



## Pennsylvania History Coalition Honoring People with Disability

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# **A User Guide for Preserving and Sharing the History of Pennsylvanians with Intellectual and Developmental Disability**

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# Introduction

This User Guide is designed to assist human service organizations in preserving and sharing written and other material that honors the history of Pennsylvanians with intellectual and other forms of disability. These organizations include advocacy agencies, providers of home and community based service, facility-based programs, administrative entities, and generic health, social, and educational establishments.

Information is intended to assist these and other organizations as they express the historic value of their work and mission, organize historic materials using state of the art practices, and apply resources to enhance community and other stakeholder engagement.

Preserving and sharing the past are ways to correct society's interpretation that people with disability have been a burden. Learning the history of disability with a focus on people (not programs) offers important perspectives that are critical to informed public policy, inclusion, services and support.

The guide reflects the experience and recommendations of experts, Coalition affiliates, advocacy associations, universities, and other organizations. The report is made possible by a grant from the Pennsylvania Developmental Disabilities Council.

The following affiliates of the Pennsylvania History Coalition Honoring People with Disability (PHCHPD) participated in various projects funded under this grant, including those referenced in this work. Great thanks to:

- Speaking for Ourselves,
- The Arc of Pennsylvania,
- The Pennsylvania State Archives
- Millersville University and its Honors College
- West Chester University and its Department of History
- Elwyn
- WITF Public Media
- The Pennhurst Memorial and Preservation Alliance (PM&PA)
- Verland
- Historic Harrisburg Association
- The Commonwealth Institute

Chapter 1 covers archival and preservation basics, from taking the 'first looks' at the collection to organizing materials and developing a finding aid.

Chapter 2 provides information for creating a heritage center such as a history center, archive or museum.

Chapter 3 offers information about organizing community outreach and public education with history as a unifying theme.

A director's summary and detailed materials related to preservation and public outreach are contained in the attachments.

Special thanks to:

- College interns and student volunteers from Millersville University and West Chester University. Student participation continues to be a hallmark of the Coalition's work, beginning with our first statewide conference in 2013.
- People with disability who worked on Coalition projects and attended our events. Their leadership and vision continue to inspire and lead us.
- Project staff, family and friends. Thanks for your dedication and support.
- Dr. Margaret Jerrido, a respected archivist with the Urban Archives in Temple University who instructed affiliates on proper archival practices and resources used in the Coalition's preservation work.
- Jack McCarthy and his team from the Pennsylvania Historic Society *Hidden Collections Initiative* who conducted an important professional review of the Elwyn Archives under a generous grant from the Andrew Mellon Foundation.

# Chapter 1: Archival and Preservation Basics

## Terms

For purposes of this report:

- *A collection* means a coherent grouping of written material and artifacts that have historic value. Artifacts like furniture are the domain of museums and curators. Written materials and paper items are archival. Clothes and certain textiles can be part of an archive or museum. Collections are associated with a place, time, person, group, movement, organization, or genre - like a collection of Appalachian Mountain music.
- *Historic value* is an interpretation of significance attributed to written material and artifacts. Items that have historic value help practitioners in understanding how people lived, a time period, attitudes and practices, events, generational differences, and changing life conditions and styles. Historic value applies to material that depicts how people with disability have been interpreted in society, and how support and services have been delivered. Material with historic value helps clarify how people have struggled for freedom, justice, community support, opportunity and respect. Society relies on historic material to authenticate what happened to people in this country on the basis of disability and why.
- *Preservation* and *Conservation* are terms that refer to protection, restoration, care and maintenance of archives, records, artifacts, manuscripts and collections. Preservation is applied to repair and the restoration work. Conservation focuses on maintaining collections in the best possible condition.
- *A preservationist, processor, conservationist or archivist* is a worker who organizes and preserves archives, collections, artifacts and documents. Professionals in related fields provide an important resource to organizations, researchers, and the public.
- *A heritage center* is a museum, library, archive, interpretive center, or dedicated area that serves to honor the organization's past and its mission in supporting people with disability.

## Summary

The process of creating an archive begins with a first look at the organization's collection, proceeds through a series of organizational and preservation tasks, and culminates in placement of the collection at a site where researchers can access information using a finding aid. The process need not be hurried and can take years.

While a poster and photos from a recent disability rights rally or testimony before a legislative panel may not seem historic at present, they will be in time. Archiving the works of contemporary society ensures that future generations have a basis of understanding this one like any other.

