A disability rights protest organized by the Ability Center of Toledo, Ohio, ca. 1980.
Photograph from the Ward M. Canaday Center for Special Collections, University of Toledo
Overcoming Another Obstacle:
Archiving a Community’s Disabled History

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In 2001 the University of Toledo (hereafter UT) and the Ability Center of Greater Toledo in Ohio formed a unique partnership that resulted in a new academic program on disability studies within UT’s College of Arts and Sciences. The Ability Center, a center for independent living, extended a $1.9 million gift to UT to create the program and also agreed to donate its disability issues library of approximately two thousand books to the university’s William S. Carlson Library to support research in the field. In the course of the donation process, the discovery of more than eighty years of archival material in the Ability Center led to the initiation of a regional disability history archives project. The archival collection and the Disability Studies Program have become valuable resources for community outreach and public history at UT. Development of this unique archival collection has enhanced the teaching and research of disability studies and public history at UT. These local developments reflect larger trends in these fields of study.

Toledo’s Disability Studies Program exemplifies how the academic study of disabled people in society has led to efforts to discover disability history. The interdisciplinary program is based on pedagogy that emphasizes disability as a cultural construct in much the same way that gender, class, and race have been used as categories of analysis in a variety of academic disciplines. Scholarship and teaching emphasize a humanities-based perspective rather than a medical-scientific one. By doing so, UT’s program reflects larger changes in the field as defined by Catherine J. Kudlick:

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By approaching disability as a social category, rather than as an individual characteristic, the field challenges long held perceptions that relegate it to the unglamorous backwaters primarily of interest to people in rehabilitation, special education, and other applied professional fields.

Seen in this way, disability should sit squarely at the center of historical inquiry, both as a subject worth studying in its own right and as one that will provide scholars with a new analytical tool for exploring power itself.¹

The Disability Studies Program at UT is guided through an advisory board that consists of 50 percent representation from the area’s disability community. Courses focus on the contributions, experiences, and cultures of disabled people.²

Early in the program’s development, faculty recognized that discovering the history of disabled people, especially those living in northwest Ohio, should be a fundamental part of their teaching and research efforts. They soon realized, however, that little had been done to document this part of the local past and that collecting historical records would provide the basis for serious study of disability history in the region. Patricia Murphy (at the time, interim director of the Disability Studies Program), working with the staff of the Ward M. Canaday Center for Special Collections and the UT Department of History, sought ways to remedy this concern and to create a research collection of use not only to faculty and students in the program but also to outside scholars and members of the disabled community.

Disability history is a recent field of scholarly interest. It is a direct outgrowth of the disability rights movement that began in the 1970s. By the mid-twentieth century, circumstances of the disabled community had begun to change. Initially, the numbers of individuals in institutions went up as a medical model of care focused on dependency and charity as opposed to enabling disabled persons to fulfill their family, occupational, and civic responsibilities.³ Poor conditions in state institutions, however, prompted the development of a parents’ movement that used collective consciousness to demand change. Challenging the status quo, parents insisted that individuals with disabilities could be helped. Their activities led to increased community services, opportunities for education and employment, and legislation outlining the rights of the disabled. A new trend, based partly on fiscal conservatism, closed large public institutions and moved services to the local level, where small nonprofit organizations contracted with state and federal governments to provide a limited substitute for formerly concentrated residential services. Many deinstitutionalized individuals took to the street actively and began demanding civil rights in the same manner other minority groups previously had undertaken. Thus was born a disability rights movement.⁴

Changing attitudes paralleled the developing movement as disabled people ceased being content to live their lives away from the rest of society. Instead, they
wanted full integration into their communities. Independent living centers provided the opportunity for the disabled to do as they wished. Establishment of the Center for Independent Living in Berkeley gave the movement visibility and provided a model for similar organizations. A philosophy that stressed self-sufficiency and independence replaced the old medical model and reliance on institutional living. Instead, advocates of the disabled promoted the ideas of consumerism and self-help, demedicalization and deinstitutionalization. Through its activism, the disabled community changed the laws of government and the rules of society. Its greatest victory came in 1990 with the passage of Public Law 101–336, the Americans with Disabilities Act (ADA). The story of its passage mirrors many of the great civil rights struggles of the 1960s.5

