpretation, integral to the work of many organizations for the deaf, and one based in a "face-to-face tradition" as Ben Bahan calls it. This face-to-face tradition is not reducible to the (false) binary of "oral" versus "written" communication and often involves vital provision of information and access to community and culture through an expansive use of media.<sup>3</sup> As we argue, the work of the DAIC often implicitly involved creating access to information through this mediatic intervention and media difference.

The Deaf AIDS Information Center operated out of St. Benedict's Catholic Church for the Deaf on Bush Street, between the Japantown and Pacific Heights neighborhoods, from 1988 until it became part of the University of California, San Francisco (UCSF) in the mid 1990s. The organization emerged out of the Deaf Services Network–North, which united agencies responding to the health and social needs of deaf and hearing impaired people in the Bay Area and formed an AIDS Task Force in response to the emerging health crisis HIV presented.<sup>4</sup> Led by Darol Nance, a straight, white woman (and parent to a gay man) who was deaf and a lifelong advocate, the organization focused on creating accessible AIDS information for deaf people through resource guides, TDD advocacy, interpretation services, and other forms of outreach. In this focus on outreach, the organization

looked like many other AIDS service organizations. What set them apart was making information accessible to deaf people experiencing a lack of access to culturally and bodily specific resources, and, from some existing deaf services, stigma around homosexuality and substance use.<sup>5</sup> This work took place within a broader national context of deaf AIDS outreach, including similar organizations in other cities and the National AIDS TDD Hotline.

In undertaking a media history of the Deaf AIDS Information Center, we ask how the organization's grounding in San Francisco's deaf, gay, and deaf-gay lifeworlds shaped its capacious understanding of information as one facet of a larger caring practice. To undertake this history, we analyze the DAIC's media technology advocacy work for TDD and ASL alongside their record-keeping and scrapbooking practices. Using techniques of bricolage, annotation, and candid photographs, these scrapbooks show how the DAIC empowered a high-touch care network and interpreting service for deaf gay men dying from AIDS. This work was an intrinsic part of their access politics and everyday information work. Portraits of men in hospice are pasted in the scrapbooks alongside documentation from workshops on ethical ASL interpretation of conversations about HIV and documentation of volunteers operating TDD phone lines. They also share space with records of deaf gay desire, and joy, like a signed headshot of Phillip Rubin, Mr. Deaf International Leather for 1992, who was an HIV/AIDS advocate. When the records of an activist or service organization survive as an archive, we often find file folders containing records of administrative paperwork, mailing lists, photographs, and ephemera—and other random dross. In the case of the DAIC, the records include similar artifacts like papers, photographs, certificates, and posters, but they are compiled in these five large scrapbooks.

In the scrapbook archives of the DAIC, living, dying, and finding information were deliberately entwined; as Nance explained at the annual deaf memorial service, a speech delivered in ASL and translated to written English in the scrapbooks, the organization was guided by, "REMEMBRANCE for those who have died of AIDS.... HOPE for cure, better treatment, understanding, communication.... ACTION for better services to improve networking and accessibility.... [and] LOVE for everyone." By reading these scrapbooks as an archive, we argue that the intersection of deaf culture and HIV in San Francisco enriches an understanding of information as crucial to care and provides a disability studies context to the history of modems, computing, and information media.<sup>7</sup>

Our analysis is grounded in intersecting literatures. Recent scholarship has revisited questions about information, access, and HIV from a historical perspective, framing AIDS activist work with information and networks as critical experiments. These histories build on media studies written during the North American AIDS crisis and complement recent theorizations of care and care networks developed in and through AIDS and its structures of harm and survival. We bring these literatures into dialogue with media studies of deafness and deaf culture and the literature on scrapbooks as affective media in queer and trans archives. We ask how the remediation of information reorients our understanding of care and technology.

# DEAFNESS, AIDS, AND SAN FRANCISCO

AIDS has always been both a crisis of survival and a crisis of information. Information can save lives and reduce suffering. This could be a matter of bringing the epidemic to public awareness (seeing a pattern of suffering, giving it a name, calling attention to the scores of people—gay men, IV drug users and their partners, Black and brown people—who were dying, and demanding care); it could be a matter of spreading information about possible routes of infection or methods for safer sex and substance use. As AIDS gained public coherence as a "crisis" in the 1980s, AIDS Service Organizations (ASO) emerged from the nonprofit sector to generate information about community support, treatment options, and medical rights. <sup>11</sup> The DAIC replicates this pattern as an ASO and also through the specific ways information was shaped and reshaped through deaf lives.

Beyond the fact that the DAIC undertook work that was typical of ASOs in this period, there are some other notable connections between HIV and hearing loss and deafness. For one, many HIV+ people in the 1980s and '90s reported hearing loss in one or more ears; during the earliest years of the pandemic, it was estimated that half of infected people had experienced some hearing loss (though these figures have since been complicated). This meant that people already learning to survive as HIV+ were often also learning to live with hearing loss, and often did not have a preexisting relationship with the Deaf community. There is another incredible coincidence that connects multiple viral communities. The 1964 rubella epidemic in the United States caused a dramatic bump in the number of babies born with congenital hearing loss. These children reached adulthood in the mid-1980s and faced a deaf service infrastructure (e.g., universities, social services) that was too

small to meet their needs.<sup>12</sup> A report by Mark Cairns titled "Deaf People and AIDS," clipped for the DAIC scrapbooks, posits that this over-representation of deaf people at a highly sexually active age during the early AIDS crisis, combined with a lack of access to culturally appropriate, accessible sexual health information, put them at much greater risk for contracting HIV.<sup>13</sup> Finally, San Francisco offered its own factors for bridging HIV/AIDS and deafness: the city had a high concentration of queer people and coordinated AIDS response, a large deaf population and services infrastructure, and entrenched and organized disability activists.<sup>14</sup>