Archival collections can begin quite small. While items do not need to be a certain age before they are included in a collection, researchers begin to focus on historic material that is at least a decade old, although there are notable exceptions.

While internet applications of historic material are important, web portals are not a substitute for repositories of original documents, books, film and artifacts. They go hand in hand.

Collections that are housed at original institutions and sites of historic significance have a unique potential for affecting community understanding. Historic installations at original sites represent a major emphasis of the Coalition and its affiliates.

Preserving historic material is not an invitation to hoard, wax nostalgic, go overboard on historic significance, or spend vast sums to acquire rare items. Sharing history is not a summons to be politically correct or one-sided.

Preservation requires an appreciation of history, which has a unique meaning for people with disability given the oppression that characterized their treatment in this country for hundreds of years. Preserving physical aspects of this history is a way to remind Pennsylvanians that we are still affected by the actions of generations which preceded our own. It also honors people who deserve it.

This generation does not get to pass on assessing the impact of oppression, or taking responsibility for addressing damaging vestiges of the past. Coming to terms with our tradition to reject people on the basis of disability, Pennsylvania is in a new place. History helps define where that place is and where it is heading.

For more information on this aspect of disability history, please refer to the companion publication: *The History of Oppression and People with Intellectual and Developmental Disability in Pennsylvania: An examination of Origins, Impacts, Resources, and Direction*. See our website at [disabilityhistorypa.org](http://disabilityhistorypa.org) to download copies at no charge.

## **Preservation Step 1: Taking *First Looks* at the Collection**

Preservation begins with looking at the collection as a complete entity in the context of its function and available resources. In the *first looks* stage:

- Consider items in the possession of the organization, as well as acquisitions, donations, and gifts that the organization expects to obtain.
- Consider available resources to include the space and time your organization can devote to this work, which requires a concentrated effort to organize the collection in the beginning followed by ongoing attention related to acquisitions, conservation, and using history to engage the public and other stakeholders.
- Consider acquisitions from board members, employees past and present, friends of the organization, people receiving services and their families, local historic centers, and other potential donors.
- Involve key stakeholders in this and subsequent steps. Include board members, community resources like a local historical society, employees, people who receive services past and present, and their families.
- Consider what has historic value. Items that are questionable often deserve further consideration.

Example: Processors confronted the challenge of what to do with thousands of books that were part of the old institutional library. They questioned whether this trove of unremarkable works of mainly popular 20<sup>th</sup> century young-adult fiction, warranted a place in the archive more accustomed to journals and professional papers. It soon became clear that the books possessed a unique distinction as sources of education and enjoyment, actually used and touched by residents and workers for generations. Processors refocused on ways to incorporate the books into the collection after that.

- Consider end users, including employees, future leaders, board members, patrons, the community at large, and people receiving service and their families. While professional archivists deem researchers as the primary end user group, human service organizations have a broader audience to consider, including: school groups, authors and social scientists, the media, genealogists, historical societies, and public resources from libraries to civic centers.
- Seek out experts and partners. Finding space and uses for historic materials can be a challenge. Consult with a local historical society, colleagues and

school officials for technical assistance and collaborative opportunities. Coalitions provide an excellent means to engage like-minded organizations and advocates in historic pursuits.

- Consider available space. Each organization has to consider the size of the collection in terms of available space. Heritage centers tend to start small and grow.
- Consider local historic societies, libraries, and advocacy groups for housing collections on a long or short term basis. Large institutions like universities or regional museums may be reluctant to accept collections that are not permanently deeded as an unrestricted gift. Commercial space like 'stor-mors' with security, heat to prevent freezing, and humidity/vermin controls present a short term option. Using a garage, basement, or attic is not recommended but may be all right for small collections on a short term basis.
- Manage temporary storage. Ensure the collection is not standing on or next to a floor drain or air duct and that boxed items are on pallets, tables or shelving. Pack items securely before transport and pre-plan the arrangement of the storage to ensure access for periodic inspections. Use plastic containers that can be stacked if necessary. Inspect space for insect, rodent and weather damage beforehand and during inspections. Do not store artifacts, particularly paintings or items that crack or split, in frigid conditions.
- Be prepared to pare down when a collection is too large or unwieldy. Conduct this task in consultation with subject matter experts and key stakeholders. Items can be donated, sold, discarded and recycled. Generic resources like local and Regional museums, historical societies and universities accept collections or individual items based on their acquisition criteria.

