

## **SPRING 2011 DHA NEWSLETTER**

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**MESSAGE FROM THE PRESIDENT**  
**Penny L. Richards**



**Welcome!**

This issue of the DHA Newsletter is dedicated to the memory of Paul Longmore (1946-2010). Because his work was so influential, this is a longer-than-usual newsletter, but it's all well worth the space. We have a report from the AHA tribute session, a reprint of Douglas Baynton's review of Longmore's *Why I Burned my Book*, and Cathy Kudlick's more personal reminiscence about Paul as a scholar, a colleague, and a friend.

We also have the usual announcements and conference calls, two conference reports, and some DHA business in the first pages. One item that I didn't fit into the announcements seems right to mention here: Felicia Kornbluh recently wrote to let me know that her timely article, "'Disability, Antiprofessionalism, and Civil Rights: The National Federation of the Blind and the 'Right to Organize' in the 1950s,'" was just published in the March 2011 issue of the *Journal of American History* (97(4): 1023-1047)--one of the few disability history articles in that flagship journal since Paul Longmore and David Goldberger's 2000 article on the League of the Physically Handicapped. The DHA is thriving and the field of disability history is strong; this abundance is as much a tribute to Paul Longmore as any writing could ever be.

## ANNOUNCEMENTS

### **Second DHA Graduate Student Travel Scholarship**

As part of our commitment to promoting the work of disability historians, DHA is proud to announce this year's graduate student scholarship to attend professional academic conferences. This award is not restricted by the geographic location or type of professional academic conference. The fellowship committee will award either 2 applicants \$250US [or equivalent] or one applicant \$500US [or equivalent], depending on strength of proposals and need. The Association will cover expenses to convert currencies if necessary.

To apply for this scholarship applicants should provide a one-page (roughly 250- word) cover letter outlining when, where, and what kind of conference will be attended. Applicants should clearly explain their reason for wanting to attend the conference and what benefits are anticipated by this experience. For example, a candidate may have been accepted to present a paper or may want to interview for jobs at the conference; another may want to do both or may want to learn more about subjects presented that relate to his/her own work.

This year's award covers Spring 2011 through summer 2012; applications may be submitted beginning on April 4, 2011. The current scholarship review committee includes DHA members Phil Ferguson, Susan Burch, and Graham Warder.

Awardees will be announced on the H-Dis listserv. In accepting the scholarship, winners commit to writing a brief article (500-750 words) about the conference for the next DHA newsletter appearing after the event.

For more information on the scholarship please contact Susan Burch at [sburch@middlebury.edu](mailto:sburch@middlebury.edu)

### **Paul K. Longmore Memorial Fund**

Donations to the Professor Paul K. Longmore Memorial Fund at San Francisco State would be welcomed and appreciated. The fund will be used to honor, preserve and advance Paul's legacy and work in Disability Studies. Please make your check payable to the San Francisco State University Corporation, with "Dr. Paul Longmore Memorial Fund" written in the memo. A tax deductible contribution can be mailed to:

San Francisco State University  
University Development  
Attention: Andrea Rouah  
1600 Holloway Ave., ADM 153  
San Francisco, CA 94132

## **Two Podcasts**

If you want to have a nice long listen to Paul Longmore talking about his career and the field of disability history, check out Jana Remy's **Making History** podcast, episode 8, which is an almost-hour-long chat with him, recorded in 2008:

<http://www.makinghistorypodcast.com/2008/12/25/episode-8-paul-k-longmore/>

And Ellen Samuels was the guest on a recent episode of **University of the Air** on Wisconsin Public Radio, talking about disabled characters in classic literature and popular culture. The episode is available for download on this page (look for the program dated 2/27/2011):

[http://wpr.org/webcasting/audioarchives\\_display.cfm?Code=uo](http://wpr.org/webcasting/audioarchives_display.cfm?Code=uo)

(Note: These podcasts don't appear to have transcripts available at this time.)

## **NLM Traveling Exhibition**

**Life and Limb: The Toll of the Civil War** is a new six-banner traveling exhibition from the National Library of Medicine, touring US libraries through 2013. "The medical history of the Civil War traditionally focuses on the heroics and brutality of battlefield medicine," notes curator Manon Parry, of NLM's History of Medicine Division. "By focusing on the lives of injured and disabled veterans, this exhibition provides a different perspective on a familiar story and offers new insights into the image of the soldier in nineteenth-century society."

The narrative highlights aspects of life after the amputation of a limb, from military service in the Veterans Reserve Corps to civilian life and the use of artificial limbs. The exhibition Web site features digitized images and documents, as well as educational resources for high school and undergraduate students and references for further research:

<http://www.nlm.nih.gov/exhibition/LifeandLimb/>

## **IN BRIEF**

### **Recent Publications page at DHA website updated**

The "Recent Publications" listing at the DHA website was updated in February. If you have additions/corrections, please submit them to Penny Richards ([turley2@earthlink.net](mailto:turley2@earthlink.net)).

### **Coming Soon: A DHA Publications Award**

We're getting a committee together to launch a second DHA award, this time focused on publications (books and articles). Stay tuned for more details as they become available.

***The Encyclopedia of American Disability History* is “Editor’s Choice”**

In the January issue of Booklist, three encyclopedias were named “Editors’ Choice Reference Sources,” and one of the three was the Encyclopedia of American Disability History (Susan Burch, ed., Facts-on-File 2009).

**H-Disability Milestones**

The listserv H-Disability turned ten years old on March 26, 2011--and also recently reached 500 subscribers for the first time, on February 10, 2011. Ten years of discussion logs for H-Disability, including ten years of discussions, announcements, reviews, and monthly bibliographies of new publications, are open access here:

<http://www.h-net.org/~disabil/>

**UPCOMING CONFERENCES**

**15-18 June 2011**

**The Society for Disability Studies** will hold its 23rd Annual Conference at the Doubletree Hotel in San José, California. The theme is “Beyond Access: From Disability Rights to Disability Justice.” For more information:

<http://www.disstudies.org>

**18 June 2011**

**2nd Annual History of Medicine Postgraduate Summit** will be held at the University of London as a one-day event to develop and strengthen the UK’s Postgraduate History of Medicine network. Free registration, but places are limited. Deadline for proposals is April 25.