Through the disability rights and the related independent living movement, those living with disabilities not only claimed their civil rights and liberties but also sought to uncover the stories of their pasts. No longer locked behind doors as they had been for centuries, they employed the discovery of their history as an important component of empowerment and fueled a whole new, active area of research. Histo-
rians and archivists, however, have been slow to preserve the records that document the largely unknown past of disabled people. The Disability Rights and Independent Living Movement Research and Documentation Project of the Bancroft Library at the University of California at Berkeley constituted one of the first major efforts to undertake this task. Its emphasis lies on the recent past, specifically the period of the disability rights movement. Few archival repositories document the lives of disabled people prior to the birth of the disability rights movement, and little is known about life within the institutions that shielded them from society’s view. In addition, the history of local organizations, their disabled clients, and families is ignored in most standard historical interpretations. According to Douglas C. Baynton, “Disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write.”

In October 2002, the Ward M. Canaday Center, the UT Department of History, and the Disability Studies Program sought to address this void in historical consciousness locally by sponsoring a day-long conference on disability history in northwest Ohio. Funded in part by the Ohio Humanities Council, the conference brought together seventy-five individuals from many organizations assisting the disabled. The conference’s planning committee included representatives from the disability community, including the Deaf Resource Center, the Epilepsy Center, the Toledo Chapter of the National Alliance for the Mentally Ill, the Lucas County Board of Mental Retardation and Developmental Disabilities, Assistance Dogs of America, and the Ability Center of Greater Toledo. During the conference, guests were urged to talk about the history of their organizations. Representatives from some of the longest-running programs gave formal presentations on their agencies’ pasts. Through this exchange, it became clear that little had been accomplished to document the rich history of these groups individually and disability history in northwest Ohio collectively.

As a result, the Ward M. Canaday Center for Special Collections at UT launched the Regional Disability History Archive Project. The conference not only helped get this initiative off the ground but it also offered an opportunity for the Disability Studies Program to promote itself within the local community and began to raise the collective consciousness of how disability history forms part of the area’s overall social and cultural fabric. According to Simi Linton,

It was, at one time, seamless. There were no disjunctures between the dominant cultural narrative of disability and the academic narrative. They supported and defended each other. But in the past twenty years, as the flaws in the civic response to disability have been exposed, as changing social structures and legislative victories reassemble that narrative, the academic tale slips further behind. It neither reflects the change that has occurred nor offers the space or the means to think in more progressive ways about disability.
Disability studies connects the academy with the community. Toledo’s conference promoted another level of inclusion for the local disabled community as it was invited to share its stories and contribute to the scholarly record of its own experiences.

UT’s partner, the Ability Center of Greater Toledo, presents an example of how the rich history of disabled people in northwest Ohio has remained unexplored and undocumented. The organization dates back over eighty years and reflects

The Toledo Society for Crippled Children provided medical care to children with polio at its Opportunity Health Center, ca. 1963. Photograph from the Ward M. Canaday Center for Special Collections, University of Toledo
the changing story of disability locally, while it is also indicative of what happened across the country. The Ability Center started in the 1920s as the Toledo Society for Crippled Children. At the time, it was a residential institution treating children with disabilities, mostly those stricken by polio. By the 1980s, it had evolved into a center for independent living (CIL). Today it is a recognized CIL leader. However, the records documenting the Ability Center had not been collected and preserved in an archival repository until the creation of the Regional Disability History Archive Project. This collection will likely attract researchers from around the country.

Because all history starts with the written record, what records archivists choose to collect shapes our historical knowledge in significant ways. From its birth in the 1930s until the 1960s, the archival profession in the United States based its decisions of what records to keep and what records to discard on a traditional view of history as the story of the privileged class. The archivist Nancy Sahli pointed out that the dominate culture not only defined what was collected and what history was transmitted to future generations but that it also held the keys to power in those institutions charged with preserving the records of the past. As Howard Zinn noted, archivists did little to include others in the historical record for these reasons, and also because their professional philosophy was one of passive, neutral collector, not activist: “The archivist . . . tends to be scrupulous about his neutrality, and to see his job as a technical job, free from the nasty world of political interest: a job of collecting, sorting, preserving, making available, the records of society. But the archivist, in subtle ways, tends to perpetuate the political and economic status quo simply by going about his ordinary business.”