The relative weight and effect of any of these social confluences is difficult to prove, but such an endeavor is beside the point anyway. What matters is that the DAIC collected and clipped articles and ephemera that made claims about each of these causes and their effects. In other words, the DAIC's information work, and documentation of this work, records how deaf people understood their experience of HIV as fundamentally shaped by deafness and distinct from the AIDS crisis experienced by nondeaf people. These circulating ideas about deafness and HIV/AIDS in this geographic location and historical moment shaped how the DAIC imagined, carried out, and archived their work. Their information work complicates how we understand media and access in histories of AIDS. Access does not just allow entrance into an able-bodied world of AIDS response. Instead, access is a durational and embodied practice shaped by the temporalities of illness and disability and the mediations of relational technologies and instruments.

# **DISMEDIATION-REMEDIATION**

As part of their care work, AIDS activists, educators, and service organizations frequently created and distributed information about HIV. This included publicizing the existence of the virus, sharing information about vulnerability, demystifying and countering misinformation and lies, and brokering access about and to treatment options. AIDS service organizations were also central in channeling rage and anger at official responses to HIV and the stigmatization of death and illness. As such, these were also centers of commemoration and mourning. In the ongoing recognition of the HIV epidemic's harm, it is artifacts like protest posters produced by ACT UP or the NAMES Project AIDS Memorial Quilt that signify this period in the American context of a "viral culture."

The DAIC was like other ASOs in the ways it engaged in this same care, labor, information-brokering, and commemoration. The DAIC fundraised through bake sales, walkathons, and clothing donation drives. The scrapbooks also record the DAIC's participation in the Deaf NAMES Project, which aimed to add the names of Deaf victims of AIDS to the national memorial quilt.<sup>19</sup>

The Deaf AIDS Information Center was distinct, though, in the forms of access *remediation* that it documented and performed. Here we mean remediation as repair/healing and remediation as the movement of information from one medium to another, to make it newly present.<sup>20</sup> The DAIC collated evidence and advocated for information about HIV—including the virus's known routes of infection, its contagiousness, its symptoms, and its possible treatments—being remediated through TDD, ASL, and community service provisions. AIDS service organizations already understood that providing access to information was a major purpose for their work but did not often bring a disability justice lens to what they meant by access. The DAIC's practices intervened directly in existing information infrastructures, which frequently failed to consider how the virus would interact with the lives and bodies of disabled people and the higher rates of infection and mortality within Deaf communities.

To understand this history, we must understand the ways disability and media are shaped together—without treating disability as an impediment, a conceptual supplement, or a "lens" through which mediation must pass. By approaching the care work of the DAIC through their use of information and access, we understand this history through the ways disabilities shape conditions of communication, a process that Mara Mills and Jonathan Sterne call dismediation.<sup>21</sup> A dismediation approach to the history of HIV and care begins with the many forms of embodiment and disability that shattered already fraught understandings of HIV. As a theory, we see dismediation as transecting practices of remediation, and queer and trans media theories that complicate the relationship between differently situated bodies and media history.<sup>22</sup> If people living with HIV and AIDS were already living at the margins of US society, deaf people living with HIV/AIDS were doubly exceptionalized. By telling this history through the DAIC, their scrapbooks, and their care work, we aim to de-exceptionalize the experience of HIV+, deaf life within the network infrastructures of the late 1980s and 1990s. The DAIC undertook its care and service work at a time in which the US government, the legal system, and broader society was failing to respond with

necessary urgency to the HIV epidemic and to care for vulnerable communities. The scrapbook archive documents both this failure and the day-to-day care that followed in its wake.

The DAIC's scrapbooks often capture and highlight how the official responses to HIV failed to imagine a case where a deaf person would need accessible information and care to prevent infection or to manage its consequences. This lack of concern for the specific effects of the HIV epidemic on deaf people threatened to relegate discourse about this intersection to overly basic terms. Many of the newspaper clippings in the scrapbooks are mainstream press accounts that present the fact of deaf infection as a quirk of the epidemic, as if such an intersection was unimaginable within mainstream HIV/AIDS discourse.<sup>23</sup> The DAIC addressed this lacuna with workshops and outreach about the textures of HIV/AIDS information paucity, by bringing focus, for instance, to the politics of access involved in the interpretation of sensitive medical appointments or the development of an ASL vocabulary for HIV/AIDS (figure 1).

The period of the late 1980s and early 1990s—when the DAIC was most active—coincides with the debate and passage of the Americans with Disabilities Act (ADA) in 1990, in which many people were campaigning for recognition of HIV positivity as constituting a disability, a framing that remains contentious among some AIDS activists.<sup>24</sup> These debates often rendered disabilities into discrete categories, ignoring and erasing how different embodiments interacted with HIV and failing to imagine intersectional



FIGURE 1. Activist Tommy Saavedra delivers an ASL workshop on HIV/AIDS for the Living with AIDS Day of Activities and Information, May 14, 1988. Scrapbook volume 1, 1987–1993, 2011, Deaf AIDS Center Collection (SFH 71), San Francisco History Center, San Francisco Public Library.

experiences of disability and illness. People do not lead lives that neatly sort their discrete identities, but a discourse of discrete identities pervades the politics and policies of disability and was reproduced in the popular and institutional responses to HIV/AIDS.<sup>25</sup> One news clipping, saved by the DAIC in their scrapbooks, describes a 1994 conference on HIV and disability: "The conference features experts in the fields of disability and HIV who will speak on several pertinent issues concerning the *two communities*." It's not the (student) journalist who created this division of two communities but the conference organizers themselves, who state: "The whole point is to bring the two (communities) together... We have a lot of HIV educators who do not know much about disability. And we have a lot of people who work with disabled people who don't necessarily know about HIV, so they can't provide HIV education."<sup>27</sup>