Example: In the example of the trove of books at the old institution library, the organization may eventually decide to limit this series to a representative selection of popular fiction for different ages; texts and primers used in classrooms, representative subjects/authors from different eras, and first or signed editions.

## **Preservation Step 2: Sorting the Collection into Series**

This step involves sorting materials into manageable *series* and *sub-series*. For purposes of preservation tasks, *series* and *sub-series* are synonymous with categories and sub-categories.

The eleven (11) separate series created in this step establish the basis for determining where items are located in the organization with the use of a finding aid explained in Step 4. For example, the organization's series of administrative records, sorted by year and department, would be located on shelves in the organization's archive and identified in the finding aid so researchers would know where this material is located.

**An outline of the eleven (11) series is contained in Attachment 1.** This attachment is recommended for organizations that choose to develop their own finding aid. Other options are explained below.

As this step is being planned, consider the final location of the various series, broad categories, and storage options. For example: books and periodicals might be located in an archive or separate library, apart from the archive. Consider too how some materials might have to remain in temporary storage or be housed in certain offices or a spare room.

Some sorting occurs in steps. For example: a set of 20 pamphlets from the 1880s by the same publisher is discovered after sorting through a large box of unrelated paper goods. The set is stored together and identified by its common title: *Lippincott pamphlets on insanity treatments (1881-1924)*.

When a folder of paper is already created with a title, keep the contents of folder together after checking that they appear to be consistent. For example, a folder titled: *1971 licensing reports* would remain with that designation going forward as one item in a series. Remove items that do not belong in the folder, create new folders for these items or place them in another existing folder.

Processors who sort historic materials prefer: tables to organize and a desk with locking drawer and a file; access to reference material, archival supplies, the internet and a copier, protective gear, a first aid kit, and work related instructions. A phone on premises may not be needed if processors can use their own.

- Use pencil, never pen and ink, to write on originals, folders, cartons, labels and other surfaces. Use archival erasers and tape, not commercial options. Never use tape or a rubber band with an original document.
- Original photos, cards, pamphlets and other materials that are annotated or accompanied with a provenance should not be altered or separated.

Provenance is a term used to verify authenticity by the chronology of ownership, custody or location. Items with a provenance include: an original receipt or label associated with an artifact, a note about how an object was passed down, a list of names taped to the back of an old photo, or a photo that authenticates an artifact.

- Include contemporary items that are expected to have historic value in this step. Architectural plans for the new office wing, budgets for current services, program materials used in habilitation, recent position papers, recent studies, board and committee minutes, photos and annual meeting programs all have a place within existing series.
- A policy for considering the appropriateness of material for a heritage center is recommended. The policy would suggest the types of material that the organization acquires as well as a standard number of years before different series, like financial records, would be available for researchers. It would also indicate whether other collections are accepted and on what basis.
- Keep no more than three copies of a document for archival purposes. If additional copies are warranted, these can be kept separately.
- Use archival quality supplies in this and subsequent steps. Refer to a Gaylord or other catalog to see what vendors suggest. See listing on page 19.
- Preservation of emails, documents stored on the cloud or servers, and documents shared only by the internet require different protocols. Consult with an expert on including these resources into collections. Items created on software can be copied into text, with documentation noting date and author. Virtual archives can also be created using any number of programs.

This Guide provides little information on virtual archiving due to the Coalition's lack of experience in this area. Note that archival websites referenced later on in this report may provide some direction in this area.

## **Preservation Step 3: Organizing the Collection**

After Step 2, prepare to place sorted materials by series and sub-series in archival quality acid free folders, sleeves, grey so called Hollinger boxes, and clear plastic bags. See vendor catalogs for variety of organizing materials.

Each container has its contents marked with pencil and numbered in a way that corresponds to the finding aid explained in Step 4. Cartons are placed on metal or sturdy shelving.