In the 1960s, however, archivists began to react to an emerging generation of historians who sought to write what was called the new social history. This approach broadened the story of America’s past by including groups previously excluded in the Great White Man view of events—women, blacks, Native Americans, religious minorities, immigrants, the working class, and gay men and lesbians. Archives began special projects to collect records to document underrepresented groups, and some collections developed into separate repositories devoted to documenting one or more of these groups.

From these projects came the recognition by archivists that documenting all aspects of society in the modern age would require significant, activist effort. Rather than waiting passively for records, archivists developed strategies to ensure that the historical record documented all groups and actively sought out records that were key to their goal. Terry Cook summarized this new activism when he stated:

In any appraisal model, it is thus important to remember the people who slip through the cracks of society. In western countries, for example, the democratic consensus is often a white, male, capitalistic one, and marginalized groups not forming part of that consensus or empowered by it are reflected poorly (if at all) in the programmes of public institutions. The voice of such marginalized
groups may only be heard (and thus documented)—aside from chance survival of scattered personal papers—through their interaction with such institutions and hence the archivist must listen carefully to make sure these voices are heard.11

This new activist concept was framed generally by the term *documentary strategy*, and it marked an important step by archivists toward taking their role as the definers of history more seriously. The acquisition of archival material became more theoretical and thoughtful.

Curiously, however, one sector of society remained largely neglected in the effort to document society more fully: the disabled. The 1988 *Directory of Archives and Manuscript Repositories in the United States* listed only one repository as collecting records of the disabled.12 While the historical community embraced the emerging field of disability history, archivists did little to systematically address the need to collect the records documenting the lives of disabled people. Even records that have been collected are often not recognized as contributing to disability history and therefore not cataloged as such or promoted as disability history materials. For example, while the records of the Rotary Club of Toledo deal mainly with the administration of the organization, a significant part of the collection includes information on the club’s involvement in the 1921 creation of the Ohio Society for Crippled Children and, later, the Toledo Society for Crippled Children. Researchers seeking to study this organization, however, would have to be aware of the connection between the Rotary Club and the programs for disabled children to know to search the collection to study disability history.13

The Ward M. Canaday Center’s efforts to collect records that document disability history on a regional basis are more unique than imagined when the project began two years ago. Historians and the disability community have enthusiastically supported the initiative. “One of the great difficulties of [disability history] research is that because the significance of disability has been recognized by historians only recently, archives have neither sought out disability-related materials nor cataloged their collections to make such materials easily located. The University of Toledo is a national leader in the collection and preservation of records related to disability rights and activism that, until now, have been scattered, inaccessible, and often lost,” stated Douglas Baynton, an associate professor of history at the University of Iowa.14 Walton O. Schalick, an assistant professor of history at Washington University, echoed Baynton’s statement: “The field of Disability Studies is still comparatively young. Its archival roots are younger still. Across the United States there are very few centers which can claim to be local, archival centers of excellence in disability related materials, let alone regional ones.”15

Daniel Wilkins, a past chairperson of the Ability Center of Greater Toledo’s board of trustees, spoke to the project’s importance as a person living with disabili-
ties: “To seek out and archive ‘real’ disability history will provide a body of knowledge that will forever give substance and credibility to the thoughts, dreams, and actions of those who went before.” His feelings resemble those that project staff have heard expressed by others in the disability community who are deeply committed to the project and proudly participate in efforts to document their own history. Their support is inspiring to the project archivists, especially during recent difficult times when the archival endeavor is struggling with severe budget restrictions that can breed poor morale.

But the experience of the Regional Disability History Archive Project has shown that while disability history remains a largely untapped area for collecting historical records with great potential, there are obstacles to success unique to these materials as well. At the most fundamental level, archivists seeking to collect disability records have discovered that major gaps exist in the documentation because of the loss of records following the closure of large state-run institutions in the 1980s. The loss of disability history continues today. For example, in 2002, the state of Oregon destroyed records of the Board of Eugenics and its successor, the Board of Social Protection, which chronicled the forced sterilization of over twenty-five hundred Oregonians in the early to mid-twentieth century.