Frank Lester, a longtime member of the DAIC and other Bay Area organizations for the deaf, and a keynote speaker at the conference, is quoted as saying, "A person who is deaf and HIV (infected) is like being doubly disabled." In 2005 Lester quantified the effect of this intersectional disability, stating that there was an "eight-year gap" between the hearing and the deaf, "when it came to awareness and knowledge about AIDS."<sup>28</sup>

Based on this perceived gap and the prevalent discursive separation of otherwise inseparable experiences of disability, we position the information work at the DAIC within the embedded and lived experience of varying deaf embodiments. For the DAIC's specific caring response to the HIV epidemic, this meant creating resources, educational materials, and access provisions for people who had lived some or all of their lives as deaf as well as people who were newly deaf, including those whose hearing was specifically affected by their infection with HIV (figures 2 & 3).

One of the longer clippings in the scrapbooks of the DAIC is a four-page letter, typewritten and signed by Darol Nance, with some handwritten details and edits. The title is, simply, "FRIENDS/CLIENTS," and we take it that the letter is an account of how the DAIC formed, and the kinds of work Nance set out to accomplish. The dates in the document range from 1988 to mid-1989, and we infer the letter is from 1989 or shortly thereafter. The focus of the letter is the remediating work Nance was doing for those dying of AIDS and their loved ones. She begins with one of her earliest cases, translating for a seventy-eight-year-old deaf woman from the Midwest, who had come to San Francisco to visit her ailing son:



FIGURE 2. Darol Nance, founder and leader of the Deaf AIDS Information Center, staffing the center's information booth at the National AIDS Update Conference, held in San Francisco October 10–14, 1989. Scrapbook volume 1, 1987–1993, 2011, Deaf AIDS Center Collection (SFH 71), San Francisco History Center, San Francisco Public Library.



FIGURE 3. Nance poses in front of the Deaf AIDS Information Center's new offices, pointing toward an empty pegboard that would soon be filled with information brochures and pretending to talk on a phone that would soon be connected to a Telecommunications Device for the Deaf (TDD). Scrapbook volume 1, 1987–1993, 2011, Deaf AIDS Center Collection (SFH 71), San Francisco History Center, San Francisco Public Library.

At that time I was sharing an office with [St. Benedict Interpreting Service in San Francisco] and I became a volunteer in a newly formed Deaf Services Network AIDS Task Force in 1988. I was recommended by an assistant to have a visit with his mother. I went over to the hospital to meet this woman and her son. I then have become her buddy. We agreed to meet once a week. I helped her with food shopping and kept her company. Also I took her to a senior citizen organization for the deaf. She returned home in early January but I received a TDD message from her saying that her son was back to the hospital in late February. Several times a week in the morning on my way to my office I offered this woman rides to the hospital where she could be with her son. This way she could communicate with me about the condition of her son and how she could cope with it. I had given her my listening support. A few days before he died, I visited him in the hospital and he was in a semi-coma. He heard and recognized my voice. He then fingerspelled my first name clear and loud. He seemed to want to tell me that he wanted me to take care of his mother. The day before I left for the South for a wedding this son passed away on March 15, 1989 and I spent the next morning to be with her and comforted her.<sup>29</sup>

Among the remediating work Nance did here was helping the son broach the topic of his queerness, helping him tell his mother that both his father and stepfather had abused him, and that he was dying of AIDS. The story is also layered in Deaf culture and deaf speech—the brokered connection through the hospital, the TDD message signaling the son's final decline, the son's clear and loud fingerspelling of Darol's name at the end of his life—all speak to the inflections of HIV+ deafness in the late 1980s and the dismediated history of this moment. The remaining pages of the letter repeat these themes, as the DAIC forms around the need for interpretation and deaf-accessible information and care. The letter attests to what Margaret Price describes as the importance of the kairotic in creating access, where kairos refers to an opportune or timely moment. The kairotic stands in contrast to "universal design" as a response to exclusion; kairotic access, like that provided by Nance, is the kind created by caring networks that are attuned to the "real-time unfolding of events," like the need to communicate at the end of one's life, to disclose, and connect with one's parent in ways that are both "impromptu" and "high-stakes."30

The "FRIENDS/CLIENTS" letter reads as a personal recollection of Darol Nance's early involvement in AIDS service alongside another accompanying sheet that attests to the earliest work of the broader DAIC

organization. On a single sheet of paper in a DAIC scrapbook, the title reads "MAIN ACCOMPLISHMENTS OF DSN AIDS TASK FORCE" (this is the task force that gave way to the DAIC). The list is telling, covering everything from Deaf AIDS's bake sales and a Walk/Run fundraiser in Oakland, to a retreat at Darol's cabin, to a "practical and emotional support training workshop" to be held in January 1990. One paragraph of the list details the DAIC's involvement with a local (KQED) telethon:

On April 5, 1989 some of us were KQED (TV) night volunteers. We answered TDDs during KQED's televised 4 hour AIDS program. The purpose of this event was to encourage volunteers to all agencies providing AIDS/HIV services. Our presence was good exposure for the deaf community and instructive for the KQED staff. But education about closed captioned sentences and its use for calling via TDDs still needs to be better.<sup>31</sup>

The paragraph captures some of the remediation involved in the DAIC's service and activism. Their involvement in the telethon (1) is good exposure for the organization, (2) an important access provision, and (3) a further intervention in the media and information system, reminding the news affiliate that the use of TDD technology is undermined if it is not accompanied by closed captions.

