

## THE WESTERN PENNSYLVANIA DISABILITY HISTORY AND ACTION CONSORTIUM

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**ABSTRACT:** The Western Pennsylvania Disability History and Action Consortium is a community-based archives. Founded in 2015, it preserves and honors the historic struggle of Western Pennsylvanians with disabilities to attain human and civil rights. It shares their lived experiences in order to promote community access, participation, and equal opportunity. Written by two founding members, this article describes the Consortium's mission, goals, activities, and partnerships.

**KEYWORDS:** Western Pennsylvania Disability History and Action Consortium, disability history, rights, archives, disability studies

The Western Pennsylvania Disability History and Action Consortium (WPDHAC) is a community-based archives. Founded in 2015, it preserves and honors the historic struggle of Western Pennsylvanians with disabilities to attain human and civil rights. It shares their lived experiences in order to promote community access, participation, and equal opportunity.

The Consortium is dedicated to engaging the public in the dynamic history of people with disabilities. It also honors mistreated people and/or those denied their rights. It recognizes the efforts of individuals with and without disabilities to effect positive change and to raise public awareness of contemporary issues that affect thousands of people with disabilities across Pennsylvania and millions across the nation.

The organization ensures that people with disabilities are the primary and leading force in telling their story. Founding members include

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individuals with disabilities. Affiliated organizations include the Senator John Heinz History Center (a Smithsonian affiliate); Institute on Disabilities at Temple University (Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research, and Service); Achieva; Community Living and Support Services (CLASS); National Alliance on Mental Illness-Keystone Chapter (NAMI); Western Pennsylvania School for the Deaf; and two Centers for Independent Living (Disability Options Network and Transitional Paths to Independent Living).

Western Pennsylvania has a notable history of advocacy and progress on disability rights. This includes activism by Arc Allegheny (now Arc of Greater Pittsburgh, a component of Achieva) to expose abuses at Polk State Center and other state-run institutions in the 1970s. Western Pennsylvania advocates also participated in a 1971 lawsuit to ensure the "right to education" in Pennsylvania, created a model paratransit system in Allegheny County in 1979, and founded one of the commonwealth's first independent living centers in 1984.<sup>1</sup>

Many more Western Pennsylvania stories have yet to be told. Prior to the Consortium's founding in 2015 through a grant from the Pennsylvania Developmental Disabilities Council, relatively little of this history had been preserved and shared. With a grassroots understanding of the pressing need, members of Western Pennsylvania's disability community came together to make it happen.

The Consortium conducts outreach to the twenty-six counties of Western Pennsylvania to identify historic materials and stories and takes timely steps to ensure their preservation. We encourage community members to think about the stories and materials they have and how they can take steps to preserve them (either on their own or with the Consortium's help).

We are driven by the reality that undocumented records and materials are at risk of deterioration and loss, and sometimes held by people unaware of their value. In addition, older advocacy leaders who were directly involved in the twentieth-century disability agenda—those who possess the "community memory"—are aging and passing away. Capturing their stories is urgent.

Equally important is ensuring that the region's history of disability rights is easily available to the public for education and advocacy. Our website (<https://www.wpdhac.org>) serves as a central resource for information about historic materials collected by the Consortium and its partners, as well as historic materials collected by other repositories. Our eNewsletter, social media and presentations to student, community, academic and professional groups

reinforce the community connection. Our “Voices of Change” multimedia histories project highlights pivotal aspects of the regional story.

Each year the Consortium sponsors or co-sponsors public events that explore the past, present, and future of disability rights topics such as employment, voting rights, accessible transportation, and community-based services. Public events such as “We Count: Pennsylvanians with Disabilities and the Right to Vote” and “No Longer Locked Away: Amplifying the Voices, Visibility and Legacy of Individuals with Mental Illness” bring the disability community together with community leaders to raise awareness of the historic and ongoing struggle for disability rights and to galvanize advocacy. They also provide a platform to highlight the work of emerging advocates and new ways of thinking about disability rights.

“Action” is a part of WPDHAC’s name and mission. People with disabilities are a historically oppressed and marginalized population that has struggled to attain rights. People with disabilities experience high rates of poverty, unemployment, segregation, and abuse. Through events, presentations, and media, the Consortium uses historical materials to actively advance the inclusion of people with disabilities in their communities. These activities generate discussion of contemporary issues and promote policies and laws that ensure civil rights and social justice.