<http://www.qmul.ac.uk/emotions/>

**29 June-1 July 2011**

**80th Anglo-American Conference 2011: Health in History** will be held at the Brunei Gallery, School of Oriental and African Studies, London. Inquiries should be directed to:

[IHR.Events@sas.ac.uk](mailto:IHR.Events@sas.ac.uk)

**7-8 September 2011**

**Transformative Difference: Disability, Culture, and the Academy** is the title of a two-day conference to be held at Liverpool Hope University (UK), with keynote speakers Len Barton, Fiona Kumari Campbell, Dan Goodley, and Stuart Murray. Please send enquiries to the coordinator Irene Rose: [rosei@hope.ac.uk](mailto:rosei@hope.ac.uk)

### **23-25 February 2012**

**Medical History of WWI** will be a conference held at the Army Medical Department Museum in San Antonio, Texas. Deadline for proposals is 1 September 2011. The conference website:

<http://www.wfa-usa.org/new/fgsw2012jointseminar.htm>

### **11-13 July 2011**

**The Drama of Medicine: All the World's a Stage** will be held at the University of Leicester and feature explorations of dramas/stories, players/people, and stage/setting of healthcare past and present. For more information:

<http://www.amh.ac.uk>

### **30 July-1 August 2012**

**Disability and the Victorians: Confronting Legacies** will be held at Leeds Trinity University College, hosted by the Leeds Centre for Victorian Studies. The Call for Papers says that they are already accepting proposals for panel sessions and papers, and will continue to do so until the final call in the summer of 2011. For more information:

<http://www.h-net.org/announce/show.cgi?ID=177390>

## **CONFERENCE REPORT: The Society of Early Americanists' Seventh Biennial Conference, Philadelphia, 3-5th March 2011**

Amy Renton

Set in the Historic Old District of Philadelphia, within walking distance of sites such as Independence Hall, Franklin's Grave, Penn's Landing and City Tavern, over 350 early Americanists met to share provoking and stimulating presentations. With the assistance of the Disability History Association's generous Graduate Student Scholarship I was fortunate enough to be one of the 350. As one of only a handful of British scholars at the conference, I was warmly greeted as a representative of British Americanist historians.

This was the largest conference thus far for the Society, and, as such, the breadth of topics was astounding. They included panels on Early American Novels, Portraiture of the American Revolution, Approaches to Teaching Early American Literature and History, The Early American Grotesque, and my particular favourite 'The Early American Body in Material and Visual Culture.' This last panel showcased early prosthetic devices, with a particularly interesting case study of Guveneur Morris, an early American diplomat who lost a leg in a carriage accident (although at the time it was said he received the injury which resulted in amputation fleeing from a lover's husband after an illicit tryst was uncovered!) Other related panels discussed health,

disease and how the state of the individual and collective body was scrutinised as the colonies split from Britain in 1776.

Bringing together scholars of History and literature prompted lively debate, with many different viewpoints and an eclectic range of panels. It prompted everyone to consider how their work fit within an interdisciplinary framework, and also how best we can incorporate this into teaching. We were also lucky enough to be treated with guided walking tours of Franklin's Philadelphia, a specialist plenary panel on Benjamin Franklin's life, talks from the curators at Pennsylvania's Academy of Fine Arts (which currently holds an excellent and highly recommended exhibition entitled 'Anatomy/Academy,' focusing on the intersection of the role of the body in bringing art and science together) and the finale of a staged reading of Royall Tyler's *The Contrast* at the famous Society Hill playhouse.

Although topics related to disability certainly remained in the minority, it was exciting to see that slowly but surely, this approach to history and the study of disabled people themselves, are beginning to appear at conferences outside the discipline of disability studies. Probing and questioning other panelists on how disability related to their work at the numerous social receptions was energising, as was the response I received to my work on representations of disability and the American Revolution. Talks by scholars on the collections of the Library Company and Historical Society of Philadelphia were invaluable for my work as they have specific holdings related to disabled veterans of the American Revolution. I also discovered a fascinating portrait exhibition at the Old National Bank, which included paintings of many former Revolutionary War veterans disguising their scars with cleverly placed clothing.

I want to wholeheartedly thank the Disability History Association for enabling me to attend this wonderful conference, and giving me the opportunity to (rather over-enthusiastically at times) talk about my work, and that of others, in the field of disability history.

**CONFERENCE REPORT: American Historical Association 2011, Report on Taskforce on Disability and Paul Longmore Tribute**  
Heather Munro Prescott

[This report originally appeared on Prescott's blog, Knitting Clio, on 9 January 2011.]

I'm back from the annual meeting [American Historical Association](#) and am going to split my reporting into several parts. I'll start with the main reason I attended, which was to represent the [Disability History Association](#) at the [Open Forum on Disability and](#)

[Tribute to the work of Paul Longmore](#) on Friday afternoon. When I first arrived at the session, the room had a bunch of press people taking pictures of the [Task force on disability members](#) and frantically moving around equipment. I thought, wow, this must mean that disability history has arrived. Awesome!

Wrong: the press were left over from the previous [roundtable](#) on Beverly Gage's book, *The Day Wallstreet Exploded*, and the frenzy was to get the sound equipment and cables out of the way so that [Michael Rembis](#) could navigate his wheelchair to the table at the front of the room. Hopefully the pictures the press folks took will appear somewhere along with a report on the Taskforce, and not just be presented to them as souvenirs!

Seriously, what better way to illustrate Michael's personal accounts of how degrading, exhausting, and humiliating it is to continually have to ask for accommodations so that he can do what others take for granted. For example, Michael couldn't reach any of the public computers set up in the Hynes convention center because they were on tables too high for him to reach. I didn't ask him what he thought about the conference venue — presumably having the various session locations connected by the Prudential center shopping mall was better than trying to navigate the snowy streets of Boston.

The overall results of the Task force's survey indicate a major disconnect between what chairs/administrators report (i.e. most cases involving disability are resolved satisfactorily), and reports from persons with disabilities, who state that it's up to them to make requests and continually badger their HR departments and other powers that be to get those requests honored. Those who are adjuncts or untenured are reluctant to ask or if they do fear making too many waves by persisting in getting these requests fulfilled. Michael summed this up by persuasively observing that the notion of "reasonable accommodation" perpetuates the stigmatized, medicalized, individualized model of disability that those of us in disability history have been fighting to eliminate. Right on! I'll wait until the full report comes out before I comment on this further.

Other issues that were discussed included a mentorship program matching graduate students/junior faculty with senior faculty with disabilities; ongoing efforts to get AHA to validate disability history as a legitimate field of study; and how to recruit panels and papers on disability history for the next AHA meeting in 2012. I made a plug for folks to join DHA (somewhat awkwardly because I didn't have the forethought to bring promotional materials with me).

The tribute to the late [Paul Longmore](#) was incredibly moving — I will try to get a PDF of the testimonials that were read. He will be sorely missed.



## **EXHIBIT REPORT: Willard Suitcase Exhibit and Unspeakable Lecture and Film Series (University of Washington, Jan.-Mar. 2011)**

Joanne Woiak

This winter, the University of Washington hosted the traveling version of the Willard Suitcase Exhibit at Odegaard Undergraduate Library. The exhibit brings a patient-centered view of the history of psychiatry to a wide audience, through the stories told by the contents of suitcases that were abandoned in the attic of a New York state mental hospital that operated from 1870 until 1995. The [UW Disability Studies Program](#) was asked to co-sponsor the exhibit's visit by members of a Seattle organization called Live Inclusive, who are committed to enhancing community living opportunities for people with developmental disabilities. The Live Inclusive team planned a series of eight weekly evening presentations featuring personal stories and policy discussions about community living options for individuals with disabilities. My colleagues and I in Disability Studies (especially the director Sherrie Brown and student leader Rosanna Sze) saw this community-campus partnership as an opportunity to highlight issues around disability history, identity, and rights in the contexts of the UW campus, the state of Washington, and beyond. Our DS Program has a tradition of presenting timely and thoughtful public symposia, and so to complement the exhibit we decided to develop free public programming consisting of documentary film screenings and invited lectures by people from a variety of disciplinary and activist perspectives, including disability historians. The [entire series of 22 events](#) was a great success—attendance averaged about 40 people per event and as many as 80 attended the opening reception and several of the guest lectures. The UW librarians reported that the exhibit itself was one of the best attended and received that they have ever hosted.