The moment captures the dismediation/remediation dynamics of the DAIC's work in the peak of the AIDS crisis. As Paul Longmore has argued, the history of the American fundraising telethon has long served a pedagogical role, as "Charity professionals sought to prepare the public to see particular diseases and disabilities as major health problems that urgently demanded attention. They instructed prospective donors, not only what to fear, but how to fear."32 As Longmore notes, telethons were also spectacles of mediation, bringing together the liveness of American over-the-air TV, telephone infrastructure, celebrity, and the fundraising event. Even the giant checks that are often handed out are spectacular and unwieldy. Kevin Gotkin argues that telethons (and walkathons and other "-athons") "stage extreme tests of endurance" that "enshrine able-bodiedness as a cultural ideal." 33 Disabled activists intervened in telethons in the early 1990s, launching access critiques that threw the genre's ableism into relief.<sup>34</sup> The DAIC's intervention at KQED is a softer example of what happens to AIDS as a category of difference when deaf, HIV+ volunteers work the telethon in service of their community.

To understand the list of accomplishments produced by the DAIC, then, and to take it as crystallizing much of what the organization sought to do, we have to place it within the broader context of information remediation and care for deaf people in the HIV/AIDS crisis—and the mediatic interventions of care work. The DAIC scrapbooks do this—gathering clippings, articles, speeches, plays, and cultural ephemera that contextualize the care and information work of the organization.

For instance, newspaper clippings gathered by the DAIC often highlight multiple, interacting, and compounding forms of marginalization along axes of disability (including deafness and HIV positivity) but also literacy and sexuality. A clipping about a DC conference for "Deaf Gay and Lesbians of the '90s" notes the importance of a lecture on AIDS, stating, "because of deaf Gays' isolation from hearing society, such lectures are a source of critically needed information.<sup>35</sup> As [the speaker] conceded in an interview, 'the rapid impact of AIDS on the deaf Gay community is due to the lack of interpreters and educational resources.'"<sup>36</sup>

Another story profiles a man, Robert Arton, who was diagnosed HIV+ in 1985 and, due to the virus, lost hearing in both ears in the subsequent years.<sup>37</sup> Again, groups like the DAIC, Shanti Project, and the Hearing Society stepped in to provide interpretation services, which most AIDS service organizations were unequipped to provide. Funding for voice hotlines, TDD lines, and interpretation services eventually came from the federal government's Ryan White CARE Act of 1990—though this funding was limited and required states to criminalize HIV exposure to receive funds.

In a clipping from a now-defunct Dallas-area newspaper, the *Times Herald*, titled "Deaf Lack Vital AIDS Information," Nora Zamichow details the difficulty of deaf patients trying to seek out care in a hearing-biased society. She notes a prevalent statistic that a deaf person is six times more likely to contract HIV than a hearing counterpart (because of vulnerability, not a predisposition) and exposes the fact that the US government's official informational brochure about AIDS—mailed to every American home—did not include any access provisions for deaf or hearing impaired Americans seeking more information.<sup>38</sup> Designed over a five-month period, and approved by a team of physicians, the brochure was available in Spanish, Chinese, and Braille and included a toll-free number but no access to TDD. Following protest, the brochure was updated to include a TDD hotline. This trajectory of brokered access following exclusion and complaint is a familiar one to disability activists, and those caring for disabled and sick people.<sup>39</sup>

In this context of isolation, marginalization, and broad social ignorance, the DAIC undertook its work to provide care and information remediation—a process whereby the potential to access and share information was shaped by social, economic, and cultural capital, and the willingness to mobilize this capital. A clipping from the *Bay Area Reporter* from 1989 describes the fight to get interpretation services for deaf and hearing-impaired people with AIDS (PWAs). The article describes a critical case in 1986 in which a deaf man with AIDS, John Canaday, was strapped to a hospital bed, unable to move or communicate with his hands. Groups like the DAIC worked in response to cases like Canaday's to alleviate suffering and shore up the access and media failures of the medical system.

Reading these news clippings—some of which clearly exploit the tragic aspect of the stories—alongside Nance's own recollections, the photographs of DAIC fundraisers, the ephemera of events like "Mr. Deaf Leather," the bake sales, and the walkathons captures the many information-brokering roles of the DAIC as well as its everyday care and community building, and the ways that information and media history were being shaped through viral realities and lived disabilities.

#### SCRAPBOOKS AS INFORMATION WORK

The DAIC's remediation practice extends into the ways they assembled their own records into an unusual archive made up, primarily, of scrapbooks. Nance arranged clippings, photographs, flyers, and other ephemera into five separate books using glue, photo-sleeves, and a pen to add occasional annotations, embellishments, and illuminations. Nance carried out this practice herself, as part of her regular administrative work, and considered scrapbooking to be a high-level activity within the organization's workflow, noting in that same annual summary from 1989 of the DAIC's major accomplishments that "albums will be filled with pictures and events from time to time." This scrapbooking practice resists some of the more analytical and linear aspects of organizational archiving, and is itself a form of dismediation.

Scrapbooking is an extension of Nance and the DAIC's commitments to care. Among the images and artifacts of comfort, celebration, and loss, we find markings like a glittered heart sticker she placed next to a handwritten inscription on one scrapbook's endsheet: "Album assembled by Darol Nance." As Marika Cifor argues, AIDS activists and service organizations in the 1980s saw the work they were doing as needing deliberate and

thoughtful archiving, partly in response to the stigma-driven erasure of AIDS from public discourse and their belief that AIDS was about structural vulnerabilities that were ongoing. In other words, AIDS activists thought about the things they were making as worth holding onto and imagined other people using them in justice work in the future. AIDS organizations archives from the 1980s and '90s are most often composed of file folders containing records of administrative paperwork: meeting minutes, flyers, news clippings, budgets, speeches, event documentation, printouts of emails, and objects such as T-shirts, posters, or pin-buttons. Often, these records move directly from file cabinets in an office space or in someone's home, into banker's boxes, and then onto shelves in an archives when an activist or service organization shuts down, maintaining their original order.