### **Cartons and Shelves**

- Archival cartons are acid free, brown or white, with handle openings and a lid. The standard size of a carton is 11" high, 15" long, and 12" deep. Stacking of up to three standard cartons is accepted although not necessarily recommended. Each carton is numbered according to the finding aid, with contents identified by series and sub-series. The underside of the lid may contain a listing of individual items or subseries in clear plastic sleeve.
- The carton number and contents are visible on the shelf for the researcher. Carton costs start at about 3\$ each from reputable sources. Paige boxes may be less expensive than other brands, and are sometimes used for initial sorting purposes. Use oversized cartons sparingly and keep the weight of cartons under 25 lbs. Having a sturdy step stool for accessing cartons on the shelves is recommended.
- Books, journals, and periodicals are generally placed on library shelves with a separate inventory or catalog system. Old card catalogs are kept and included in the finding aid by reference. Consult with an expert or vendor on shelving standards, organization, and tips.
- The standard for shelving allows for up to 8 boxes in a row on one shelf, 3 boxes high. Shelves are 36" high and 15" deep, except as required for oversized items. Be sure shelves are securely attached to a wall and floor to prevent them from falling when boxes are removed.
- Stack cartons on a pallet if shelving is not available. Do not stack cartons on the floor, close to a drain, or below a window that may be opened or unshaded. Limit stacking height to three rows. Cross-stack rows so that containers are not prone to lean, fall, and crush contents in a lower row.

### **Individual Items**

- Remove paper clips, pins, ribbon, string-ties, staples, and rubber bands from personal papers, manuscripts and papers. Flatten folded papers. Newspaper

clippings can be placed (not glued) between acid free paper individually and in their original scrapbook. Remove tape carefully to prevent damage to paint, print or surface. If surface separation begins, stop removal and cut off tape that is safely removed.

- Rag content in older documents helps in the preservation process. The ink is also stronger in older documents.
- Bugs, like mites and worms, create tiny holes, dust, and stains on paper goods. Careful dusting with a fine brush can be helpful. Damaged and infested materials are removed from the general collection and treated separately.
- Have an experienced carpenter or conservationist repair artifacts. Do not paint or refinish original wooden surfaces.
- Active mold and moisture damage, and items fading by sunlight, are addressed as soon as possible. Try not to discard materials that are crucial to the collection or part of a set. Items need not be in pristine or even good condition when they have historic value. Toleration to certain chemicals, like insecticides, varies.
- Water damaged books are placed separately on a table to dry for weeks or months. As condition stabilizes, separate sticking pages by hand, wearing gloves and using a letter opener or similar tool. Brush away mildew especially on cover. Do not return water damaged items to a set or series until dry and dusted. Use book press or other weight to bring item back to shape. Wrap item in a clear prophylactic bag if necessary. When item is returned to the collection, check periodically for mildew or staining.
- Items that are removed from the collection should be noted on a “remove list”. The list is kept with the finding aid though not necessarily accessible to researchers without a specific request.
- Auction, EBay, and private sales of historic items can fund preservation, conservation and new acquisitions. Do not underestimate the value of items and contact an appraiser or auction house for their opinion. Consider establishing a minimum bid with auctioned items of high value.

Example: Among the most highly anticipated lot at a highly publicized 2016 national auction is an Andrew Clemens (1874-94) sand bottle picturing an eagle and other patriotic images. An Iowa resident who had been deaf as a child, Clemens is known for his unique and meticulous folk art themes using multi-colored sands. At 8.75 inches high, the sand bottle was valued at \$20,000 to \$25,000.

## **Preservation Step 4: Completing the Finding Aid**

The finding aid is the last step in the preservation process. Once completed, the organization has the basic ingredients of an archive or heritage center. The finding aid serves as the table of contents and key for locating items in the collection.

Researchers use the finding aid to locate information and gauge the relevancy of the collection to their work. The finding aid serves as an accession log and is updated with new acquisitions. Keep receipts of new acquisitions for audit and appraisal purposes.

Finding aids are organized by carton listing, and by reference to other inventories needed to locate collection material. A finding aid also includes background information, an overview of the collection, and a carton/folder listing.

Microfiche, microfilm, and digital transcriptions are sometimes the only remaining record of original items. An index or table of contents associated with this body of material is included with the finding aid. Researchers will generally rely on the organization's microfiche and microfilm equipment to review these records.

A separate finding aid is established for an entity outside the general collection's scope. For example, a separate finding aid would be established for the collection of an early 19<sup>th</sup> century almshouse that once occupied the grounds of the present organization. The archivist's motto: "If it comes together, it stays together", applies to collections as well as series, subseries, and the contents of original folders.

A finding aid can be developed by or in consultation with an expert from an historical society, library, university or college history department. Organizations with a small collection can generally complete this step independently by following the advice contained in this User Guide.

Copies of affiliate finding aids are available on the Coalition's website: [disabilityhistorypa.org](http://disabilityhistorypa.org). A finding aid is also available at the affiliate. See the *Hidden Collections* website at [HSP.org](http://HSP.org) for further information on its Elwyn finding aid.