After the large institutions closed, nonprofit agencies at the local level assumed many of the services provided to the disabled. But because the nonprofits tend to focus on a particular disability, a concerted and ongoing effort is required to collect records from the breadth of these agencies in order to have complete documentation. Archivists hard pressed in times of budget constraints may not be able to adequately devote the resources necessary to pursue disability documentation in a way that presents a complete picture of the community—both because of the fractured nature of the documentation and declining resources for archival endeavors overall.

In addition, there are other challenges to developing programs that document the disabled community. All archival acquisitions programs are based on communication of their goals to potential donors. Donor cultivation often takes years before important collections are acquired. Disability can have an impact on communication, especially with the vision-impaired and hearing-impaired communities. Record formats create difficulties in collecting some kinds of documents. Braille, for example, presents significant appraisal, organization, and reference challenges.

Much disability history is told through personal life narratives. But documenting individual stories presents challenges to the archivist. Under provisions of the Health Insurance Portability and Accountability Act of 1996, no differentiation is made in defining the requirements for confidentiality between historical records containing personal data and current patient records. Since case files at agencies and institutions that would document individuals contain confidential medical information, it is difficult for the historian to gain access. Many archival reposito-
ries would question devoting resources to collecting records—particularly records of great bulk—that cannot be accessed by researchers. If institutional and agency records are not available to tell the story of individuals with disabilities, archivists may have to rely on oral-history interviews and personal records such as diaries and letters. But time constraints make such individualized efforts unattractive to archivists struggling with limited resources.

The public nature of many disability service agencies may also prohibit archivists from collecting records that document the disabled. Some states only allow the official archives to serve as the repository for state and local government records. Because many disability agencies receive significant public funding, their records may only be preserved in these designated repositories. Hence they are not available to other repositories, even those with projects devoted to preserving such materials. Once collected, however, an even greater obstacle exists to making these records available to the disability community: most archival repositories lack equipment and staff to assist disabled patrons. Archivists lack the training to make records intellectually accessible to researchers with disabilities, particularly those with visual impairments. For example, archivists have not begun to address what descriptive elements are necessary to make photographs intellectually accessible to the blind. So even after these records are collected, there remain impediments to the very community that seeks to discover its history.

Despite these obstacles, the experience of those involved with creating the Regional Disability History Archive Project has been positive in ways unimagined when the project began. As an urban institution, the University of Toledo has a public responsibility to serve as a resource for the larger community. Civic engagement constitutes one fundamental value of UT as defined by its strategic plan. Implementation of this plan includes a commitment to enhance “outreach and engagement programs in the community.” Cooperative development of the Disability Studies Program and the creation of the Regional Disability History Archive Project in support of the academic program help to fulfill the university’s mission to both educate and empower related constituencies.

In addition, the disability archives project expands areas of opportunity and research for professional training of public historians and contributes to the goal of institutional community outreach. The mission of the National Council on Public History (NCPH) states that “it aspires to make the public aware of the value, uses, and pleasures of history.” Outreach efforts address specific professional goals as expressed by the NCPH, help to fulfill the mission of urban public institutions like UT, and provide one level of training for students interested in pursuing public history careers. Research topics and audiences for public history reside beyond the traditional boundaries of academe. Public history encourages thoughtful and critical analysis of humanistic issues in all areas where historical knowledge and methodology may enhance understanding. In addition, many who practice public history seek
to democratize the study of the past, to write history about all people and to make it useful, relevant, and easily accessible to a variety of groups and individuals. 20

This “total history” approach aims for an inclusive view of the past that encompasses a broad range of topics and people, especially those previously excluded from study. The variety of social concerns and human experiences subjected to historical perspective has mushroomed over the past several decades. When combined with public history, these studies contribute to a movement that some activists label as “people’s history,” that is, the effort to encourage historical understanding and vision in a variety of community and organizational contexts. Proponents of people’s history believe that the discovery and knowledge of one’s own history can be empowering and a catalyst for social change. People’s history is an applied approach that seeks direct connections between the past and present. 21

Public historians who support the concept of people’s history strive to make it a partnership between those with historical expertise and those with historical experience. Academic departments that train public historians tend to be service and advocacy oriented. Public history outreach programs and projects, designed to train students and promote scholarship, also develop partnerships with community organizations. 22 Historical questions for these projects are framed within a local context, but their study goes beyond unique experiences to help document national trends. Beginning at the local level, we can expand our understanding of the past in general by exploring previously ignored or hidden histories. Regional projects contribute to the creation of a larger historical context for local and individual studies.