The DAIC's archives are not random paper files sorted in a cabinet according to a folder-level classification scheme; they are vital records hand-picked and arranged by Nance, who carefully taped and glued them into these books. This means that in addition to the collection of these materials, we also get their side-by-side layout, the collage of images and ephemera, their sequence, and a careful stitching together of the community's response to the epidemic. The scrapbooks are assembled out of Nance's volunteer work leading this organization and are informed by her unique perspective as a Deaf woman whose first language was ASL and whose work was marked by affective experiences interpreting and caring for deaf gay men as they lived with and died from AIDS (figures 4 & 5). As both institutional records and



FIGURE 4. Darol Nance sits at her desk in the Deaf AIDS Information Center, reading. Scrapbook volume 1, 1987–1993, 2011, Deaf AIDS Center Collection (SFH 71), San Francisco History Center, San Francisco Public Library.



Telecommunications Device for the Deaf (TDD). A phone receiver was placed in the acoustic coupler on top of the teletypewriter (note the two black cradles designed to hold the receiver). When a user typed on the keyboard, acoustic tones corresponding to letters could be sent and received through a modem and telephone line. Scrapbook volume 1, 1987–1993, 2011, Deaf AIDS Center Collection (SFH 71), San Francisco History Center, San Francisco Public Library.

documentation of Nance's own perspective, these documents participate in the scrapbook genre that Rebekah Edwards argues "allows us to take notice of the co-constitutive forces of personal and public narrations of embodiment, identity, and nation." Edwards is writing in the context of transgender life as it crosses traditional archival genres. This can be productively extended to the ways HIV and deafness intersect to produce stigma and marginalization from information, but also a unique practice of embodied remediation

informing the DAIC's work to provide information and record that work for their archives.

Scrapbooks are a form of information work that use clipping and assembly to detach materials from their original sources, then construct new meaning by bringing them into relation with other materials and contexts. 45 This is evident, for example, in the ways Nance clipped a wide range of newspaper articles about Deaf community responses to HIV and set them in relation to photo documentation of everyday events at the center; the photos emerge as much more than snapshots when situated next to the wider context these articles furnish. Nance was, in other words, telling a story about the DAIC rather than simply filing the photographs away in order to store them. <sup>46</sup> Ellen Gruber Garvey argues that scrapbooks are an accessible genre of writing and research in terms of class, education level, and gender.<sup>47</sup> Building on Gruber Garvey, we extend this notion of access and approach these scrapbooks as a part of the DAIC's larger remediation practice and the organization's multimodal information activism. Using techniques of bricolage, annotation, and candid photographs, the scrapbooks show how the Deaf AIDS Information Center facilitated a high-touch, face-to-face care network as an intrinsic part of their access politics and everyday information work. Portraits of men in hospice appear alongside documentation from workshops on how to ethically interpret ASL conversations about HIV and documentation of deaf volunteers operating TDD phone lines. The scrapbooks show how living, dying, and finding accessible information were deliberately entwined.

Practices of memorialization figure prominently in these scrapbooks. Members of the San Francisco Deaf community who died from AIDS are each commemorated with their own page(s), which include photographs taken as these clients volunteered with the DAIC or accessed services while alive, alongside clippings of their obituaries, photos taken at their funerals, or of the AIDS Memorial Quilt squares DAIC volunteers made to represent each man. The clients remembered here are all men, most are white or Latinx, and a few are Black or Asian. Some of the men Nance commemorates were well-known deaf gay activists, such as Tommy Saavedra, pictured elsewhere in the scrapbooks doing interpretation work, leading workshops, and staffing the DAIC (figure 1). The personalities of these men and the way they were loved within this very small community often emerge through Nance's archiving practice. For example, Julio Nuñez Genao, a Dominican-American gay man who died in 1989 at the age of thirty-three and often accessed DAIC services, is remembered in his obituaries, submitted to newspapers by DAIC

volunteer Frank Lester, then, once published, clipped and glued by Nance. Nuñez Genao was clearly beloved, and Lester, speaking for the DAIC community, describes him as "Deaf, short, and very cute," alongside a portrait of his handsome, smiling face under a mop of curly hair. Here, and elsewhere in the scrapbooks, the playful, queer shorthand of AIDS obituaries that marked gay men's print cultures during this time is further inflected by an intersection with deafness and the Deaf community. These practices of commemoration and AIDS archiving from a deaf perspective persist online through the San Francisco–based Deaf AIDS memorial, which is updated annually and includes tributes to Nuñez Genao and several other DAIC affiliates. DAIC affiliates.