The UW organizers put together a diverse set of events that we titled “Unspeakable: Disability History, Identity, and Rights.” Our major sponsors included student groups that arranged the film showings as well as a visit by disability and queer writer and activist Eli Clare (Student Disability Commission and others), and a wide variety of departments that collaborated with Disability Studies to bring other invited speakers (among them the Haring Center for Applied Research and Training in Education, Office of Minority Affairs and Diversity, Department of History, and Program on Values in Society). We advertised heavily across campus and to disability organizations in Seattle and elsewhere in Washington. Our DS students participated in the events for class credit and several helped out as volunteers, and we were pleased to see attendance by many students and faculty from programs such as Education, Social Work, Women Studies, Comparative History of Ideas, and Law, Societies, and Justice. There was also tremendous community interest in the exhibit and the programming. The Live Inclusive group invited disability service professionals from supported living and employment organizations, as well as leaders of government agencies and advocacy groups such as The Arc. The UW organizers contributed to these outreach efforts by publicizing the

events to self-advocacy organizations, CILs, and state-wide disability rights agencies. The exhibit also gave us the opportunity to make valuable connections with people in the psychiatric consumer-survivor movement, local professionals in the mental health field, and activists doing work on restoring and memorializing cemeteries at state hospitals.

The films we screened for “Unspeakable” included documentaries on the histories of institutionalization and sterilization, *Willowbrook* and *Lynchburg Story*, as well as the biography of activist Arthur Campbell, *If I Can’t Do It*. Richard Cohen’s just re-released documentary *Hurry Tomorrow*, filmed in an L.A. psychiatric ward in 1974, attracted the largest crowd and a lively discussion about how much things have and haven’t changed in psychiatric care from the time of the Willard Hospital patients to the 1970s to the current day. Live Inclusive sponsored a wonderful talk by Darby Penney, who is not only the researcher and curator for the Willard Suitcase Exhibit but also a long-time leader in the rights movement for people with psychiatric histories. The UW student commissions for disability, women’s, and GLBT issues jointly hosted two presentations by Eli Clare that drew overflow crowds. Eli’s powerful interpretation of the story of the sterilization of Carrie Buck made an especially valuable contribution to our disability history programming, and it was great to see our local disability and queer communities joining together for these activities. Another highlight of the quarter was a collaborative performance response to the exhibit created by a UW undergraduate dance class taught by a Dance professor who is also a member of the DS faculty.

Our line-up of invited scholars included disability historians Geoff Reaume and Jeff Brune, professor of education Phil Ferguson, and philosopher Licia Carlson. York University’s Geoff Reaume gave an impassioned talk on “Memorializing Mad People’s History” that helped us to gain greater appreciation for the public history and archival work being done in Canadian disability studies and activism by current and former psychiatric patients. Phil Ferguson had a large audience for his presentation of his important research findings from the files of inmates, families, and professionals associated with Oregon’s Fairview Training School. Phil also led discussion about a couple of compelling films that document official portrayals and family memories of Fairview. Jennifer Stuber, a faculty member in UW’s School of Social Work, lectured on “Transforming the American Conversation about Mental Health.” Licia Carlson was inspired by the Willard suitcase exhibit to write a completely new and fascinating paper analyzing some of those individuals’ stories from her disciplinary perspectives in feminist philosophy and disability ethics. And I gave the wrap-up presentation for the series, on my studies of archival materials from Washington state mental institutions dealing with eugenics and forced sterilization.

I am extremely grateful to these colleagues who came out to the Pacific Northwest during a cold, rainy winter to generously share their expertise and their support for this

project. I especially want to thank Jeff Brune for coming back to Seattle and spreading his enthusiasm for disability history. I was initially inspired to organize the “Unspeakable” series because of conversations with Jeff—whom I had not previously met despite both of us having been located at UW until just a few years ago. In early March, he led a well-attended and productive brownbag seminar that brought faculty and students of DS and History into conversation. Jeff also delivered a public talk about his research into the shifting identities of *Black Like Me* author John Howard Griffin, which helped us to think about disability history and identity formation outside of institutional settings. His arguments about the intersections between disability and other identity markers such as race and gender in Griffin’s life resonated with the personal narratives of the “lives left behind” told by the Willard exhibit. Jeff is doing a vital service in raising awareness of our field in the history profession and the general public.

The tremendous support that the DS Program received from our campus and community partners made it possible to maintain a high level of interest throughout this eight week series of activities. I think our efforts generated good critical dialogues on the complex issues surrounding institutionalization and power, and disability identities and social justice in the past and present. The exhibit was a powerful catalyst for interactions among academics, disability service professionals, agencies, families, self-advocates, and the public. Everyone who attended had the opportunity to gain some appreciation for disability history and the social model perspective on the meanings of disability and disability rights. In retrospect, we might have tried to do more to draw the communities involved in intellectual disability and mental health supports into sustained dialogue with each other, and to explore more alternative approaches. Given the complicated politics and current social climate in the state of Washington around issues of mental disability, as well as the ongoing policy discussions at UW regarding issues of accessibility and disability services, the exhibit and events were especially timely. Our “Unspeakable” series contributed to giving voice to diverse scholarly and community views on empowering people with disabilities.

*Joanne Woiak is a lecturer in the Disability Studies Program at the University of Washington and her areas of specialization are history of medicine and eugenics.*

## **DISABILITY HISTORY: NO LONGER HIDDEN**

Douglas Baynton

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**Paul Longmore. *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple University Press, 2003. 288 pp. Index. \$22.95.**

In 1985, *Reviews in American History* published a book review by Paul Longmore of a new Randolph Bourne biography. Longmore began by praising the book for its perceptive accounts of Bourne's advocacy of socialism and cultural pluralism and of the important work he accomplished even as his opposition to the Great War isolated him among American intellectuals. Following this conventional opening, however, Longmore commenced a sustained and pointed critique on grounds never before seen in a scholarly review: the biographer, like others before him, had utterly failed to understand the significance of Bourne's disability and had therefore gotten Bourne all wrong.

This groundbreaking review is included in a new collection of Longmore's essays, *Why I Burned My Book and Other Essays on Disability*, published as part of Temple University's "American Subjects" series. Probably more than anyone, Longmore has been responsible for bringing disability studies to the field of history, and in this respect he has several important firsts to his name. His review essays in RAH were the first to bring a disability studies critique to journals of history; he was the first to have an article published on disability history in the *Journal of American History*; and he was co-editor, with Laurie Umansky, of the first collection in the field, *The New Disability History: American Perspectives* (2001).<sup>(1)</sup> Since the publication of his first book—*The Invention of George Washington* (1988)—a biography of George Washington's early years that Edmund Morgan called "probably the best account of Washington's character in the making," Longmore has worked primarily, and skillfully, in the essay form.<sup>(2)</sup> The most important of the many essays that Longmore has written on disability over the years are collected here. Consistently accessible, the book as a whole would serve as a fine introduction to the contemporary study of disability, yet still offers much that is original and provocative to specialists in the field as well.

