

When Grassroots Advocacy Sparks Grassroots Preservation: Working alongside Advocates, Archivists, and Curators to Document the Historic Experiences of People with Disabilities

Remarks

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I'm grateful to explore with you today what can happen when a museum has the honor of building trust within a community to collaboratively preserve and share its history.

Background on Consortium/History Center

Origins- Heinz History Center

- To begin, here's a hyper-condensed intro to who we are at the Heinz History Center
- We trace our roots to 1879 as the Historical Society of Western Pennsylvania
- Fast forward to the 1980s, when there arose a movement in Pittsburgh to establish a regional history museum.
- This movement joined with the Historical Society to create the Senator John Heinz History Center. Our museum opened in 1996 and today features exhibits and the Detre Library and Archives.
- What has remained constant is our geographic collecting focus- we're dedicated to preserving and telling Western Pennsylvania stories.

Origins- Western Pennsylvania Disability History and Action Consortium

- The origins of the Western Pennsylvania Disability History and Action Consortium are tied to an archival collection-
 - This collection illuminates a little-known but powerfully significant chapter in the Disability Rights Movement. It reflects how parent advocates exposed cases of horrifying living conditions and human rights violations as well as chronic overcrowding and understaffing at state-run institutions for people with intellectual and developmental disabilities. These advocates brought about real change and contributed to landmark legislation and the rising tide of deinstitutionalization across the state.
 - Knowing the lack of awareness about this story- one advocate-Bob Nelkin-then CEO of our region's United Way, facilitated the donation and partial digitization of these records to the History Center in 2013.
- In addition, the United Way partnered with other local disability advocacy organizations to organize a public event to celebrate this story, which took place at the History Center in 2013.
- With the collection and this event as a spark, the Consortium coalesced in 2015 thanks largely to the efforts of Mary Hartley and Tina Calabro, two parent advocates who worked to bring that 2013 event to fruition.

- The idea of collectively preserving the experiences of people with disabilities resonated with a wide array of regional organizations and community members
- Here's our mission: to educate the public about disability history in order to achieve equal opportunity and full participation in all aspects of community life and to emphasize humane and just policies. We as the Consortium fulfill our mission through research, preservation, and outreach activities.
- And just a note on Governance-
 - We have a Project Director as well as a
 - Steering Committee with representatives from the founding organizations as well as community members who self-identify as advocates
 - Our founders consciously cultivated a cross-disability membership for the Consortium
 - The History Center staff who sit on Steering Committee alongside me are: Anne Madarasz (Curatorial Division Director) and Emily Ruby (Curator and Manager of Museum Acquisitions)
- It's a joy to also note that the organization is award-winning thanks to the American Association on Intellectual and Developmental Disabilities, who presented the Consortium with the Hervey B. Wilbur Historic Preservation Award this year

Themes that have emerged

Now I want to use the remainder of my time to share the defining themes that, from the History Center's perspective, have made this partnership so special and successful.

Pursuing Preservation and not Collecting as Goal

- The first is the principle of pursuing preservation and not collecting as the goal.
- Early on the Consortium defined as a group the value of serving as a source for preservation information- and by this we mean preservation in two ways-
 - The first is **Gathering and sharing information about collections** that form the community's histories
 - The Consortium is achieving this by generating and distributing a survey to community members that prompts them to describe their collections. Simultaneously, we collaborated to create an online bibliography that categorizes and lists known collections in archival repositories pertaining to the experiences of people with disabilities. We aspire in the future to include collections held by community members as well.
 - The second is **Preserving collections according to community members' wishes**
 - In this survey, respondents can express interest in receiving preservation guidance. During initial follow-up undertaken by my colleague Bridget or Tina, the Consortium gets a sense of next steps
 - Picking up the baton from there, my colleague Emily and I usually make a site visit. The outcome of these visits varies based on the community member's wishes- it can look like conveying preservation guidance, providing council on creating inhouse exhibits, or facilitating donation of materials to the History Center.

- We've been actively collaborating in this way for three years and here are some of my reflections-
- When going about this work authentically with the goal of preservation in mind, I've seen mutual respect and meaningful trust organically blossom.
- I believe that taking the time to sincerely affirm the genuine value of these stories and expressing gratitude for a willingness to share in these moments matters.
- Finally, this work would not be possible without the support of Emily and I's supervisors as well as the shared consensus amongst us on interpreting the History Center's mission to preserve Western PA history within *and outside of* the museum walls.

Coordinating amongst Repositories

- To the next theme. As with most any community group, the historic experiences of people with disabilities can be found in many places. This reality has underscored the importance of effectively communicating with the repositories that care for these stories.