The DAIC scrapbooks were made within the AIDS epoch Jules Gill-Peterson names as epidemic time, prior to the endemic time of living with illness introduced by effective HIV treatments in 1996.<sup>50</sup> Epidemic time is an AIDS temporality in which an anticipated slow death gets reflected in the practices of archiving and commemoration that cohere around AIDS.<sup>51</sup> The DAIC scrapbooks bear this out in their orientation to mourning. Looking at these scrapbooks from a present in which HIV is a manageable illness for those in the United States who are resourced, the gap between the scrapbooks' epidemic time and our present endemic time produces a palpable dissonance. However, the DAIC's work around not just AIDS but also deafness and deaf media practices complicate the temporal scripts of epidemic activist archives. The conviviality at the organization, its high-touch, holistic interpretive practices, and overall politics of remediation, exceed the aesthetics of AIDS dying and commemoration we are used to, as epidemic time meets a care network led by disabled people. These practices matter and have ongoing resonances because, as Marty Fink explains, 1980s and '90s AIDS caregiving narratives are portals to present cultural understandings of disability. They model how disabled people, and their allies, organize, love, and provide material forms of support to each other as "response to state refusal to care about HIV," in the face of institutions that have failed "to care for the self-determination of disabled people."52

Nance's choices about what to include in the scrapbooks demonstrate an awareness of the need to create and keep records about how deaf people were affected by, and responded to, HIV/AIDS. This is perhaps most evident in Nance's news clipping practice, which focused on local San Francisco publications, deaf-focused publications with a wider geographical reach, and clippings sent to her from collaborators elsewhere in the United States.

The Dallas *Times Herald* clippings are photocopies, which suggests that someone in Dallas clipped them, copied them, and mailed them to the DAIC (most other clippings are originals). The *Times Herald* folded in 1991 and is not available through any online databases, and so Nance's clipping and the subsequent digitization of this article as part of an AIDS-focused digital



FIGURE 6. Documentation of Darol Nance's speech at the Deaf Memorial Service, delivered June 29, 1991. The text combines written English with ASL gloss. ASL gloss are signs that can be approximated with written English and are signified by being written in all caps. Scrapbook volume 1, 1987–1993, 2011, Deaf AIDS Center Collection (SFH 71), San Francisco History Center, San Francisco Public Library.

humanities project (The No More Silence dataset, see below), because it is in the scrapbook, is what resuscitates this regional, disability centered story.<sup>53</sup> In other words, the DAIC's clipping practice assembles a niche archive on deafness and HIV that large-scale digitization projects miss.

Nance's commitment to assembling an archive is also evidenced by her inclusion of certain records that reflect a conscientious translation practice. A speech Nance gave at the DAIC's 1991 memorial service was delivered in ASL but was also typed on a word processor, printed, and glued in the scrapbook (figure 6). The "transcript" combines ASL gloss with English translation, which we understand not as Nance imagining a hearing audience for these scrapbooks, but rather as Nance adapting an ASL-centered documentary practice to both the scrapbook and the archive's orientation to print.

The DAIC's records are housed at the San Francisco Public Library. They have been digitized and are offered online as scans with accompanying metadata and full text through the Online Archive of California and the University of California San Francisco Library's No More Silence dataset, which combines thousands of records from Bay-area AIDS activism in an openaccess corpus. We worked with Michael Joyce, Joey Takeda, Julie Jones, and Rémi Castonguay at Simon Fraser University's Digital Humanities Innovation Lab to develop an online database that allowed us to search across the scrapbooks to surface connections. For example, a search for Frank Lester, a lead DAIC volunteer, returns fourteen results, among them: the obituary Lester wrote for Nuñez Genao; Lester's column for an HIV newsletter, "Deaf HIViews"; the program from DAIC's 1990 open house (Lester ran the fundraising raffle); and a clipping from the University of San Francisco's newspaper announcing Lester's selection for a community service award. Through search, the behind-the-scenes aspects of Lester's service work (staffing a raffle table) take up the same prominence as his public-facing advocacy. In this respect, our digital archival method preserved and remediated the scrapbook's original strategy of documenting a multimodal caring practice.

In other ways, our method risked severing some of the intimate connections and throughlines in Nance's scrapbook. To be effective, the search function required our team to convert the five narrative scrapbooks into 162 discrete files that could be returned as results, to make those results meaningful and actionable. These cuts make the information in the scrapbooks more legible to researchers but sever the records from their original proximities, curated by Nance, imposing new ones generated out of metadata, machine-readable text, and a search interface, all of which rely on written

English, not ASL. Anticipating this challenge, Michael Joyce also maintained the full scrapbook PDFs in the database and added corresponding page numbers to the new, smaller files so that they could be more deeply referenced in their original contexts. This solution notwithstanding, it's worth considering how digitized archives and digital methodologies are themselves oriented to some kinds of information practices over others, which requires careful design of research systems that open rather than foreclose dismediation practices present in these archives.

#### CONCLUSION

Reading across the DAIC scrapbooks we see how an interpretive media practice, grounded in care, emerges as a vital (literally life-giving and saving) response to suffering. This media practice is crystallized beneath the taped sheets and glue of the scrapbooks—constituting their own mediatic, memorial practice. To put this another way: there is already a significant body of scholarly work in fields such as counseling psychology and public health that addresses the unique information needs of deaf people around HIV in the 1980s and '90s.<sup>54</sup> But in these literatures, the intersection emerges as a problem of paucity. Through the scrapbooks of the DAIC, however, a richly complex remediation practice is assembled with clippings, photographs, and other print ephemera to construct a singular, if necessarily partial, record of an organization's work with media technologies. The DAIC's media practices show how HIV/AIDS and deafness coconstituted a distinctive approach to making and sharing information. This media history, written through the scrapbooks of one organization in San Francisco, is modest in its scope but enriches our understanding of information as care, as well as our histories of technology, social networks, and modem-based communication.

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# **AUTHOR CONTRIBUTION**

The authors shared equally in the research and writing of this article and either author may list themselves first in the author order when citing the article.