In the Bourne review, Longmore argues that Bourne's life and work were fundamentally shaped by beliefs about disability in early-twentieth-century America. "Bourne lived in an era," Longmore writes, "when prejudice and discrimination against disabled people seem to have been intensifying sharply" (pp. 36–7). It was a time of increasing assaults on the liberties of disabled people, including widespread institutionalization and

exclusion from American economic and social life. Disabled people were being stigmatized as defective and degenerate, threats to the genetic health of the nation and burdens on the economy. Congress was establishing increasingly restrictive immigration laws to prevent disabled people from entering the country, while public health officials and superintendents of institutions sterilized thousands. Widespread discrimination prevented many disabled people from earning a wage, at the same time that so called “unsightly beggar” ordinances in cities such as Chicago prohibited those who were “diseased, maimed, mutilated, or in any way deformed” from begging (p. 20). Bourne lived during the rise of the international eugenics movement that would culminate in what Longmore termed the “handicapped Holocaust” in Nazi Germany, in which hundreds of thousands of disabled people would be killed, yet historians writing about Bourne have largely discounted the significance of that context. Christopher Lasch, for example, wrote in 1965 that perhaps all of his “disappointments and frustrations were the inevitable result of Bourne’s deformity . . . and that they tell us nothing, therefore, about the society in which Bourne lived” (p. 37). But then only recently have histories of the eugenics movement and the Holocaust given serious attention to disability.(3) As Bourne himself made clear in his essay, “The Handicapped,” it was grappling with his experiences as a disabled person in such a cultural climate that brought him to question “inherited platitudes,” as he put it, and to reflect on “the reasons for the crass inequalities and injustices of the world.” Longmore argues convincingly that disability was the starting point for Bourne’s entry to radical politics, but his larger point is that historians will “misunderstand individuals like Randolph Bourne as long as the history of disabled people as a distinct social minority remains largely unwritten and unknown” (pp. 38–9).

Bourne actually experienced little functional impairment, but had “a highly visible disability, a twisted mouth, face and ear from a difficult birth, a severely curved spine and stunted growth from childhood spinal tuberculosis.” As with many disabilities, how he appeared to others was fundamental to his disability:

People reacted primarily, and often with extreme aversion, to his appearance. Ellery Sedgwick, editor of the *Atlantic Monthly*, could not overcome his revulsion and invite the young man to stay for luncheon at New York’s exclusive Century Club. In Paris, concierges catching sight of him repeatedly refused him lodgings, until after two days he finally found a vermin-ridden flat. At Columbia University, recalled a friend, some were “instinctively hostile to him, either because of his radical ideas, or because of his personal appearance.” “His writing shows he is a cripple,” said Amy Lowell. “Deformed body, deformed mind.” Other enemies of his agreed (p. 36).

The significance of Longmore’s insight into the role of appearance in disability can hardly be exaggerated. A growing body of literature argues that abnormal appearance is

an essential aspect of prejudice against disabled people. Martin Pernick has described the prominence of aesthetics in eugenics literature—how fitness was equated with beauty and disability with ugliness. The political scientist Harlan Hahn has argued that much discrimination against visibly disabled people results from “aesthetic anxiety,” a discomfort with unusual and stigmatized physical characteristics. Lennard Davis points out that “disability presents itself to ‘normal people’ through two main modalities—function and appearance.”(4) In my own research on immigration policy in the late nineteenth and early twentieth centuries, I have found that what immigrants looked like played an important role in the general debate over restriction, as well as in determining whether or not particular individuals were allowed to enter the country.(5)

The radical reorientation of disability that Longmore brought to the study of history locates the problems disabled people face in defective social structures rather than impaired bodies. Numerous studies have documented the perilous position of disabled people, who today constitute the largest and most impoverished minority group in America. Their unemployment rate is today five times the national average. When they do work, they are paid significantly less. They are far less likely to complete high school and attend college (p. 20). Deinstitutionalization in the 1960s and 1970s transferred thousands of the mentally disabled from the massive asylums founded in the nineteenth and early twentieth centuries to community placements, but spending cuts in the 1980s transferred them again, this time to the streets. Minimum sentencing laws for repeat offenders in the 1990s sent many of them to the prisons, where they are frequently kept in solitary confinement because they cannot follow prison rules. There they sit for years on end, often without treatment or medication. Estimates are that 15 to 20 percent of those in the prison system are mentally ill, and disabilities of all kind are overrepresented among the prison population. (6) In addition, thousands of physically disabled young people are incarcerated in nursing homes, where Medicaid rules consign them in spite of the fact that this costs more than the in-home aides that would allow independent lives in the community.(7) The best public policy response that most American reformers seem able to come up with is facilitated access to suicide.

Why is this so? Disability, Longmore argues, is primarily a social rather than a physical problem, while the medical model of disability that has shaped policies and cultural attitudes in modern times “renders disability as a series of physiological, psychological, and functional pathologies originating within the bodies of individuals” (p. 1). What has been termed the “social” or “minority group model” of disability he describes as the recognition that “for most people with most kinds of disabilities, most of the time the greatest limitations are not somatic but social: prejudice and discrimination, inaccessibility and lack of accommodations” (p. 2). Like race, disability is usually seen as fixed and rooted in biology, but in fact is a highly ambiguous and malleable concept that varies over time and from culture to culture. Defining disability in social terms is not new. Sociologists began exploring disability as a social construct in the 1940s and 1950s.

(8) Disability activists have long maintained that social arrangements mattered at least as much as the impairments themselves. In 1949, Jacobus ten Broek, president of the National Federation of the Blind, declared in a “Bill of Rights for the Blind” that the real handicap of blindness, “far surpassing its physical limitations,” was “exclusion from the main channels of social and economic activity” (p. 219). In the 1930s, the League of the Physically Handicapped produced a “Thesis on Conditions of Physically Handicapped,” which, as Longmore describes it in a *Journal of American History* article reprinted here, “attributed their economic disadvantages, not to their disabilities, but to job discrimination, unjust policies, and haphazard, unfair rehabilitation and relief programs” (p. 73). Going back still further, in the 1850s John J. Flourney advocated the establishment of a separate state for deaf people, arguing that irrational prejudices oppressed disabled people. Flourney wrote (in his distinctive phrasing): “The old cry about the incapacity of men’s minds from physical disabilities, I think it were time, now in this intelligent age, to *explode!*” (9)

However, it is only since the 1970s that a sustained challenge has been mounted against the prevailing view of disability as merely an individual problem. As in African American and women’s studies, disability studies originated in a movement for equal rights. The formulation of the modern social model is usually traced to 1976, when an organization based in London, the Union of Physically Impaired Against Segregation, defined disability as “the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities” (p. 3–4). (10) Although much debated and elaborated since, the social model as first proposed stands in its general outlines largely intact today. Framing disability in this way, rather than as a more or less random misfortune inflicted on individual bodies and minds, makes disability of potentially enormous interest to historians. The significance of the category extends not only to the social condition of millions of disabled people who constitute a large and growing minority group, but well beyond to the general structuring of social relations, as we have learned with gender, sexuality, and race. (11)