Online catalog systems such as RLIN, or NUCMC have finding aids as part of their software packages. Online programs can be of assistance in organizing and creating a finding aid. For further information, see:

1. <http://www.archivistoolkit.org>;
2. <http://www.CLIR.org>
3. <http://www2.archivists>

# Chapter 2: Establishing a Heritage Center

## Introduction

An organization can develop a lasting appreciation of its work and mission by creating a heritage center. A heritage center means an archive, museum, history center, and/or dedicated area devoted to the organization's history, the people the organization supports, and relationships within the broader disability and social movements.

A heritage center constitutes an extension of historic awareness. It's a way of honoring the past and more specifically the work of founders, dedicated workers, advocates and the community in supporting the organization's mission.

Private and public organizations have created heritage centers to memorialize their legacy and traditions. An excellent example is the original Pennsylvania Turnpike eastbound service plaza at Midway (Milepost 147.3). After a series of renovations, Midway has been restored to include a pleasing array of artifacts, reproductions of old photographs, displays of memorabilia, and streaming closed circuit documentaries. Original architectural features of the service plaza were also preserved. The overall effect is an enhanced traveling experience focused on a compelling aspect of Pennsylvania history.

As a point of reference, the Coalition's experience suggests that a heritage center for a small sized organization can be established in 6 months to a year, with work being shared between employees, volunteers, students and people with disability.

## National Repositories

The Smithsonian Institution in Washington D.C has archival resources, along with traveling and virtual exhibits relating to people with disability. Contact [si.edu](http://si.edu) for additional information.

The nation's sole disability museum, called the *Museum of disAbility History* is located in Buffalo New York. Contact [museumofdisability.org](http://museumofdisability.org) for additional information.

Another national repository is the University of Minnesota McGoogan Library that houses a substantial disability collection, including the life works of Dr. Wolf Wolfensberger, a pioneer in Normalization, noted author, and social scientist who influenced Pennsylvania services and support beginning in the early 1970s. Contact [jshleicher@unmc.edu](mailto:jshleicher@unmc.edu) for further information.

## Pennsylvania Repositories

In Pennsylvania, certain archives, organizations and museums have significant repositories of disability history for people with intellectual and developmental disability. These centers are open to researchers and generally have a program for accepting historic materials for their archives and collection.

**A listing of these resources, together with a summary of repository collections relative to people with developmental disabilities, is contained in Attachment 2.**

In addition to these repositories, a significant body of records and artifacts are maintained at individual State Hospitals and Centers, notably Polk Center in Polk, Venango County. Contact facility administrators for additional information.

Additional repositories that have minor collections are identified in the Coalition's companion report to the User Guide: *History of Oppression and People with Intellectual and Developmental Disability in Pennsylvania: An Examination of Origins, Impacts, Resources, and Direction*. Contact the Coalition's website at [disabilityhistorypa.org](http://disabilityhistorypa.org) for further information.

While Elwyn and other "hidden" collections have been discovered in South East Pennsylvania as a result of the work of the Pennsylvania Historic Society, most areas of the state remain uncharted. For example, the collection of internet radio recordings by the Arc of Luzerne County provides a significant body of untapped history. Contact [thearcofluzernecounty.org](http://thearcofluzernecounty.org) for information.

Media outlets, from television to newspapers, provide important repositories for disability history as well. Local historic societies are probably the best source of discovering how people with disability were supported in community life before the advent of special schools and institutions in the mid-1850s.

## Climate Control and Security

Humidity levels of heritage centers that contain an archive should not exceed 60%. Iridescent ceiling lights are best covered. Impact of halogen lights is unknown. Cool, dry and dark conditions are preferred.

Security procedures are posted, shared with researchers and other users, and updated. Consider the following amenities, practices and protocols:

- A handout that indicates research or heritage center hours, registration requirements, lockers and space for belongings, research procedures, finding aid location, archival assistance, microfilm reader and printer access, children's policy, food and drink, parking, rest rooms, nearby eateries and

resources, emergency exits, and a map of the building and other sites on grounds. The State Archives and other established repositories have templates to review for further details.

- A sign-in sheet for processors, researchers and guests
- An area for sorting materials that is locked and secure when processors and preservationists are not present
- A protocol for visitors to leave bags and coats in a locker or designated area
- Assigning an employee or volunteer to be at the heritage center while guests are present
- Extra security for materials that are confidential, rare, and of high value, including off site storage
- A signed agreement with researchers regarding the scope of material that can be accessed and the purpose of their work at the repository. The organization can require references and criminal history clearances, human rights review for research papers, and confidentiality assurances.
- Policy clarifying organizational response to violations of policy, theft, etc., and researcher responsibility to comport with applicable privacy statutes.