117

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#### NOTES

- I. We have chosen to spell "deaf" with a lowercase "d" throughout the article except in quotations or names of organizations, when describing someone who we know identified as culturally Deaf, or when deaf immediately precedes the word "community." This is because of the difficulty of knowing whether people who accessed the center for HIV-care identified with or considered themselves part of the Deaf community.
- 2. TDDs are a form of a teletypewriter device, or teletype, or TTY, specifically meant for use by deaf and hard-of-hearing users. While TDD and TTY are often used interchangeably, we will use TDD throughout this article (unless quoting a use of "TTY") as it is the term most often used in the archival documents.
- 3. Ben Bahan, "Face-to-Face Tradition in the American Deaf Community," in Signing the Body Poetic: Essays on American Sign Language Literature, ed. H-Dirksen L. Bauman, Jennifer L. Nelson, and Heidi M. Rose (Berkeley: University of California Press, 2006), 21–50.
- 4. Robin Adler, "Need Help? Try Deaf Services Network," Deaf AIDS Information Center Collection, SFH 71, box 1, volume 2.
- 5. Susan Gaskins, "Special Population: HIV/AIDS among the Deaf and Hard of Hearing," *Journal of the Association of Nurses in AIDS Care* 10, no. 2 (1999): 75–78; Helga Stevens, "AIDS, Not Hearing Aids: Exploring the Link between the Deaf Community and HIV/AIDS," *Health and Human Rights* 2, no. 4 (1998): 98–113; James R. Peinkofer, "HIV Education for the Deaf, a Vulnerable Minority," *Public Health Reports* 109, no. 3 (1994): 390–96; Christine Gannon, "Developing HIV/AIDS Resources for the Deaf," *SIECUS Report* 26, no. 2 (1998): 19–20.
- 6. Signed Headshot Mr. Deaf International Leather Philip Corey Rubin, 1992, Deaf AIDS Information Center Collection, SFH 71, box 1, volume 2. Jennifer Tyburczy has written about the complex disability politics of international leather competitions, in response to which the Deaf leather community formed its own award. She argues that the context is a space where the compulsory able-bodiedness of gay men's sexual cultures is both contested and disciplined. Jennifer Tyburczy, "Leather Anatomy: Cripping Homonormativity at International Mr. Leather," *Journal of Literary and Cultural Disability Studies* 8, no. 3 (2014): 275–93.
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- Joy Lisi Rankin, *A People's History of Computing* [Cambridge, MA: Harvard University Press, 2018]).
- 8. Joan Lubin and Jeanne Vaccaro, "AIDS Infrastructures, Queer Networks: Architecting the Critical Path," *First Monday* 25, no. 10 (2020); René Esparza, "Qué Bonita Mi Terria": Latinx AIDS Activism and Decolonial Queer Praxis in 1980s New York and Puerto Rico," *Radical History Review* 140 (2021): 107–41; Kathryn Brewster and Bonnie Ruberg, "SURVIVORS: Archiving the History of Bulletin Board Systems and the AIDS Crisis," *First Monday* 25, no. 10 (2020); Marika Cifor, *Viral Cultures: Activist Archiving in the Age of AIDS* (Minneapolis: University of Minnesota Press, 2022).
- 9. Alexandra Juhasz, AIDS TV: Identity, Community, and Alternative Video (Durham, NC: Duke University Press, 1995); Douglas Crimp, "Introduction, AIDS: Cultural Analysis/Cultural Activism," October 43 (1987). Marty Fink, Forget Burial: HIV Kinship, Disability, and Queer/Trans Narratives of Care (New Brunswick, NJ: Rutgers University Press, 2020); Celeste Watkins-Hayes, Remaking a Life: How Women Living with HIV/AIDS Confront Inequality (Berkeley: University of California Press, 2019); Jallicia Jolly, "From 'at Risk' to Interdependent: The Erotic Life Worlds of HIV+ Jamaican Women," Souls 21, no. 2–3 (2019): 107–31.
- 10. Jaipreet Virdi, Hearing Happiness: Deafness Cures in History (Chicago: University of Chicago Press, 2020); Brenda Jo Brueggemann, Deaf Subjects: Between Identities and Places (New York: New York University Press, 2009); Louise Hickman, "Transcription Work and the Practices of Crip Technoscience," Catalyst: Feminism, Theory, Technoscience 5, no. I (2019): I-IO; Mara Mills, "Do Signals Have Politics? Inscribing Abilities in Cochlear Implants," in The Oxford Handbook of Sound Studies, ed. Trevor J. Pinch and Karin Bijsterveld (New York: Oxford University Press, 2012), 320–46; Jonathan Sterne, The Audible Past (Durham, NC: Duke University Press, 2003); H-Dirksen L. Bauman and Joseph J. Murray, Deaf Gain: Raising the Stakes for Human Diversity (Minneapolis: University of Minnesota Press, 2014); Rebekah Edwards, "This Is Not a Girl': A Trans\* Archival Reading," TSQ 2, no. 4 (2015): 650–65; Ellen Gruber Garvey, Writing with Scissors: American Scrapbooks from the Civil War to the Harlem Renaissance (Oxford: Oxford University Press, 2012).
- 11. Theodore "Ted" Kerr has been critical of this crisis periodization, and the raced and classed economies of attention it produces, throughout his work. See in particular Theodore "Ted" Kerr, "AIDS 1969: HIV, History, Race," *Drain* 35 (2016), http://drainmag.com/aids-1969-hiv-history-and-race/.
- 12. A 1980 special issue of the *American Annals of the Deaf*, titled "Deafness and Rubella: Infants in the 60s, Adults in the 80s," addressed the ways health and social services could prepare to serve the needs of these young adults (vol. 125, no. 8 [November 1980], www-jstor-org/stable/i40184033).
- 13. "Deaf People and AIDS," Deaf AIDS Center Collection, SFH 71, box 1, volume 2 (c. 1988–95).
- 14. Emily Hobson, Lavender and Red: Liberation and Solidarity in the Gay and Lesbian Left (Berkeley: University of California Press, 2016); Juana María Rodríguez, "Activism and Identity in the Ruins of Representation," in AIDS and the Distribution of

