EMERGING RESEARCH OPPORTUNITIES IN DISABILITY HISTORY AT THE HEINZ HISTORY CENTER

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ABSTRACT: The Heinz History Center was a founding member of the Western Pennsylvania Disability History and Action Consortium. This partnership has resulted in the acquisition of foundational archival and artifact collections connected to local disability history. This article demonstrates how these recently acquired records reflect the pioneering role of Western Pennsylvania in the national struggle for disability rights. Given their recent acquisition and the general paucity of scholarship on Pennsylvania disability history, these records are largely untapped by scholars.

KEYWORDS: deinstitutionalization, disability history, people with disabilities, special education, transportation

As a founding member of the Western Pennsylvania Disability History and Action Consortium, the Heinz History Center has had a nearly unparalleled opportunity to preserve local disability history. This partnership has resulted in the acquisition of foundational archival and artifact collections connected to Western Pennsylvania disability history. This article will demonstrate how these recently acquired materials reflect the pioneering role of Western Pennsylvania in the national struggle for disability rights. Significant themes running through these records include deinstitutionalization, accessible transportation, and education. Notably, many of these collections are derived from individuals with disabilities and as such are essential primary sources that inform Western Pennsylvania disability history. They also frequently shine a poignant light on the discrimination faced by generations of disabled people. Given their recent acquisition and the general paucity of scholarship on Pennsylvania disability history, these records are largely untapped by scholars.
THE PARTNERSHIP

Established in 1879 as the Historical Society of Western Pennsylvania, the Heinz History Center is a museum dedicated to Western Pennsylvania history and home to the Detre Library and Archives, one of the largest archival repositories of Western Pennsylvania history.1 With the History Center’s regional focus comes the imperative to document stories that reflect diverse communities in the region.

Formed in 2015, the Western Pennsylvania Disability History and Action Consortium (WPDHAC) preserves, honors, and shares the historic struggle of people with disabilities to attain human and civil rights. The History Center partook in preliminary conversations that helped to shape the Consortium. When constructing a steering committee, Consortium founders astutely selected advocates and self-advocates representing a spectrum of disabilities. The steering committee has since included two curators and an archivist from the History Center. Crucial to this successful partnership has been the mutual respect cultivated over this multiyear collaboration.

Steering committee members have leveraged well-earned reputations within their community to further the Consortium’s mission of identifying, preserving, and sharing local disability history. The staff of the History Center have aided in this effort by sharing their expertise in collections care, exhibit development, education, and other facets of public history work. For the purposes of this article, the most relevant aspect of the partnership is the identification and preservation of archival and artifact collections.2

Acting on community survey results and referrals from the steering committee, Consortium and History Center staff work collaboratively to preserve collections within the disability community. The collaboration prioritizes preserving over collecting. Most fundamentally, this means that not every archival and artifact collection identified is donated to the History Center.3 The outcome of these interactions varies based on the community members’ wishes, but often includes conveying preservation guidance, providing council on creating inhouse exhibitions, or facilitating the donation of materials to the History Center. Despite this postcustodial approach to preservation, many community members have chosen to donate their collections to the History Center.
DEINSTITUTIONALIZATION

There is a justifiably growing body of scholarship exploring the centrality of Pennhurst State School and Hospital in the struggle for disability rights. More specifically, Bill Baldini’s exposé *Suffer the Little Children* and the late Thomas Gilhool’s masterful legal maneuverings have been the objects of scholarly inquiry. Less studied are the efforts of grassroots advocates throughout the state that significantly contributed to this groundswell of activism propelling deinstitutionalization in Pennsylvania.

Collections pertaining to the institutionalization and deinstitutionalization of people with intellectual and developmental disabilities remains a core interest of the Consortium. As a result, the History Center has rich documentation on this topic in three archival collections. The largest of these is the Bob Nelkin Collection of ACC-PARC Records, which documents the measures taken by disability rights advocates to expose human rights violations, abuse, and neglect at state institutions and other smaller facilities across Pennsylvania in the 1970s. Many of these advocates, including future First Lady of Pennsylvania Virginia Thornburgh, were mothers who drew attention to the chronic overcrowding and understaffing at state-run institutions.