Much has been accomplished in recent years to connect public history and disability studies, especially through the use of internet technology. This broad access promotes the concept of people’s history by connecting scholarship with wide and diverse audiences, including disabled persons with historical experience. For example, the Regional Oral History Office at the Bancroft Library, University of California at Berkeley, recently launched the Disability Rights and Independent Living Movement Web site. This resource includes oral histories, documents, photographs, and other items that record the story of the disability rights movement beginning in the 1960s. 23 The Disability History Museum, a project initiated in 2001, emerged from research undertaken for the PBS series Beyond Affliction: The Disability History Project. While admittedly noncomprehensive, the Disability History Museum works to provide representative samples of the types of historical evidence documenting the lives of disabled people from the late eighteenth century through the present. The approach is interdisciplinary and emphasizes the shared experiences of individuals instead of their diseases. 24 The Disability Social History Project epitomizes the idea of people’s history with its goal of providing “an opportunity for disabled people to reclaim our history and determine how we want to define ourselves and our struggles.” 25 Efforts to promote the study of disability history reach beyond the United States. The Disability Archive UK Web site provides
a good example of an international perspective, as well as an inclusive approach that seeks to reach “disabled people, students and scholars” with “access to the writings of those disability activists, writers and allies whose work may no longer be easily accessible in the public domain.”

By the late 1990s, academic public historians increasingly became aware of the disabled community’s efforts to share their pasts with a larger public. The controversy over the Franklin D. Roosevelt (FDR) memorial drew the attention of historians concerned with whether the former president should be depicted in his wheelchair. The original design included only a subtle reference to FDR’s disability, with one statue that “showed him seated, covered by a cape, on a chair with small wheels barely peeking out.” Threatened with a public protest from disability activists, President William Clinton convinced the designers to construct an addition that includes a life-sized statue of FDR seated in his wheelchair. This event helped to open a dialogue among activists, scholars, and museum professionals about the incorporation of disability issues in public interpretations of the past. In May 2000, the Smithsonian Institution sponsored a conference titled “Disability and the Practice of Public History.” The conference focused on the need for academic and cultural institutions “to go beyond what they are already doing to respond to legal mandates to make their facilities accessible to disabled people. They need to integrate ideas about people with disabilities into their exhibits, scholarship, and curricula. Too often, museums have focused primarily on providing access to their buildings and to their public-education programs, but have paid scant attention to the content of their exhibits and what those presentations say—or don’t say—about disability.” Recognition of the connections between public history and disability studies culminated in a special recent thematic issue of the Public Historian that included articles relating disability studies to the content and practice of public history.

It is within this larger context of public disability history activism that the University of Toledo undertakes the Regional Disability History Archive Project. Programs like this provide unique opportunities for public history training and research. Students offer a valuable source of assistance for the Regional Disability History Archive while at the same time gaining experience to take into their careers. For example, Lisa Sudlow, a graduate student in public history, processed the Toledo Rotary Club records in 1998 as an internship project. Daniel Wilkins, a graduate student in the Liberal Studies Program, processed the Ability Center of Greater Toledo records as part of an independent study class. Wilkins is a person living with disabilities and serves on the Ability Center of Greater Toledo board of directors. He also sponsors a Web site called The Nth Degree that provides a forum for the voices of disabled persons and incorporates some of Wilkins’s own historical research. Other students have given voice to disabled persons while exploring historical topics.

The huge, untapped resources of the disability community, and the coopera-
tion of the Ability Center of Greater Toledo, provide areas of local history research related to larger national trends in scholarship. At the same time, much of this work focuses on the cooperative nature of public history activities, combining those trained in history with individuals who have historical experience they are seeking to understand. Creation of the regional archives at UT invites the disability community to connect to the campus in meaningful ways, thus promoting inclusion. Emphasis on partnership indicates not only the importance of the materials collected but also recognition of the significance of the voices of those with historical experience as disabled people.