- Crises, ed. Jih-Fei Cheng, Alexandra Juhasz, and Nishant Shahani (Durham, NC: Duke University Press, 2020). While these histories have been explored through academic scholarship, they are also each documented within the pages of the DAIC scrapbooks themselves, primarily through news clippings. See, for example: "Center on Deafness Teams with Hearing Society to Provide AIDS Education, Counseling," Deaf AIDS Center Collection, SFH 71, box 1, volume 2 (c. 1988–95), 33; "HIV Services Limited for the Deaf," SFH 71, box 1, volume 2 (c. 1988–95), 17; "Deaf Community AIDS Service Providers List," SFH 71, box 1, volume 2 (1992), 38.
- 15. We should note here that there is another linguistic collision in the DAIC. In the United Kingdom, "Deaf aids" is an outdated and offensive term for "hearing aids" and so, at first blush, the "Deaf AIDS Information Center" can read like an ironic reclamation of this term.
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  - 18. Cifor, Viral Cultures.
- 19. "Deaf Names Project; Deaf Gays Battle Oppression and Others," Deaf AIDS Center Collection, SFH 71, box 1, volume 2 (c. 1988–95); on disability and the quilt, see Robert McRuer, "Disability and the NAMES Project," *Public Historian* 27, no. 2 (2005): 53–61.
- 20. Jay Bolter and Richard Grusin, *Remediation* (Cambridge, MA: MIT Press, 1999).
- 21. Mara Mills and Jonathan Sterne, "Dismediation: Three Propositions and Six Tactics (Afterword)," in *Disability Media Studies: Media, Popular Culture, and the Meanings of Disability*, ed. Elizabeth Ellcessor and Bill Kirkpatrick (New York: New York University Press, 2017), 365–78; Elizabeth Ellcessor, "Call If You Can, Text If You Can't: A Dismediation of US Emergency Communication Infrastructure," *International Journal of Communication* 13, no. 20 (2019).
- 22. Daniel C. Brower and Adela C. Licona, "Trans(affective) Mediation: Feeling Our Way from Paper to Digitized Zines and Back Again," *Critical Studies in Media Communication* 33, no. 1 (2016): 70–83; Whitney "Whit" Pow, "A Trans Historiography of Glitches and Errors," *Feminist Media Histories* 7, no. 1 (2021): 197–230.
- 23. See, for instance, Kent Bradley, "Deaf PWAs Share Stories, Educate Others," Deaf AIDS Center Collection, SFH 71, box 1, volume 2 (c. 1988–95); "Deaf Awareness Month," Deaf AIDS Center Collection, SFH 71, box 1, volume 2 (1990).
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- 25. Dylan Mulvin and Cait McKinney, "The Girl in the Bubble: An Essay on Containment," *Catalyst* (forthcoming).
- 26. Cynthia Pickerrell, "Disability and HIV Conference," Deaf AIDS Center Collection, SFH 71, box 2, volume 5 (1994), emphasis added.
  - 27. Pickerrell, "Disability and HIV Conference."
- 28. Matthew S. Bajko, "Deaf Gay Men Tackle AIDS and Speed Use," Deaf AIDS Center Collection, SFH 71, box 1, folder 2 (2005).
- 29. Darol Nance, "Friends/Clients Speech by Darol Nance," Deaf AIDS Center Collection, SFH 71, box 2, volume 4 (c. 1988–95).
- 30. Margaret Price, *Mad at School: Rhetorics of Mental Disability and Academic Life* (Ann Arbor: University of Michigan Press, 2011), 61.
- 31. "Main Accomplishments of DSN AIDS Task Force," Deaf AIDS Center Collection, SFH 71, box 1, volume 1 (1989).
- 32. Paul K. Longmore, *Telethons: Spectacle, Disability, and the Business of Charity* (Oxford: Oxford University Press, 2015), 15.
- 33. Kevin Gotkin, "What Was the Telethon?" *Medium* (blog), September 5, 2015, https://medium.com/@kgotkin/what-was-the-telethon-48f0f28aceee.
  - 34. Gotkin, "What Was the Telethon?"
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- 41. "Deaf PWAs Need Special Services," Deaf AIDS Center Collection, SFH 71, box 1, volume 2 (1989).
- 42. "Main Accomplishments of DSN AIDS Task Force 1988–1989," Deaf AIDS Information Center Collection, SFH 71, box 1, volume 1 (1989).
  - 43. Cifor, Viral Cultures.
  - 44. Edwards, "This Is Not a Girl," 651–52.
  - 45. Gruber Garvey, Writing with Scissors, 22.
- 46. Diana Kamin, "Cards, Cabinets, and Compression in Early Stock Photography," *Information and Culture* 56, no. 3 (2021): 232, 239-40.
  - 47. Gruber Garvey, Writing with Scissors, 5.

- 48. Frank Lester, "DEAR HIViews," Deaf AIDS Information Center Collection, SFH 71, box 1, volume 2 (c. 1988–95); "Julio Nuñez Genao Obituary," Deaf AIDS Information Center Collection, SFH 71, box 2, volume 4 (1989).
  - 49. "About," Deaf Lost to AIDS, https://deafaids.info/.
- 50. Jules Gill-Peterson, "Haunting the Queer Spaces of AIDS: Remembering ACT UP/NY and an Ethics of an Endemic," *GLQ: A Journal of Lesbian and Gay Studies* 19, no. 3 (2013): 279–300.
  - 51. Cifor, Viral Cultures.
  - 52. Fink, Forget Burial.
- 53. The only official archive for the publication is on microfilm that must be consulted in person at the Dallas Public Library.
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