Two years after his Randolph Bourne essay, the editor of *RAH*, Stanley Kutler, recognizing the importance of the topic, invited Longmore to review three new works in disability history: Harlan Lane’s *When the Mind Hears: A History of the Deaf* (1984), Peter Tyor and Leland Bell’s *Caring for the Retarded in America: A History* (1984), and Hugh Gallagher’s *FDR’s Splendid Deception* (1985). In the review, “Uncovering the Hidden History of Disabled People,” Longmore argued that taken together these pioneering books gave powerful support to the contention that disability is primarily a socially constructed identity that changes over time. On the basis of these and the few other histories of disability in existence, he proposed a tentative periodization for modern disability history, with the emergence of a medical model of disability beginning to replace notions of supernatural causation in the eighteenth century. This new

definition of disability as biological insufficiency entailed wide-ranging professional intervention, a mandate that sharply intensified at the end of the nineteenth century, leading to “the construction of enormous edifices in health care, social-service, special education, vocational rehabilitation, and private philanthropy” (p. 42). As part of a general sense that greater supervision of disabled populations was required, schools for the deaf attempted to stamp out sign language, while institutionalization and sterilization were used to manage “the menace of the feeble minded.” The early twentieth century appears to have been a nadir for disabled people, while the years following World War I, including the social reintegration of thousands of disabled veterans and the career of Franklin Roosevelt, constituted a turning point. Disabled people began the long and difficult process of building a social movement for change. Longmore ends the essay with the nationwide disability rights demonstrations of 1977 and the federal policy victories of that decade. It was an admittedly sketchy outline, since the raw materials for a general synthesis did not yet exist. As Longmore ended his essay, “That nearly untouched terrain, the hidden history of disabled people, awaits excavation by historians” (p. 51).

The contemporary importance of exploring that “untouched terrain” is brought home in Longmore’s three essays on assisted suicide, perhaps the most powerful of Longmore’s collection because they deal with lives not just needlessly damaged but lost. As he writes elsewhere, “When devaluation and discrimination happen to one person, it is biography, but when, in all probability, similar experiences happened to millions, it is social history” (p. 39). He accordingly puts the stories of individuals who requested assisted suicide in context to tell a larger story about the historical devaluation and dehumanization of disabled people, in particular in the context of the twentieth-century history of eugenic sterilization and euthanasia that reached its apotheosis in Nazi Germany. He reminds us that most German doctors in the Nazi era were also “well-intentioned, even compassionate men” who acted according to widely shared values to relieve disabled people of “burdensome lives.” The terms of the assisted suicide debate today suggest that “many of those values continue to operate today” (pp. 153–4). “Elizabeth Bouvia, Assisted Suicide, and Social Prejudice” recounts one of the earliest right-to-die legal cases. Bouvia, who was quadriplegic as a result of cerebral palsy, was confined from age ten to eighteen in a series of institutions. Upon reaching adulthood, she was able to strike out on her own and live independently thanks to a California state program that paid for inhome aides (in most states she would have had to remain institutionalized, as is still the case today). Bouvia earned a bachelor’s degree at San Diego State University where she subsequently began a master’s program in social work. Then, at age 26, she entered a difficult period that would lead to her request for assisted suicide. Setbacks at school, including refusals by her program to make accommodations that she (and the law) required and a professor who told her that she would be unemployable, led to her dropping out. She became pregnant but miscarried. Not long after, she and her husband divorced. Her brother drowned. Depressed and despairing of



her future, she checked into a hospital psychiatric unit and requested assistance in ending her life.

What followed is an all-too-common story. The legal and medical professionals involved took for granted that it was her disability that had made her life unbearable. A court found that her desire to die was entirely reasonable, in that she was “imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness.” As Longmore notes,

this is a woman who operated a power wheelchair and was on her way to a master’s degree and a career in social work. This is a woman who married, made love with her husband, and planned to become a mother. This is a woman who aimed at something more significant than mere physical self-sufficiency. She struggled to attain self-determination, but she was repeatedly thwarted in her efforts by discriminatory actions on the part of her government, her teachers, her employers, her parents and her society. Contrary to the highly prejudiced view of the appeals court, what makes life with a major physical disability ignominious, embarrassing, humiliating, and dehumanizing is not the need for extensive physical assistance, but the dehumanizing social contempt toward those who require such aid (p. 160).

Longmore describes the ways in which, “typical of discussions regarding disabled people and the right to die,” the court’s reasoning was riddled with basic errors, such as seriously mischaracterizing her disability as progressive and referring to her as bedridden by her disability and in need of constant care (p. 159). Fortunately, by the time the court ruled in her favor, Ms Bouvia had recovered from her suicidal crisis and had chosen to live.

In “The Resistance: The Disability Rights Movement and Assisted Suicide,” Longmore describes how, until the serial killings of Jack Kevorkian, few disability rights activists had addressed the issue of physician-assisted suicide, in part because of ambivalence about the issue itself. Then, “the juggernaut known as Jack Kevorkian, and more particularly the public response to him, suddenly spurred disabled activists into action” (p. 176). A central problem in the physician-assisted suicide debate is how often disability and illness are conflated. News coverage of Kevorkian, who was often portrayed as a folk hero, repeatedly described his victims as terminally ill, while in fact three-fourths were not. Most were disabled people whose lives had recently taken a difficult turn, and most (perhaps all) were coping with depression. Nondisabled people in such circumstances are recommended counseling, but when disabled people face similar circumstances, the depression is presumed to be an untreatable and inevitable outgrowth of disability. Longmore points out further that seven of his ten victims were women, which corresponds with the trend in “mercy killings” generally: “two out of

three such killers are men; two out of three of those killed are women.” According to one expert on these homicides, this may be in part because the men are those who are not always able to accept this reversal in traditional caring responsibilities, and in part because women are more likely to request assisted suicide, internalizing the society’s low estimation of their worth (pp. 186–87).

Longmore returned in several essays to his argument that disability is as much a matter of appearance as function, in particular in his work on media images of disability. “Screening Stereotypes: Images of Disabled People in Television and Motion Pictures” was one of the earliest explorations of the subject. Although the essay is now dated, with its references to *Wild, Wild West*, *Hawaii Five-O*, and *The Fugitive*, it remains still the most concise and effective introduction to media images of disability. Far more than the black hat or oversized shoes, disability announces who are the villains and who are the clowns. Longmore found that movies and television programs had “hundreds of characters with all sorts of disabilities: handicapped horror ‘monsters’; ‘crippled’ criminals; disabled war veterans . . . , central characters of television series temporarily disabled for one episode; blind detectives; disabled victims of villains; animated characters like stuttering Porky Pig, speech-impaired Elmer Fudd, near-sighted Mr. Magoo, and mentally retarded Dopey” (p. 131). Disabled characters are rarely people who happen to have disabilities. Instead, their disabilities function as potent and easily exploited symbols. A widely used screenwriters’ manual explains that in a visual media “images reveal aspects of character” and cites as illustration the film, *The Hustler*, in which “a physical defect symbolizes an aspect of character. The girl played by Piper Laurie is a cripple; she walks with a limp. She is also an emotional cripple; she drinks too much, has no sense of aim or purpose in life. The physical limp underscores her emotional qualities—*visually*.” (12)