The documentation they produced and preserved reveals their strategies to appeal to the public, civil servants, the press, and all three branches of government to dismantle the institutional system. Record types include news clippings, memos to legislators, photographs, notes from concerned parents, numerous reports of unannounced site visits to institutions, and press releases exposing unexpected deaths at institutions. Notably, this collection also documents the tangible results of advocates’ efforts, including treatment reform, a multimillion-dollar emergency legislative appropriation, the closure of an interim-care facility, and the firing of a state center superintendent. More broadly, these records also provide valuable insights into advocates’ efforts to normalize the inclusion of people with intellectual and developmental disabilities in broader society as an alternative to institutionalization.

Further enriching documentation of this era is the Patricia Clapp Papers. Patricia “Pat” Clapp was a Western Pennsylvania native and pioneering disability rights advocate whose work extends back to the early 1950s. Clapp’s records reflect her leadership in local and statewide efforts to ensure human and civil rights of people with intellectual and developmental disabilities, including the right to education and the right to live in the community.
Of particular note is documentation created in response to the Right to Education Consent Decree, including outreach materials such as pamphlets and awareness-raising campaigns directed at parents whose disabled children were newly entitled to a free public education.\(^9\)

It bears emphasis that most of these advocates were women. Research opportunities abound in both the Clapp Papers and the Nelkin Collection to explore how gender and motherhood impacted advocacy in the deinstitutionalization and parent movements.\(^10\) While their efforts were largely successful, the advocates frequently met with resistance. Many institutional staff members and many parents of institutionalized individuals opposed alternatives to the institutional model. Both collections are rich in correspondence articulating strong resistance to these advocates’ work, revealing the longstanding and enduring tension between proponents of the institutional and community-based models of care for individuals with intellectual and developmental disabilities.\(^11\)

The third collection pertaining to deinstitutionalization predominantly documents the evolution of organizations like ACC-PARC (now known as Achieva) into community-based service providers. Achieva Records reflects the process of transitioning formerly institutionalized individuals to community-based housing.\(^12\) Also noteworthy in this collection is a copied portion of the “Delp diary,” a daily record created by Department of Public Welfare (now the Department of Human Services) employee Russell Delp while he was an undercover staff person at Western State Center in 1989. His investigation led to wider exposure of mistreatment and abuse at the center, as well as the severance of staff, and a lawsuit.\(^13\) Rare film footage of the local disability rights movement during the late 1960s and early 1970s is also present in the Achieva Records.\(^14\)

Collectively, these records cover the 1970s through the 1990s, crucial decades in the deinstitutionalization movement. Over 1,000 pages from the Clapp Papers and the Nelkin Collection have been digitized and are now keyword searchable on Historic Pittsburgh, a collaborative website with Western Pennsylvania historic resources from numerous repositories that is hosted by the University of Pittsburgh Library System.\(^15\)

**INSTITUTIONAL AND COMMUNITY-BASED MODELS**

While compelling, the History Center’s collections pertaining to deinstitutionalization do not reflect the perspectives of people with disabilities
emerging research opportunities in disability history

themselves. A central lesson learned from the History Center’s partnership with the Consortium is the imperative to preserve historic records that reflect the firsthand voices of individuals with disabilities. This embodies the oft-repeated adage in their fight for civil rights: “nothing about us without us.” The History Center has a growing aggregate of collections from individuals with intellectual and developmental disabilities whose lived experiences were shaped by the evolving educational and support services offered to them and their families over the past sixty years. These collections present personal lenses to study the impact of strides made during the early years of the disability rights movement.