Organizations are advised to know the latest on privacy protections, like HIPPA, affecting: photos, film, health care confidentiality, personal/family identifiers, and clinical records. While there are exceptions, current interpretation is that a person generally needs to be deceased for 50 years before historic material with the person's name and image can be shown for commercial purposes. Out of respect for family privacy, some organizations continue to restrict access to all case records. Consult with the State Archives or a subject matter expert on privacy updates and interpretation.

Artifacts and old papers that are not in a secure space can all too easily disappear. While an organization can generally share or dispose of its property in any number of ways, a policy that prevents unlawful taking by employees and researchers is preferred. Act 95 (1982) provides rights to detain and prosecute under the Libraries/Archives Act. Heritage centers located in a room must be locked when not in use. Security cameras may be appropriate as well.

To prevent loss of this nature, organizations with a large inventory of historic appointments, furnishings, and artifacts are advised to have a professional inventory the facility and grounds, including offices where the materials are currently in use. The inventory would include provenance of historic items like

“Superintendent desk, purchased in 1897”, the item’s current location, a photograph of the item, and an inventory number. Numbers or a collection identifier can be made indelible or difficult to erase by various methods, including a chalk marking on a bottom of a drawer or chair. A stamp with “Property of XYZ Center” burned into an inconspicuous place on the bottom of furniture is an excellent marker. Experts and insurance brokers can be consulted for appraisal purposes.

## Protocols for Practitioners

The following protocols apply to processors who organize collections, as well as preservationists, researchers, conservationists and visitors.

1. Gloves. Ensure that processors and other handlers use hospital or archival gloves for sorting and handling items. Do not use cotton gloves due to their detergent content.
2. Reprints and Copies. To prevent over handling and damage, consider making copies of items that are frequently used, unique, or fragile. Examples include annual reports of 19<sup>th</sup> century institutions, programs about the opening of institutions and organizations, and news worthy events. Copies of historic materials are well received as handouts at outreach events.
3. Being Gentle. Open books and pamphlets only as much as needed without putting undo pressure on the spine. Turn pages carefully. Use bookmarks and slips of paper to identify pages that you want to go back to or have copied. Do not leave books open after research is completed and return items to their correct location. Do not repeatedly lay an old book face down on a copier. Make one copy, create a reprint, and make subsequent copies from that.
4. Training and Instructions. New processors require instruction on the proper handling of items to avoid damage and misplacement and for health related reasons. Provide instruction and support until the processor is comfortable with work tasks. Those with experience in proper handling can orient new workers.

Designate a supervisor to organize and oversee work sessions, check in periodically, point out areas of concern, and praise for completion of tasks. Break down tasks as necessary and stress standard practice, but allow for deviation as long as outcome is achieved in a consistent cost effective manner. Quality improvement focuses on taking one’s time, staying accurate, being gentle with the materials, and enjoying the work and company of others. Written instructions should be included in the processing area for reference.

5. Groupings and Amenities. Encourage processors to work in pairs or a small team to promote interaction, quality control, and consistency. Ensure that processing newcomers, including people with disability, are welcomed and paired to promote appropriate interactions. Be sensitive to arrangements where people with disability or newcomers appear to be left out. Bring in snacks and coffee, and encourage processors to take frequent breaks from what can be dirty, meticulous, and tiring work.
6. Dress. Processors dress in work clothes appropriate to the climate, rubber-soled/closed-toe shoes or sneakers, and a hat, scarf or visor in dirty conditions. When lifting and transporting boxes, wear heavy work gloves, a light overcoat to cover clean clothing, hard-toe boots to absorb a falling carton, and a pocket rag to wipe off dirt and grime. Do not wear long brimmed baseball hats where head room is impeded.
7. Protective Gear and Precautions. Processors use a mask and goggles or work glasses to ameliorate allergic reactions, irritation to skin and eyes, and trouble breathing. Processors should be reminded to use masks in dusty places or when there is ongoing direct exposure to old paper and books over a period of consecutive days, weeks or months. People with extreme sensitivity to dust and mold should not be assigned to initial sorting in dirty places. Mild and frequent coughing suggests that there may be a problem.