- Which brings us back to the Polk Center Receipts case study

Polk Center Collection

- After a clarifying conference call with the State Archives, we began the appraisal process.
- What we observed affirmed our preliminary estimation of the collection's research value.
 - Because of our relationship with the Consortium, we at the History Center were poised to recognize how this collection can be used by researchers to inform and challenge the overarching narrative of underfunding and understaffing surrounding these institutions, as they can spark analysis of day by day decision-making of how institutions allocated public funds
 - Discussing all this with our other colleagues, the collection was accepted via our internal Leads Committee.
- Up to this point, all this work was done in the trenches- but administrative signoffs were still needed- which meant forming an MOU
- And as these things go- what began as a simple draft agreement morphed into a 16-page mammoth rife with boiler-plate language that we couldn't agree to without significant edits. Thankfully the State Archivist intervened and returned us to a simple one-page MOU- one to which both parties quickly agreed.
- Today we currently have a volunteer, Emily Dahlin, engaged in rehousing the collection. Emily is also graciously entering the major data points for each receipt into a spreadsheet so that the collection is primed for critical research inquiry.

Learning how Community Members See and Describe Themselves and Their Records

- Now for the third theme.

- Through our broader involvement with Consortium events and participation in meetings, we History Center staffers have learned more about how community members see and describe themselves and their records.
- These moments during events and meetings have been opportunities to listen for both individual and collective choices in self-description and self-identification
- In this context, it's worth emphasizing again the wisdom and foresight of our founders to cultivate cross-disability membership in the consortium
- What we have heard must and has informed the language choices that we make in our professional work at the History Center
 - Here are some measurable steps that we've taken:
 - Number one- we use people first language and endeavor to avoid harmful language in collection description
 - Second- we've incorporated cross-disability representation in our digitization initiatives (some of which are funded by the Consortium or other community partners).
 - Thirdly- Recognizing the limitations of our own knowledge, we've incorporated suggestions during the selection and metadata review process from Consortium members
 - All these actions came as a direct result of our work with the Consortium

Offering Our Institutional Strengths, Even When They Expose Shortcomings

- Which brings me to the fourth theme- Offering Our Institutional Strengths, Even When They Expose Shortcomings that we're working on
- From the very start of the Consortium, my colleague Anne Madarasz has championed and modeled extending our strengths to the Consortium in order to further its mission.
- As a large museum with visibility and a fair amount of public trust, we at the History Center have resources we can offer- I've categorized them in this way-
 - Strengths
 - Space
 - The first is space.
 - Space for meetings
 - Space for events... not to mention the internal staff to set up, break down events
 - Megaphone
 - We also have a megaphone in our exhibits, publications, public programs, and learning programs- we can and have chosen to highlight collections that reflect the experiences of people with disabilities in our region
 - Collections
 - Expertise in care, storage, curation, and access
 - Shortcomings
 - Space
 - Accessibility in exhibits

- We were the first museum in the city to have a hearing loop installed in one of our exhibits, yet incomplete; consciously meet ADA requirements for exhibits, but so many more improvements that we need to make to be more accessible to people with disabilities
 - Refrain I'll reiterate here- *Progress made, but significant progress still to be made*
 - Accessibility in programming- Treasures in the Archives
 - I'm ashamed to say that until last year, I had not facilitated a public program at the History Center with accessibility in mind
 - During the planning phase of our annual public program celebrating American Archives Month, another archivist and I chose to highlight two collections pertaining to people with disabilities. Having attended accessible Consortium events, I realized it was imperative that this program be more accessible and inclusive
 - Thanks to the support of my supervisors and the recommendation of Consortium members, we incorporated open captioning and ASL interpretation into this event and are dedicated to doing so for future programs whose mission is to raise awareness of archives and archival work
- Collections
 - Accessibility
 - If we're committed to preserving stories of people with disabilities, then promoting engagement, research within community is ethical imperative
 - We now have SAA's newly released Guidelines for Accessible Archives for People with Disabilities to guide us in this process and we're eager to implement the recommendations in order to make our space and our collections more accessible
 - Progress made, significant progress yet to be made

Born of, Led by Community Members

- And finally, the most important theme- that the Consortium was born of and led by community members
- The History Center is a part of the conversation, but we did not start it and we aspire to not dominate it
 - As a result, we've been in a position to value and partake in the organization's goals rather than imposing a false and unfounded authority over the organization, its community members, and their histories.
- From the start, consortium members have generously lent their revered and well-earned reputations as advocates to this organization. They've leveraged their

connections and time to further the Consortium's mission. The accomplishments that the organization has achieved would have been impossible otherwise.

- Additionally, the community members' persistence and the leadership of former director, John Tague, current director Mary Hartley, and founding member Tina Calabro are integral to success of the organization thus far.
- Yet, sustainability is perennially a concern
 - My colleague Bridget will pick up here

Conclusion: When a museum has the honor of building trust within a community, committing to collaborative, long-term preservation benefits everyone. This type of preservation begets a rich and deep knowledge exchange- one that values lived experiences alongside professional expertise.

Thank you.