The Chevon Hendzel Papers and Photographs provide an opportunity to witness the educational opportunities that were only just emerging in the mid-twentieth century for people with intellectual disabilities.\(^{16}\) Born in 1961, Chevon Hendzel grew up in the Elliott neighborhood of Pittsburgh. Acting against medical recommendations at the time, the Hendzel family insisted that their daughter remain at home with the rest of her family rather than being sent to a state-run institution. As a child, Hendzel learned how to walk and talk despite an initial pessimistic prognosis in an era with few early intervention services for children. One of six children, she enjoyed traveling, clothing, hats, shopping, dancing, art, water, exploring the neighborhood with friends and siblings, and laughing (she loved to prank family members).

Prior to the groundbreaking Right to Education Consent Decree in 1972, school districts throughout Pennsylvania could turn away children with disabilities, thereby denying them a public education. From the mid-1960s to the early 1970s Hendzel received educational instruction through local organizations, including the Easter Seals Center and the United Cerebral Palsy Association (now Community Living and Support Services).\(^{17}\) Hendzel became one of the first students to attend Conroy Education Center, a special education school created by Pittsburgh Public Schools to comply with the 1972 court decision. As such, Hendzel’s school records reflect how educational opportunities evolved during a pivotal era in the history of special education.\(^{18}\)

Similar to Chevon Hendzel, Jolene Elder was a graduate of another Pittsburgh Public School created for students with complex support needs. Born in 1981, Elder was diagnosed with cortical blindness and developmental delays caused by an infant brain-stem injury. Elder’s mother, Paula, pursued the kind of early intervention services that were unavailable to the Hendzel family twenty years earlier. Paula enrolled eleven-month-old Jolene in the infant program at the Easter Seals Center. At four years old, Jolene
began attending Pioneer Education Center in the Brookline neighborhood of Pittsburgh. Beginning in 1996, Paula also worked at Pioneer, assisting students with self-help care, music activities, movement support, and equipment changing, as well as reading and math support.

The Paula and Jolene Elder Papers and Photographs consist of lesson plans, Individualized Education Program documents, a scrapbook, school records, commencement materials, medical evaluations, and photographs documenting Jolene’s experience as a student and Paula’s career as a para-professional at Pioneer Education Center.¹⁹ Building on Chevon Hendzel’s collection, the Jolene and Paula Elder Papers and Photographs provide a compelling individual vantage point from which to examine the extended legacy of the Right to Education Consent Decree.

Institutionalization was the predominant form of support for individuals with intellectual and developmental disabilities dating back to the nineteenth century. The experiences of the Flavin family offer an alternative vantage point on institutionalization throughout the deinstitutionalization movement. Doctors diagnosed Daniel Flavin, born in 1946, with a genetic disorder that resulted in an intellectual disability. The fifth of seven children, Flavin received a poor prognosis from doctors who believed that he would not live beyond four years. Similar to Hendzel, Flavin grew up in an era with few early intervention services for children with intellectual disabilities. Despite this, Flavin learned to walk and developed a limited vocabulary due to the support of his family. He had a passion for horses, food, soda, dancing, and frequently wore cowboy hats. Flavin attended classes for children with disabilities at Sample Elementary School in Millvale. At fifteen Flavin entered Polk State Center, where he lived the remainder of his life. Satisfied with Daniel’s care there, the Flavin family also noted the fondness that Polk Center staff had for him.

The Daniel Flavin Papers and Photographs primarily consist of photographs documenting Flavin’s life at home with his family and at Polk Center. The collection also contains some insights into the education and care that he received at Polk. These records include Individualized Support Plans, care and medical treatment intervention records, and legal documentation of Daniel’s guardianship to other Flavin family members. Of note here are two pieces by Kathy Flavin Haddock. One is a poem reflecting on the challenges her brother faced as a person with disabilities. The other reflects her family’s support of Polk Center and the institutional model for people with intellectual and developmental disabilities.²⁰ Further contextualizing this
collection is an oral history with two of Daniel Flavin’s sisters conducted by the Consortium in 2018.\textsuperscript{21}

Collaborating with Consortium members and collection donors has underscored the importance of taking a person-centered approach to disability history. The collections of Chevon Hendzel, Jolene Elder, and Daniel Flavin provide compelling and revelatory perspectives from which to explore historic changes in education and care of people with disabilities. These collections give researchers the opportunity to directly engage with the humanity of each person and in so doing, offer a deeper understanding of the struggle for supports, justice, and rights.