Use double strapped dusk masks when sorting old paper, film and negatives, and materials affected by water damage. Wash hands, exposed skin, and face regularly. Encourage breaks if processors are feeling fatigued. Before commencing work in an attic, cellar, warehouse or storeroom, check for vermin, birds, lighting, electrical outlets, and hazards.

Special precautions apply to photographic negatives and cellulose acetate film. If a vinegar or chemical odor is present or if handling presents skin or breathing issues, discontinue work and leave the area immediately. Wear leather gloves and a mask when bagging and transporting old canisters containing decaying film. Store canister horizontally in a freezer, and mark it to avoid accidental opening. Find an expert to assess the film for digital conversion. Discard original film after this and note on "remove list".

8. Work Areas. Processor desks, tables and supplies are generally in the same room or area where the collection is located. Work scheduling and placement should not disrupt organization routines and programs, or present ongoing distractions. A cupboard with preservation supplies and historic materials needs to be accessible for sorting, carton construction,

and other preservation work. Access to copiers and other equipment can be approved on a fee basis.

Work area protocols are useful in limiting the number of items that can be removed by a researcher at one time. A full or half cart of items is an accepted standard. Call slips are used when items are pulled by other than the researcher. A separate call slip is filled out for each item. Items that are not in the cart are kept on the practitioner's desk. All items are returned to their proper location after use and before new materials are obtained. Taking an "arm-full" of material from the shelves or more than two cartons at a time is not recommended.

Items can be taken from the stacks or shelving by series, sub-series, or folder. Items taken in this way need to be identified by their carton number, and have a "placer" in the space where the material is to be returned. Individual papers in a folder are taken out of and returned to the folder by the researcher during his/her work.

9. Clearances. Criminal history clearances may be required for students and non-employees to process collections at a facility or human service center, or to review clinical information related to people with disability who received inpatient or other health related services.
10. Display protocols. Original written materials and small artifacts are generally displayed under locked glass in a case or cabinet. Signage in the work area or archive is advised to:
  - Direct visitors to areas where exhibits are open and away from rooms and areas that are closed or restricted
  - Offer reminders relating to food and drink, hours of operation, and availability of associates for assistance. Food and drink are not permitted in an archive or sorting area.
  - Remind guests that exhibits, paintings, artifacts and other displayed items are never to be handled or touched. Be sure children are accompanied by an adult.
  - Note whether closed circuit security features are functioning.

## **Working with People with Disability**

People with disability have been successful in various forms of archival preservation. Volunteers and paid workers with disability participate as part of the Coalition's work.

Archival work with people with intellectual disability has a rich history. Before computers and digital cataloging, people with intellectual disability

were regularly employed and had careers as card catalog technicians in large institutions like the Library of Congress and the National Archives in Washington, D.C.

Job requirements are that people want to do the work, agree to learn the practices, have an aptitude or interest in tasks which he or she can manage with appropriate support. Support is intended to promote appropriate interactions, state of the art practices, and cost-effective completion of tasks.

Workers with disability who participated in preservation work sponsored by the Coalition have included individuals who were able to read and comprehend subject matter with and without ongoing assistance. People without these skills have also contributed.

Individuals with disability have been supported by student interns, family assistants, volunteers, and professional job coaches or employment specialists. Task analysis and other advanced practices apply. Processors suggest that candidates with a passion for the work be preferred.

Honoring the history of people with disability requires that team members and supervisors be patient, respectful, and inclusive. Supervisors and work colleagues have a responsibility to ensure accessibility and take direction in terms of effective communication styles, work assignments, seating, and scheduling.

Depending on the individual's aptitude and other factors, assignments can range from complex tasks involving the interpretation of written materials to repetitive responsibilities like removal of paper clips, unfolding correspondence, and material handling.

Workers are expected to take their time and be methodical in handling materials. Payment should never be based on time studies or a piece rate, ruling out sub-minimum wage in all cases.

Supporting people with disability in preservation and conservation work can be reimbursed as part of an individual program plan funded by Medicaid ICF/IDD or home and community based services, as well as programs administered by the Office of Vocational Rehabilitation. Recent service definitions have included various forms of habilitation, supported employment, vocational training, and community based work assessment. Contact the appropriate administrative entity or the individual's supports coordinator for details.

## **Working with Volunteers and Students**

Volunteers and students are important resources for organizations that have a heritage center or need qualified workers to conduct preservation and conservation tasks. Student internships can be paid or unpaid.