The Consortium is the only organization solely dedicated to Western Pennsylvania disability history. We received the American Association on Intellectual and Developmental Disabilities’ Hervey B. Wilbur Award for Historic Preservation in 2019. We are also included in the Society of American Archivists’ list of organizations that preserve disability history.

#### COMMUNITY PARTNERSHIPS

Strong community partnerships add viability and strength to the Consortium’s mission. As mentioned earlier, key relationships with the Senator John Heinz History Center and the Institute on Disabilities at Temple University provide access to knowledge, technical assistance, and collaborative opportunities. Achieva, a Pittsburgh-based disability organization, serves as fiscal sponsor for the project. The Arc of Greater Pittsburgh, a component of Achieva, is a key resource for the history of people with intellectual and developmental disabilities. The Pennsylvania State Archives is also an important partner

## PRESERVING PENNSYLVANIA'S HISTORY OF DISABILITY RIGHTS

and advisor, especially in regard to the public records of Polk and other state centers that are important to our work.

The Consortium's Steering Committee has deep roots in the disability community and reflects a range of ability and disability, backgrounds, ages, genders, and experience. Our activities are led by, organized by, and feature people with disabilities. In keeping with our mission, activities are accessible (e.g. ASL-interpreted, open-captioned, readable by screen readers, etc.) so everyone can participate. A large circle of community advisors is involved in the organization's work. We are also members of statewide and national networks of disability history organizations, such as the Pennhurst Memorial and Preservation Alliance and the Institute on Disabilities at Temple University. These relationships connect Western Pennsylvania to the larger narrative and plans for a national museum of disability history in Washington, DC.

### COMMUNITY ARCHIVES

The Consortium conducts outreach throughout Western Pennsylvania to identify sources of disability history, including personal stories and collections already in repositories. Through these efforts, we are aware of a large amount of important historic material that is not yet preserved in repositories.

An online survey of organizations and individuals throughout Western Pennsylvania, launched in 2016, has resulted in more than 100 leads on potential collections and requests for preservation guidance. In addition to the ongoing survey (available on our website and in our newsletter), we hear informally from members of the disability community about people who may have historical materials or be interested in being interviewed about their experiences. We follow up on leads and maintain a spreadsheet inventory detailing existing collections and potential donations of papers, photographs, film, and video, audio recordings, artifacts, oral histories, and other items, either to our archives or to other repositories.

The Consortium's archives, which is digital-only, is small but growing. It includes video interviews with people who led or participated in advocacy, as well as interviews with people recounting personal experiences of disability, including institutionalization. Using these interviews and other sources, the Consortium produces its "Voices of Change" multimedia histories series. Stories in the series include a short documentary about Paul

Dick (1940–2010), a person with disabilities who contributed to the effort to create accessible public transportation in Pittsburgh, and an interview with Father George Strohmeier, a Catholic priest and one of the founders of L'Arche Erie, the first residential community of its kind in the United States. Other videos in the series include individuals with personal and professional connections to institutional history and renowned advocates who help create inclusive communities.

The Consortium's digital archives also includes more than 100 commissioned photographs of Polk Center in Venango County, as well as more than 50 photographs and videos with permission for use in our ongoing efforts. For example, the archives include the original recordings for "Voices of Our Region," a 2005 Allegheny County project featuring fifty-seven first-person interviews, and videos of a 2019 statewide meeting about the contested closing of Polk Center.

The Consortium collaborates closely with the Senator John Heinz History Center to physically preserve and make accessible to the public the archival collections, artifacts, and other materials that the Consortium does not have the physical capacity to preserve. Following leads from the community, Heinz History Center archivists and curators work with the Consortium to preserve many stories related to disability history in Western Pennsylvania. Links and finding aids to disability history collections at Senator John Heinz History Center are included on the Consortium's website.

Examples of historic collections that reflect the Consortium's collaboration with the Heinz History Center include the papers of Patricia Clapp, a renowned disability rights advocate; communication boards that predate the advent of electronic devices; posters from disability rights demonstrations; and artifacts from Polk Center. Historical materials collected by Heinz are shared through its museum collections database, online catalog, exhibits, and through the *Historic Pittsburgh* website hosted by the University of Pittsburgh Library System (see elsewhere in this issue for details about Heinz History Center's disability history holdings and research opportunities).

Through our website, eNewsletter, and other media channels, the Consortium strives to ensure that Western Pennsylvania disability history is easily available to the public. Our social media and other online engagement efforts are growing. We regularly receive inquiries from researchers, educators, and others, and are frequently asked to present talks about our community-based work.