\textbf{ACCESSIBLE TRANSPORTATION}

People with physical disabilities and other mobility challenges did not have access to public transportation in Pittsburgh and Allegheny County until the late 1970s; more than 30,000 people according to a 1982 estimate.\textsuperscript{22} A fuller accounting of the barriers of everyday life at this time is starkly presented in the testimony of individuals with disabilities who were excluded from the public transportation system. The Robert Schmitt Oral Histories drive home the profound assertion that reliable, affordable, and accessible transportation played an integral role in pursuing a fulfilling life.\textsuperscript{23} Although a meaningful chapter in Western Pennsylvania disability history, progress in transportation and mobility has received little scholarly attention thus far.\textsuperscript{24} The History Center has a growing body of source material on nationally significant progress made in accessible public transportation dating back to 1970, decades before the passage of the Americans with Disabilities Act (ADA).

In 1970 Pittsburgh chapter members of the Open Doors for the Handicapped of PA created Magic Carpet Transportation Services, the first innovation born of this discrimination. Records of the organization, housed at the University of Pittsburgh Archives and Special Collections, illuminate its history.\textsuperscript{25} A consumer-operated, nonprofit paratransit service for people with disabilities in Allegheny County, it was one of the first paratransit services in the country established by people with disabilities for people with disabilities. Monthly newsletters and meeting minutes reveal how this community-born solution contained design features that were highly valued by its riders. Importantly, the lift-equipped van enabled people to be transported in the comfort of their own wheelchairs and the drivers provided...
doctors also knew the importance of making the service affordable; fares were at least 25 percent lower than taxi travel. Customers could schedule rides for any purpose and to any destination within the service area.26 Magic Carpet started small but had expanded to operating six vans and had provided over 85,000 rides by 1977.27

As Magic Carpet grew, congressional forces worked to propel further change. In 1973 the federal government passed the Rehabilitation Act, Section 504 of which stipulated those public institutions (including federal agencies, public universities, and public transportation systems) receiving federal funds for their services could not discriminate against people with disabilities. Through initial momentum from the Urban Systems Institute at Carnegie Mellon University (CMU), conversations started in the mid-1970s to create a model paratransit system that coordinated rides between pre-existing transportation providers for elderly people and people with disabilities.28 Carnegie Mellon partnered with the Port Authority of Allegheny County and the Southwest Pennsylvania Regional Planning Commission to pursue funding from the Department of Transportation and the Urban Mass Transportation Administration on the project.29 This coordinated paratransit system would become the largest of its kind ever attempted in the world, unique in its approach of partnering with pre-existing for-profit and non-profit transportation providers.30

Records reveal that this group of stakeholders, including key figures from Magic Carpet, worked alongside planners to shape an accessible public transportation system in Allegheny County.31 As a result, elements from the Magic Carpet operation became hallmark features of the paratransit service created through this partnership. These include door-to-door service, affordable fares, and unrestricted trip purposes for riders.32 The system determined eligibility through a straightforward interview process rather than notes from doctors, another idea brought by advocates.33 Unsurprisingly, it incorporated Magic Carpet into the paratransit service created by this partnership, known as ACCESS. Launched in 1979 ACCESS remains a national model for paratransit services that today provides 1.5 million rides annually in Allegheny County.34

The Ervin Roszner Papers and Photographs at the History Center document this significant chapter in transportation history. Roszner was the first manager of ACCESS Transportation Systems and frequently navigated its constituent groups such as carriers, social service agencies, regional transit
administrators, and paratransit riders. Included in the collection are early publications and reports demonstrating the success of this novel system. Further contextualizing these records is an oral history conducted with Roszner in September 2020.35