As Longmore points out, however, the uses of disability as a shorthand means of character development is not confined to visual media and long preceded the invention of movies. Fictional disabled characters show up everywhere: Oedipus, Quasimodo, Ahab, Captain Hook, Long John Silver, Steinbeck’s Lenny, Melville’s Black Guineau, Hawthorne’s Chillingworth, not to mention most of James Bond’s villains and Dick Tracy’s criminals. Dickens alone brought us Tiny Tim, Daniel Quilp, Barnaby Rudge, blind Stagg, Bertha Plummer, and Mr. Cripples. These are only a few of the better known examples and, as Rosemarie Garland Thomson has noted, most disabled characters are not central characters—the great majority crowding stage, page, and screen are those marginal ones “whose bodily configurations operate as spectacles, eliciting responses from other characters or producing rhetorical effects that depend on disability’s cultural resonance.”(13) Literary critics have never ignored the existence of disabled characters nor their symbolic power—they could hardly do that, given their prevalence—but they have usually treated them as natural symbols rather than markers of cultural attitudes toward disability. Longmore ends with a charge to historians that is

implicitly or explicitly contained in every one of these essays: “The scholarly task is to uncover the hidden history of disabled people and to raise to awareness the unconscious attitudes and values embedded in media images.” He adds, however, that the “political task is to liberate disabled people from the paternalistic prejudice expressed in those images and to forge a new social identity. The two are inseparable” (p. 146). Nothing better than this expresses the spirit of the work in this collection, for it brings together the writings of a scholar whose career has always combined the scholarly and the political.

This combination of activism and scholarship is most explicitly illustrated in the title essay, “Why I Burned my Book.” It tells the story of how he came to burn *The Invention of George Washington*, his first book. The story defies easy summary, but suffice it to say that because of his disability, Longmore had to overcome a series of maddening obstacles thrown in his way by academic committees and government officials in order to earn his Ph.D. Then, upon receiving the happy news that he had received a fellowship at the Huntington Library and that his dissertation had been accepted for publication by the University of California Press, he learned that the Social Security Administration classified both research fellowships and book royalties as unearned income. Either would disqualify him for the same California program that allowed Elizabeth Bouvia to escape institutional living and which he too depended on to live and work independently. It was an all-too-common example of the punitive and self-defeating government policies that stymie the efforts of disabled people to live productive and self-directed lives. When all his attempts to find his way around irrational rules and stiff-necked officials failed, and “after years of finding myself trapped and thwarted by this system, . . . something in me reached a breaking point,” he writes (p. 251). The story culminates with Longmore burning the first copy of his book in an act of public protest, in front of the federal building in downtown Los Angeles:

I somberly watched the fire consume my book. I had planned the protest. I had rehearsed how to burn the book. I had even thought about what sort of expression I should have on my face. But I could never have prepared for the emotional effect on me of the act itself. I was burning my own book, a book I had spent ten years of my life laboring over, a book that had earned me my Ph.D. in history, a book I felt proud of and, in fact, loved. It was a moment of agony (p. 253).

It is an absorbing account, both on the level of personal narrative and as an entry into the history of disability. Longmore uses the story to expand on how disability was first defined, according to the account of Deborah Stone, by eighteenth-century poor law officials as an administrative category in order to separate the deserving from the undeserving poor. Those deserving of assistance were defined as utterly unable to work, thus “disabled” from self-support. Physicians became the authorities on whether an

individual qualified, and thus was disability defined by a medical model as residing entirely within individual bodies. There it largely remains today, enshrined in dozens of government programs and policies, even to some extent in the Americans with Disabilities Act. Longmore uses his personal story to good effect, illuminating both the tribulations experienced by disabled people trapped in the system and the historical sources of the convoluted attitudes and policies we suffer from today.

Since Longmore wrote of “that nearly untouched terrain, the hidden history of disabled people” and sketched out the broad outline of modern disability history, interest in the topic and output in the field have both grown substantially. Disability studies scholars, who once had difficulty finding books for their classes to read, suddenly find themselves facing the problem that scholars of other, better established fields have long faced, the difficulty of keeping up with the literature. When Catherine Kudlick published last year the first essay to review the field as a whole, “Disability History: Why We Need Another ‘Other,’” in the *American Historical Review*, she had so much more to work with that she limited herself to publications from the preceding three years rather than attempting to do justice to the mass of work that has appeared since Longmore looked and found so little. “Not since Joan Wallach Scott heralded a new age with her ‘Gender: A Useful Category of Historical Analysis,’ she wrote, “have historians faced such an exciting time to rethink what we do.” (14) This is a field still in its infancy, and the historiography remains decidedly patchy. Nevertheless, no reviewer would today refer to this as a “hidden history,” and that fact owes much to Longmore’s efforts.

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## NOTES:

1. “The Life of Randolph Bourne and the Need for a History of Disabled People,” *Reviews in American History* 13 (December 1985): 581–87; “Uncovering the Hidden History of Disabled People,” *Reviews in American History* 15 (September 1987): 355–64; and Paul Longmore and David Goldberger, “The League of the Physically Handicapped and the Great Depression: A Case Study in the New Disability History,” *Journal of American History* 87:3 (December 2000): 888–922.
2. Edmund Morgan, “The Genuine Article,” *New York Review of Books*, February 29, 1996.
3. See Henry Friedlander, *The Origins of Nazi Genocide: From Euthanasia to the Final Solution* (1995); and Robert N. Proctor, *Racial Hygiene: Medicine Under the Nazis* (1988). Stefan Kuhl’s *The Nazi Connection: Eugenics, American Racism, and German Socialism* (1994) examines the extensive contacts between American and Nazi eugenicists.
4. Martin Pernick, *The Black Stork: Eugenics and the Death of “Defective” Babies in American Medicine and Motion Pictures Since 1915* (1996), 60–71; Harlan Hahn, “Antidiscrimination Laws and Social