**FIGURE 1.** Father George Strohmeier, co-founder of L'Arche Erie, and Mary Ann Zarnick, long-time staff member, seated for December 2019 video interview with Guy Caruso of the Western Pennsylvania Disability History and Action Consortium. Photograph by Tina Calabro.

COMMUNITY EDUCATION

Each year the Consortium hosts or co-hosts at least one major public event that explores the past, present, and future of disability topics. Led by people with disabilities, these events bring the community together and highlight archival materials.

A two-part series entitled “Let’s Not Repeat the Past: History Meets Disability Advocacy” (2018) explored the ways that mid- to late twentieth-century activism informs present-day issues and advocacy. “We Count: Pennsylvanians with Disabilities and the Right to Vote” (2019) featured national voting rights speakers from the REV! UP! campaign of the American Association of People with Disabilities and the #CripTheVote social media effort. Highlighted were the historic efforts of Western Pennsylvania voting rights activists Paul O’Hanlon and Rachel Freund. “No Longer Locked Away: Amplifying the Voices, Visibility and Legacy of Individuals with Mental Illness” (2020) discussed the history of institutionalization, new models of support, and contemporary issues of language, representation, and visibility. Other public events have featured employment, community-based services, and accessible transportation. Planning is underway for a 2023 event recognizing the upcoming closing of the 125-year-old Polk Center.

In addition to major public events, the Consortium presents to student, community, academic, and professional groups, including regional/national conferences. Venues include Friendship Circle, University of Pittsburgh, National Down Syndrome Congress Convention, the Society of American Archivists, and the “Community Dialogue” series of the Pennsylvania State Archives.

Our educational outreach prioritizes raising awareness among students about disability rights as a social justice issue. One notable example is the Consortium’s facilitation of disability history resources for the Nursing curriculum at Duquesne University. Students explore these materials to develop a deeper understanding of the struggle of people with disabilities to attain human rights and equitable services.

THE LEGACY OF INSTITUTIONS

From the late nineteenth through late twentieth century, Pennsylvania led the nation in the number of state-run institutions for people with intellectual and developmental disabilities, as well as state hospitals for people needing



mental health support. The Consortium works with community partners to ensure that the lessons of these institutions and the stories of people who lived there are not lost to future generations.

Most state hospitals in the western half of Pennsylvania for people with psychiatric illness are now closed: Mayview (opened 1893, closed 2008); Woodville (opened 1939, closed 1992); and Dixmont (opened 1862, closed in 1984). All three are in Allegheny County. Warren State Hospital (opened 1882) in Warren County and Torrence State Hospital (opened 1919) in Westmoreland County remain open.

Of the three state institutions (now called “centers”) for people with intellectual and developmental disabilities in the western half of Pennsylvania, one has closed: Western Center (opened 1962, closed 2000) in Washington County. Two remain open: Polk Center in Venango County (opened 1897), and Ebensburg Center in Cambria County (opened in 1957).

In 2019 Pennsylvania Governor Tom Wolf announced plans to close Polk Center (as well as White Haven Center in Luzerne County in the eastern part of the state). At the time of the announcement, the state Department of Human Services expected to transition Polk’s 194 residents to community-based residences within three years.

Plans to close Polk Center, much like past efforts across the state, has come with prolonged legislative processes and emotional debate among stakeholders. At issue is the benefit of institutions to their residents and to the communities where the facilities are located. In 2021 the Pennsylvania Senate passed a bill to halt the closure for at least five years. Should the legislation pass the House of Representatives, Governor Tom Wolf is expected to veto it, as he did similar legislation in 2020.<sup>2</sup> As of February 2022 146 residents resided at Polk Center.

Polk’s closure will be a historic milestone. It was the second institution for people with intellectual and developmental disabilities in Pennsylvania and is one of the most physically intact institutions of its kind in the nation. Founded as an “institute for the feeble-minded,” Polk opened to handle the overflow population from Elwyn School in eastern Pennsylvania, at that time the only state institution for people with intellectual and developmental disabilities.

At its peak population in 1955 Polk Center had more than 3,400 residents.<sup>3</sup> It was one of the most populous in the nation, as well as one of the most troubled. In the early 1970s advocates from the Allegheny County chapter of The Arc of Pennsylvania made unannounced visits to Polk Center to



## PENNSYLVANIA HISTORY

investigate complaints about poor conditions. These visits uncovered violations of human rights, including use of straitjackets and cages. The advocacy resulted in the firing of the superintendent and helped propel Pennsylvania's de-institutionalization movement.<sup>4</sup>

The Pennsylvania State Archives now houses official historical records from Polk Center. Efforts to preserve other types of historic materials and artifacts is ongoing, as is the recording of oral histories of former residents, family members and staff. The Consortium maintains an inventory of the location of Polk historical materials in a variety of repositories that are available to the public, including collections at Heinz History Center that tell the story of de-institutional advocacy.