When coupled with the Schmitt oral histories, the Roszner interview underscores the centrality of the partnership between local transit administrators and the disability rights advocates who depended on this system for transportation. This is further affirmed by advocacy documentation created by Lucy Spruill. A renowned disability rights advocate and social work administrator, Spruill was known as a strong and compelling voice in support of ACCESS. Included in her collection are pieces of formal testimony against fare hikes and service cuts. ACCESS Transportation Systems has also donated useful reports, grant applications, and photographs that document the early history of this first-of-its-kind paratransit system.36

Ample source materials abound to illuminate the fruits of this partnership between disability rights advocates and transit leaders. Beyond this early history, research opportunities also exist to investigate the ripple effect of these initial collaborations that extend through the passage and local implementation of the ADA.

CONCLUSION

Over the past seven years, the Consortium has created the opportunity for an expansion and diversification of scholarly activities in the study of disability history, both in Pennsylvania and nationally. Beyond what is highlighted above, there exist numerous other research opportunities related to topics such as voting rights, politics, labor, and the early history of institutionalization.37 Meaningfully, much of the source material that forms the foundation of these prospective topics emerged directly from the local disability community. The History Center is honored to have played a role in preserving these collections and is eager to witness their use by researchers.

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since 2016. She has a master’s degree in library and information science with a specialization in archives, preservation, and records management from the University of Pittsburgh.

NOTES

1. For more information about the Detre Library and Archives (hereafter DLA), of the Heinz History Center see https://www.heinzhistorycenter.org/detre-library-archives. To search holdings, see the online catalog at https://s92015.eos-intl.net/S92015/OPAC/Index.aspx.

2. Another important manifestation of this partnership has been the incorporation of disability history collections into History Center exhibitions and publications. The Center’s public history footprint includes museum exhibitions, archives, and a publishing entity, which enables the organization to share stories of disability history in many different ways.

3. For a listing of disability history collections open for research in repositories, see the “Explore Western Pennsylvania Disability History Collections” section of the Consortium website at https://www.wpdhac.org/explore-western-pa-disability-history-collections/.


5. Bob Nelkin Collection of ACC-PARC Records, MSS 1002, DLA, https://historicpittsburgh.org/islandora/object/pitt%3AUS-QQS-MSS1002/viewer. These advocates were affiliated with the Allegheny County chapter of The Arc of Pennsylvania, then known as ACC-PARC. They collaborated closely with ACC-PARC staff members Charles “Chuck” Peters and Robert “Bob” Nelkin. The work from which all their advocacy stemmed included numerous unannounced site visits that they made to investigate and expose conditions at all state-run institutions and interim care facilities at which a Western Pennsylvania native was confined. For an introduction to their advocacy and impact, see the From Wrongs to Rights film at https://wayback.archive-it.org/11546/20211021140152/https://uwac.omeka.net/items/show/883.


10. The aforementioned *From Wrongs to Rights* film provides an introduction to some of the women advocates active in Western Pennsylvania during the crucial era of the 1970s.


12. Achieva Records, 2019.0132, DLA. Another recent acquisition to the History Center’s holdings is the Arc of Westmoreland Records, 2021.0134, DLA.


15. For digitized materials from the Clapp Papers, see https://historicpittsburgh.org/collection/clapp-papers and for the Nelkin Collection, see https://historicpittsburgh.org/collection/nelkin-acc-parc-records. The United Way of Southwestern Pennsylvania and the Consortium underwrote the digitization
of these records. Additional support and thanks are due to Achieva, Robert Nelkin, as well as Patricia and Jeffrey Clapp.