The disability community that demanded its rights in the 1970s and 1980s is now claiming its history. True independence comes through self-discovery, and history makes for an essential component of that process. But obstacles remain to uncovering the pasts of disabled people. Archivists must make a concerted effort to locate, collect, preserve, and make available the records of disability in their communities in the same manner that they have sought to document other minorities. Historians—both disabled and able-bodied—must begin to undertake scholarly analysis of the disabled at the local level and place such history in the larger context of disability in the United States. And public historians must work to bring the history of the disabled to the community in ways that are meaningful. Only through the cooperative efforts of all of these groups can the independence that began with the disability rights movement be achieved completely.

Notes
2. The University of Toledo offers a minor in disability studies through the College of Arts and Sciences. Students take four required core courses: “Definitions of Disability,” “Issues in Disability Studies,” “Disability Studies Research and Methodology,” and “Internship.” They also complete at least three electives in related humanities and social sciences courses. In addition, students who major in law and social thought may choose a concentration in disability studies that focuses on social, political, and legal issues. *The University of Toledo 2004–2006 General Catalog* (Toledo, OH: University of Toledo, 2004), 49–50, 59, 358, catalog.utoledo.edu (accessed May 29, 2005).
5. DeJong’s “Independent Living” analyzes the change from a medical model to the independent living philosophy. For a general discussion of the disability rights movement in the United States and the efforts of the disability community to enact the Americans with Disabilities Act, see Barnartt and Scotch, *Disability Protests*; and Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Times
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10. Helen Samuels defines documentation strategy as “a plan formulated to assure the documentation of an ongoing issue, activity, or geographic area . . . . The strategy is ordinarily designed, promoted and in part implemented by an ongoing mechanism involving record creators, administrators (including archivists), and users. The documentation strategy is carried on through the mutual efforts of many institutions and individuals influencing both the creation of records and the archival retention of them. The strategy is refined in response to changing conditions and viewpoints.” Helen Samuels, “Who Controls the Past,” American Archivist 49 (1986): 115.


12. National Historical Publications and Records Commission, Directory of Archives and Manuscript Repositories in the United States (Phoenix, AZ: Orxy, 1988). Documentation of the disabled has improved in recent years. A subject search of the terms disability, disabled, or handicapped in the Archives USA database in July 2003 showed 294 collections (including oral histories) under those subjects that are held by archival repositories in the United States. Disability history reflects the new technology, and much of it is emerging in cyberspace, outside of the academy and libraries. Examples include the following: Disability Social History Project, www.disabilityhistory.org (accessed May 29, 2005); the Disability History Museum, the Center for Disability and Public History, www.disabilitymuseum.org (accessed May 29, 2005); the Disability Rights and Independent Living Movement

13. Toledo Rotary Club Records, 1912–1998, MSS-145, Ward M. Canaday Center for Special Collections, the University of Toledo. Information on the club’s activities in regard to the International Society for Crippled Children is located in box 5, folder 3. Information on the club’s Handicapped Service Committee is located in box 3, folders 24–25.


22. The importance of community outreach programs for public history training and practice is discussed in Britton and Britton, History Outreach.


28. In May 2004, the Ward M. Canaday Center for Special Collections at the University of Toledo obtained the papers of Hugh Gregory Gallagher as part of its disability history project, MSS-185. A complete finding aid is available online at library.utoledo.edu/canaday/mssguide/mss-185.html (accessed May 29, 2005). Gallagher was both a leader in the disability rights movement and a historian of disability history. He led a movement to get FDR portrayed in a wheelchair at the memorial and is the author of *FDR’s Splendid Deception*, 2nd ed. (Arlington, VA: Vandamere, 1994), one of the first books to examine FDR as a disabled person.


30. Toledo Rotary Club Records.


32. See Janice L. Hackbush, “Living with Poliomyelitis: An Account of Life during Polio’s Grip in Defiance, Hancock, and Lucas Counties of Ohio” (master’s thesis, University of Toledo, 2000). Much of the information in this thesis is based on oral histories conducted with polio survivors. The tapes and transcripts have been deposited with the University of Toledo Archives.