Notable Polk-related oral histories conducted by the Consortium include an interview with two former residents who transitioned from Polk to community living, and an interview with the sisters of Danny Flavin, a man who lived at Polk Center for fifty-six years. We also helped facilitate the donation of a small collection of archival materials and objects documenting Mr. Flavin to the Heinz History Center. Currently, the Consortium is providing resources to an independent filmmaker who is making a documentary about the transition of a resident of Polk Center to community living.

The imminent closing of Polk provides an opportunity to offer a symposium that invites people with intellectual and developmental disabilities to reflect on the history of segregation and the decades-long building of a system of community supports. The event would also explore present opportunities and challenges, and future directions for advancing disability rights and supports.

### WHERE WE GO FROM HERE

The Consortium's commitment to preserving and sharing disability history and using it to ensure disability rights remains as strong today as it was at our founding in 2015. An important new effort is to document the history of Western Pennsylvanians with disabilities who are people of color. Their stories are largely untold and unrecognized. Currently, Project Scholar Alonna Carter is researching five historical and contemporary stories. They include Henry Bell, the first student at the Western Pennsylvania School for the Deaf in the 1870s, and Florence Reed, a contemporary advocate who founded the "Working Women with Disabilities" organization.

## PRESERVING PENNSYLVANIA'S HISTORY OF DISABILITY RIGHTS

More history is being made every day, and the Consortium is taking the lead in sharing it. Current Western Pennsylvania advocates are building inclusion, equity, and justice, plus raising awareness of intersectional issues, such as race, ethnicity, and gender identity. They are driving historic progress on many fronts, including addressing systemic barriers that keep people with disability in poverty, changing the paradigm of mental health support, and groundbreaking research and development in assistive technology. As in the past, Western Pennsylvania remains home to many “firsts” in disability history, such as Jessica Benham’s election to the Pennsylvania legislature in 2020. She is the first state representative who identifies as autistic.

Moving forward, the Consortium remains in service to the “history” and “action” parts of our mission through the leadership of the disability community and the commitment of staff, volunteers, and community partners. We invite the public to use our website (<https://www.wpdhac.org>) as a portal to the region’s remarkable disability history and to reach out to us for preservation information and guidance.

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GUY CARUSO, Ph.D., is the Western Coordinator of the Institute on Disabilities at Temple University, Pennsylvania’s University Center for Excellence in Developmental Disabilities Education, Research and Service, and a founding member of the Consortium.

## NOTES

1. *Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania*, 334 F. Supp. 1257 (E.D. Pa. 1971). This lawsuit challenged a Pennsylvania law that denied a free education to children who had reached the chronological age of eight yet had not reached the mental age of five. A 1972 Consent Decree guaranteed the “Right to Education” to children with intellectual disabilities. The Consent Decree laid the foundation for federal Public Law 94-142, Education for All Handicapped Children Act of 1975 (later renamed “Individuals with Disabilities Education Act” [IDEA]).
2. John Finnerty, “Despite COVID Delays, Pa. Still Seeking to Close Two State Centers by Next Year,” *Pittsburgh Post-Gazette*, November 1, 2021. <http://www.post-gazette.com>

PENNSYLVANIA HISTORY

ps://www.post-gazette.com/news/state/2021/11/01/Despite-COVID-delays-Pa-still-seeking-close-two-state-centers-next-year-Polk-Center-White-Haven-Center/stories/202111010086.

3. "Polk State Center," n.d., *Department of Human Services*, <https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Polk.aspx>.
4. "Department of Public Welfare News Release: 'Polk Superintendent Fired,'" April 17, 1973, *Historic Pittsburgh*, [https://historicpittsburgh.org/islandora/object/pitt%3AMSS\\_1002\\_Boo4\\_F24\\_I01#page/1/mode/2up/search/mcclelland+AND+wohlgemuth+AND+fir\\*](https://historicpittsburgh.org/islandora/object/pitt%3AMSS_1002_Boo4_F24_I01#page/1/mode/2up/search/mcclelland+AND+wohlgemuth+AND+fir*).