16. Chevon Hendzel Papers and Photographs, MSS 1220, DLA, https://historicpittsburgh.org/islandora/object/pitr%3AUS-QQS-mss1220/viewer. The History Center’s museum collection includes artifacts of personal meaning and significance to Hendzel and her family. For more information, see http://museumcollections.heinzhistorycenter.org/people/20365/chevon-hendzel. Processing of this collection was underwritten by the Consortium.

17. Educational Materials, 1967–73, Box 2, Folders 1–2, MSS 1220, Hendzel Papers, DLA.

18. Ibid., c. 1974–83, Box 2, Folders 3–14. Further insights into the evolution of special education in Pittsburgh Public Schools can be gleaned from materials related to Dr. J. Kaye Cupples.


20. Daniel Flavin Papers and Photographs, 2021.0139, DLA. The History Center’s museum collection also includes artifacts related to Daniel Flavin and his family. Complementing the History Center’s documentation of Polk State Center are the papers of Mary Cimino, a speech language pathologist who worked there following the Right to Education Consent Decree. Mary Cimino Papers and Photographs, 2021.0125, DLA.


23. Robert Schmitt Oral Histories, 2018.0208, DLA. Interviews on note on this topic include Paul Dick, Holly Dick, and Jeff Parker. See also Holly and Paul Dick Papers and Photographs, MSS 1177, DLA.

24. Despite the paucity of historical inquiry on the topic, the following trade journal articles illuminate key innovations in accessible public transportation emanating from Allegheny County: Keith Forestall, Ervin S. Roszner, and Thomas V. Letky, “Impacts of Allegheny County’s Access Program,” Transportation Research Record 784 (1982): 34–38; Lester A. Hoel et al., Latent Demand for
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28. Charles River Associates, _ACCESS_, 4. Also commonly referred to as a brokerage program.

29. Ibid., xiii. The Port Authority of Allegheny County received the Service and Methods Demonstration Grant from the Urban Mass Transportation Administration (UMTA) in 1978.

30. Ibid., xiv–xv.

31. Presidential Files, 1980–82, Box 1 Folder 25, ODH Records.

32. Charles River Associates, _ACCESS_, xviii. Paul and Holly Dick, Eileen Shackleton, Lucy Spruill, Ruth Brenyo, Angelina Dorrance, and other disabled advocates advised in this process. Direct from the report: “Magic Carpet can be seen as a forerunner of the Port Authority’s ACCESS and user-side subsidy programs. It provided a visible, relatively unconstrained, and affordable service for the nonambulatory.”


35. Ervin Roszner Papers and Photographs, 2021.0066, DLA. Roszner also donated a small collection of artifacts to the History Center’s museum that document his career with ACCESS.
36. ACCESS Transportation Systems Records, 2021.0005, DLA. Additional documentation of the formation of ACCESS can be found in the Urban League of Pittsburgh Records, MSS 277, Record Group I, DLA, and the Jonathan Robison Papers, 1993.0044 and 2003.0278, DLA. Lucy Spruill Papers and Photographs, 2022.0085, DLA. Also included in the collection is a poignant memorial in which Spruill eulogizes an ACCESS driver.

37. Collections related to these and other topics include (voting rights) Rachel Freund Papers and Photographs, MSS 1224, DLA, https://historicpittsburgh.org/islandora/object/pitt%3AUS-QQS-MSS1224/viewer; (politics) Linda Dickerson Papers and Photographs, DLA; (politics) Leonard Staisey Papers and Photographs, MSS 275, DLA; (labor) Blind and Vision Rehabilitation Services, MSS 699, DLA, https://historicpittsburgh.org/islandora/object/pitt%3AUS-QQS-mss699/viewer; and (early institutionalization) Polk Center Expense Receipts, MSS 1181, DLA, https://historicpittsburgh.org/islandora/object/pitt%3AUS-QQS-mss1181/viewer. This collection of receipts documents the first two decades of Polk Center’s operation. Far eclipsing summary data available in annual reports, these records provide unique avenues to analyze the allocation of state funds as the institution grew beyond capacity. A preliminary spreadsheet with datapoints from the receipts is available.