- Research on Disability: The Minority Group Perspective,” *Behavioral Sciences and the Law* 14 (1996): 54; Lennard Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (1995), 11–12.
5. Douglas C. Baynton, “Defectives in the Land: Disability and American Immigration Policy, 1882–1924,” *Journal of American Ethnic History* (forthcoming in 2004), and “Disability and the Justification of Inequality in American History,” in *New Disability History*, 47–50.
  6. American Psychiatric Association, *Psychiatric Services in Jails and Prisons*, 2nd ed. (2000), xix; Paige M. Harrison and Allen J. Beck, *Prisoners in 2002* (Washington, D.C.: U.S. Department of Justice, Bureau of Justice Statistics, July 2003). These and other studies are cited in a Human Rights Watch report, “Ill-Equipped: U.S. Prisons and Offenders with Mental Illness,” available online at: <http://www.hrw.org/reports/2003/usa1003>. See Marta Russell and Jean Stewart, “Disablement, Prison, and Historical Segregation,” *Monthly Review* 53 (July–August 2001): 61–75.
  7. See Harriet McBryde Johnson, “The Disability Gulag,” *New York Times Magazine*, November 23, 2003, p. 59; Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (1993), 237–57.
  8. See, for example, Roger G. Barker, “The Social Psychology of Physical Disability,” *Journal of Social Issues* 4 (1948): 28–38; Lee Meyerson, “Physical Disability as a Social Psychological Problem,” *Journal of Social Issues* 4 (1948): 95–100; Lewis Dexter, “A Social Theory of Mental Deficiency,” *American Journal of Mental Deficiency* 62 (1958): 920–28.
  9. John Jacob Flournoy, “Mr. Flournoy’s Plan for a Deaf-Mute Commonwealth,” *American Annals of the Deaf* (1858), reprinted in *A Mighty Change: An Anthology of Deaf American Writing, 1816–1864*, ed. Christopher Krentz (2000), 166.
  10. On the social model, see Tom Shakespeare and Nicholas Watson, “Defending the Social Model,” *Disability and Society* 12 (1997): 293–300; Michael Oliver, *Understanding Disability: From Theory to Practice* (1996). Michelle Fine and Adrienne Asch, as editors of a special issue of the *Journal of Social Issues*, described disabled people as a minority group rooted in “differential power, differential and pejorative treatment, and group awareness.” Fine and Asch, “Disability Beyond Stigma: Social Interaction, Discrimination, and Activism,” *Journal of Social Issues* 44 (1988), 7. Simi Linton argues that “disability is best understood as a marker of identity” that has now become instrumental in building “a coalition of people with significant impairments, people with behavioral or anatomical characteristics marked as deviant, and people who have or are suspected as having conditions, such as AIDS or emotional illness, that make them targets of discrimination.” Linton, *Claiming Disability: Knowledge and Identity* (1998), 12. Others have supported the “social model” while arguing for significant revisions to it. See, for example, Bill Hughes and Kevin Paterson, “The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment,” *Disability and Society* 12 (1997): 325–40.
  11. On disability as a marker used to disqualify women and minorities from the rights of full citizenship, see Douglas C. Baynton, “Disability and the Justification of Inequality in American History,” in *New Disability History*, 33–57.
  12. Syd Field, *Screenplay: The Foundations of Screenwriting*, (expanded ed., 1982), 27, as quoted in Martin Norden, *The Cinema of Isolation: A History of Physical Disability in the Movies* (1994), 5.
  13. Rosemarie Garland Thomson, *Freakery: Cultural Spectacles of the Extraordinary Body* (1997), 9.
  14. Catherine J. Kudlick, “Disability History: Why We Need Another ‘Other,’” *American Historical Review* 108(June 2003): 763–93.

## **AN OPEN LETTER FROM PAUL LONGMORE**

Cathy Kudlick

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By the time I finally met Paul Longmore fifteen years ago, I was a complete wreck. New to disability studies and awkward about my own “legal blindness,” I had plucked up all my courage and written him a breathless, deeply personal “coming out” letter. Now here I was at SDS two years later, and he hadn't answered. What was I thinking, writing to such an eminent disabled scholar and activist? Had I said too much? Been too naïve? Had I inadvertently written something insensitive about disability and disabled people? Maybe I should have said “people with disabilities.” Or “disabled persons.”

But at last, in June 1995 lurking at the back of a session in a packed, stuffy hotel conference room, I heard this clear-voiced, witty, unnervingly articulate man in the audience respond to something one of the presenters couldn't quite explain. He spoke in a paragraph, commanding the attention of the room. His presence was simultaneously inviting and uncompromising, laced with - I searched for the right word because it wasn't one I often applied to academics - mischievousness. Swallowing hard, I knew it had to be *him*.

“Oh my goodness, I owe you a letter!” Paul moaned, once I'd managed to squeak out my name and tried to figure out if/where/how to shake his hand as nystagmus made my eyes jump. Describing himself as a “hunchback in reverse and basically all bugged up” to help clarify my confusion, he invited me to lunch in the hotel restaurant. I think it must have been just the two of us because I remember him unsuccessfully teaching me how to feed him, both of us cracking up when my lack of depth perception caused me to miss my target. “Remind me never to go to lunch alone with a blind person!” he quipped, and for reasons that say everything about Paul's way of being in the world, I felt at ease enough to tease back “next time be sure to order the piping hot soup and the spaghetti!”

Over the years when people in the disability community would swap stories about how they'd met, I'd always ask Paul when he was going to respond to my letter. “Not that letter again!” he'd say. “I'm still working on it: I have polio, so it needs to be perfect.”

I always wondered what he would have written as a response. At the time I didn't know that he typed by using hunt and peck with a pencil in his mouth to tap the keys. I imagine him stretched out on his bed, surrounded by open books and papers, or leaning

against the podium he had on his dining room table where he'd read the *New York Times* and sometimes looked over one of his print-outs, one minute exclaiming "this is the best paragraph I've ever written," and the next completely tearing it apart with equal relish, saying "now I know what I was trying to do all along!" I imagine the response to my letter flickering on his screen, interrupted by composing a long, passionate email to one of his many list-serv communities. Some of those posts should be collected and published - he's the only one I ever knew to include footnotes.

But back to his response to my letter. "Dear Cathy," and the phone rings, someone wanting his advice about how to find a lawyer specializing in disability discrimination. After an hour he has soothed the distraught mother of an autistic child and introduced her to several organizations, some related to law, others related to autism. He hangs up, only to have the phone ring again. He listens to a series of excited questions, this time soothing a department colleague after a dreary meeting. Then another call, this one about an upcoming talk to a group of physicians who want the disability perspective. "Do they, really?!" he smiles, a twinkle in his eye. His evening attendant arrives to fix dinner and get him ready for bed, but she's giving two day's notice because she has to relocate to another state to join her partner who finally got a decent job. How to find a new one, especially one who is reliable, trustworthy, and discrete? Tomorrow's lecture needs tweaking, he wants to finish watching that Greta Garbo movie he started, he wonders who among the three maintenance and grounds people he's bonded with at the university would most quickly fix the broken elevator, he's almost done reading that article on linguistic theory that will help him parse out the role of language in early America. Back to the computer: "Dear Cathy," dear Cathy, dear Cathy . . .

Words begin to flow as he considers his first important principle, that people who identify as disabled must be the ones to write their own histories: "People with disabilities and people without disabilities often perceive 'disability' in very different ways. Indeed, many times their assumptions and perceptions radically conflict. As a result, their expectations and prescriptions about 'what needs to be done' clash too. This seems to be a feature of the historical experience of disability throughout, at least, the modern era. Much of the time, in the present, as in the past, nondisabled perspectives have dominated while disabled views have typically been viewed as illegitimate. Disabled people have often been considered unqualified to speak for themselves, to interpret their own experience."

He pauses to consider the endless numbers of books and classes about disabled people, most of them missing the mark precisely because they fail to take the perspective of disabled people into account. He smiles, wondering if this Cathy or most readers will appreciate his wording: "That deficiency characterizes academic research not only in the applied fields, but also in the social sciences and humanities. Beyond the academy, that defect impairs professional practice in a wide array of disability-related fields, including

education, medicine, policy making, psychology, social work, and vocational rehabilitation.”

But maybe he first needs to explain why writing such histories should matter at all. Of course it’s obvious to him, and probably to this Cathy Person - she’s a history professor, after all! But it isn’t always so obvious to his disabled brothers and sisters just trying to get by in daily life. He contemplates the many talks he’s given over the years, to disability rights rallies, before various advocacy groups, outside of nursing homes, government buildings, impromptu gatherings, to students in his office and living room. Heroes, feel good stories, aren’t enough. Processes, Systems, Movements, Individuals all need rigorous, objective study, even if it means uncovering contradictions and unpleasant realities. Only through this understanding can we begin to address what’s wrong and bring about lasting change. Whether it’s his speeches or the words he hopes to publish, he’s on “a search for ‘a useable past’ for the disability rights movement. Even the pieces that address contemporary issues [must] seek to locate these concerns in a larger and longer-term historical context.” Then he beams triumphantly as the perfect phrase flows from his mind to the screen: “The reconstruction of a useable past can contribute to the building of an accessible future.”

Now that he’s figured out a pithy way to explain the importance of history to disabled people, he needs to find one for convincing historians why disability matters. They’re a stubborn, skeptical lot, grounded in facts and archives, the real workhorses of the humanities and bearers of that creative spark. He thinks back to the joys of researching and writing his PhD dissertation that would at last morph into one of his proudest accomplishments, *The Invention of George Washington*, published by a university press in 1988. He recalls his double life back then. In one he was the Disability Activist who fought against the cruel Catch-22 rules of the Social Security Administration that wouldn’t (and still won’t) allow him to accept fellowship money without cutting the benefits he needs to pay for in-home attendant care. In the other, he satisfied his insatiable hunger to understand America’s colonial past, pouring over documents and treatises, sparring with his professors and fellow graduate students in seminars. “Personal inclinations made me a historian,” he writes, “personal encounters with public policies made me an activist.” Only once he came upon Lennard Kriegel’s 1962 essay “Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro” almost two decades after it had appeared in the *American Scholar* did he begin to see how his double life need not be double at all. He pauses to ponder burning his book about George Washington as a PR stunt to draw attention to “work disincentives” built into aid for disabled people; it’s funny how more than anything else, this single act simultaneously underscored his double life and made it one.

But how to frame disability in terms that will satisfy the curmudgeons and animate the newcomers to history as a discipline? So simple and central, yet so complex when



applied to what historians think they already know: “It has functioned as a ubiquitous, though unacknowledged, organizing concept and symbol in the modern world, operating synergistically as public problem, cultural metaphor, social identity, and mechanism for managing social relations. Disability, then, is at once a neglected set of historical experiences, an important theme overlooked in many fields, and a central component of history in general.” If anything is ever going to change society’s attitudes toward disability and disabled people, it will have to be built on the solid foundations of historical evidence. And for historians to think of disability as important, “like gender, race, and class, it must become both a subject of comparative historical study and a standard, indispensable tool of historical analysis.” Above all, to win converts and to remain true to his own principles, these histories have to be well done, rigorous, exacting, and ever-mindful of offering real tools for bringing about change.

Of course it isn’t just about history, he thinks, as he returns to *The Letter*. There are films and television, and other representations that reinforce stereotypes, feed into all the misunderstandings about physician-assisted suicide, medical decision-making, how people with disabilities make sense of a world that mostly wishes they weren’t around. He sighs. *The Letter* is already turning out to be longer than the one that requires a response.

Maybe the best example of how his disability activism and historical scholarship work in tandem would be an idea that’s kicking around in his head, what he’s already thinking of as “*The Telethon Book*.” He imagines it as a critical, deeply researched history of the most egregious exploitation of disabled people and resources. Revealing these processes and their historical roots has everything for everyone in the worlds he cares most about: Economic incentives of maintaining and nurturing disability as a multi-billion dollar industry. Politics and policy linked to a useless healthcare system. American ideas of philanthropy and doing-good, “conspicuous contribution” (he must write that one down - could come in useful someday!) Shameless exploiting of “Jerry’s Kids” and their families to earn money by promoting pity. The impact of mass media, manipulation that trades in and perpetuates stigma.

His head hurts, plus he’s supposed to plan a second date with one of the two women he’s been flirting with on email, “*Dr. Strangelove*” is on TV, or maybe a jazz concert . . . . He closes the file and sighs.

Five years have passed, and now Paul has a “real” job as a full professor of history at San Francisco State University, where he’s thrown himself into department and university life. And still no response to my letter, as I’m always quick to remind him. But we spend hours on the phone and occasional dinners of delivered pizza in his living room, an easy meal to serve, even for someone without depth perception. He shares his excitement of getting funding from the National Endowment for the Humanities to run

a Summer Institute for faculty interested in exploring Disability Studies. He will host it at San Francisco State in July 2000 with Rosemarie Garland-Thomson a professor of English at Howard University whose own work is also shaping the field. They will bring together twenty-five scholars from a variety of humanities disciplines, and he promises to write a response to my application letter if I apply. I'm nervous, feeling unsure, not smart or disabled enough, my project about the history of blind people in France not relevant enough. He comforts me with an email about my proposed research: "You're the one to do it. You're the only one who can. It's also important because it will enable you to explore some vitally important personal stuff. And I will support you and listen to you and give you feedback all of the way. We are all embarked on truly significant work. We are developing a useable past. And you have a key role to play." (Email, November 29, 1999)

I realize that encouraging someone like me isn't just about ego maintenance; it's part of a larger strategy to build a field that will change attitudes. He sees all the pieces: the scholarship and the teaching, but also the broader institutional structures that will nurture the work and sustain the message. Not surprisingly, as he's planning for the Summer Institute, he has also been thinking of other possible allies in academe, as his May 9, 2000 email to the DS-HUM discussion list makes clear: "The presence of senior academicians with disabilities suggests some encouraging possibilities. Because these experienced professionals know the ropes of academic career-building, they could mentor younger disabled scholars. Because of their experience in academic administration and institutional politics (some have been departmental chairs, deans, and occupied other administrative and leadership positions), they could play an important role in building Disability Studies programs.

"At the same time, many of them need to be 'mentored' about a minority group perspective regarding disability. Many were taught that the way to achieve legitimacy was to 'overcome' their disabilities by personal striving. They had to operate and succeed professionally within a totally unreformed system. They got little or no encouragement to name disability prejudice as their chief burden or to resist disability discrimination. Yet at varying levels of awareness, they knew that they faced disability bias. The task on our side is to nurture that awareness. We need to do that, not just through political advocacy, but through personal relationships. Who better than we to identify and empathize with the struggles of other pwds?"

Benefitting from the five-weeks of lively, sustained, intense discussions at the NEH Summer Institute in 2000, our cohort of "Paul's Kids and Rosemarie's Babies" gets a crash course in these lessons, ones that Paul knows we'll carry out into our own institutional worlds. In fact, countless seeds sprout that will grow into interdisciplinary collaborations, conferences, articles, books, creative work . . . .

Paul rallies several of us historians at the Summer Institute to discuss the possibility of disability history being its own field. We need a discussion list, our own scholarly organization, and our own journal - one that, Paul argues passionately, must be started and maintained by established, respected historians and fed by innovative new scholarship. With the launch of H-Disability, our merry little band quickly expands to several hundred members; a few years later in 2005 the Disability History Association will bring added legitimacy. By 2008 Paul will host the first major disability history conference, again at San Francisco State, which will draw more than sixty participants from around the world. Over the years we'll also reach out to the American Historical Association, where he'll play a key role on the newly-formed Task Force on Disability Issues as the go-to person for all questions related to access and making the profession more welcoming to people with disabilities. But he's quick to remind everyone - as he has since early in his career - that access must always be interwoven with rigorous scholarship in disability history because the concrete and the cerebral inevitably nurture one another.

I tear up at the thought of Paul no longer being with us: now I'll never get a response to my letter! And worse still, I won't be able to rib him about it. But as all the quotes I've included from his published work and emails reveal, he's been responding all along.