Practicum credits and other incentives provide flexibility in accessing college and graduate students without additional remuneration. Interns who agree to work without a stipend should still be reimbursed for their transportation costs and incidentals. Access to interns and student volunteers can be arranged through internship offices, individual professors, department heads, directors, and deans.

In assigning work, determine the student's interests and skills, health conditions, especially allergies, and expertise: such as computer entry, research, and clerical. Match interests and skills to tasks. This also applies to individuals with disability and other volunteers.

Volunteers can be identified in collaboration with advocacy agencies, local historic societies, and other community venues. Friends and family of individuals with disability may want to help out as well. Seek people who are committed to this type of work and the importance of honoring people with disability in contemporary life.

## **Locating Archival Supplies and Equipment**

The following businesses specialize in archival supplies and equipment. These companies are used by advanced collectors, state and local historical societies, universities, history centers, museums, archives and research sites. Catalogs are available by contacting vendors.

- Conservation Center for Art and Historic Artifacts, 264 South 23<sup>rd</sup> Street, Philadelphia, PA. 19103. 215-545-0613
- Hollinger Corporation, P.O. Box 8360, Fredericksburg, VA. 22404-8360. Email: [www.hollingermetaleedge.com/](http://www.hollingermetaleedge.com/) 1-800-947-8814
- Gaylord Bros., P.O. Box 4801, Syracuse New York 13221. Email: [www.gaylord.com/1-800448-6160](http://www.gaylord.com/1-800448-6160). Gaylord also provides information on preservation techniques in a brochure.
- University Products, 517 Main Street, P.O. Box 101, Holyoke, MA. 01041-0101. Email: [www.universtityproducts.com/](http://www.universtityproducts.com/) 1-800-628-1912

- The Paige Company, Parker Plaza, 400 Kelby Street, Fort Lee, NJ 07024. Email: [www.paigecompany.com/](http://www.paigecompany.com/) 1-800-223-1901

Acid free and archival quality photo sleeves, envelopes and folders are available over the internet or in big box stores. Supplies marked partially acid free are not recommended due to yellowing or other material damage that can result. Boxes without removable lids and handles are not recommended for an archive.

## **Converting Film to Digital Format**

Organizations with reeled old film, along with BETA and VHS cassettes, can have these materials converted to a digital format onto a DVD. Old film deteriorates and is best converted as soon as possible.

Converted films can be used as staff orientation and training, advocacy, and for public education. Though relatively untested, showing converted documentaries as part of a disability film festival at a local independent theater has great potential for community outreach. Note whether copyright requires the film's showing to be approved by another party. Copyright stipulations of many films tend to be limited to attribution or 'no-fee' showing in the case of public media.

Previewing 16 mm films with an experienced technician at the projector is recommended in determining the film's content, historic value and condition. Charges for digital conversions range significantly according to vendor, market, and the film's condition, so obtain estimates.

The following vendors have been recommended to and used by the Coalition. No recommendations or endorsements of the Coalition or its affiliates are intended by this or other listing in this Guide. Other vendors are available on the internet.

1. TJ Clark, Video Masters of Pittsburgh, [www.videomasterpgh.com](http://www.videomasterpgh.com). 412-358-0222
2. Resurgent Solutions. [www.resurgentsolutions.com](http://www.resurgentsolutions.com). 215-947-1649

## **Preserving images**

The following information applies to photographs and images on glass, as well as artwork.

- Individual photos should be sleeved and placed in a Hollinger style box with other photos according to subject or era. Snap shots of a specific

event, like a group retreat, can be kept together in an acid envelope or bag. Photos on a digital disc should be individually sleeved, labeled and archived by date, or subject and date.

- Each photo is placed in its own standard sized (generally 8"x11") acid-free folder, plastic sleeve or envelope. Store contents horizontally, not flat. Note contents on a list placed inside the archived carton. Photos in 8" by 11" pre-holed sleeves can be placed in ringed binders for additional protection or grouping purposes.
- For archival purposes, individual photos are removed from their frames. Do not remove when the image may be used for display purposes in a museum or archive. A 19<sup>th</sup> and early 20<sup>th</sup> century photo affixed to a cardboard backing is considered one photo and should not be separated. Frames with original glass can be saved in a plastic container, numbered to correspond to the original photo, and noted on the "remove list".
- A glass or film negative can be preserved with the original paper "proof" as long as the envelope is acid free and the negatives have not 'bled' onto the original. Glass negatives require special handling, so consult with an expert.
- Until items are placed in acid free conditions, do not remove images from original sleeves unless deterioration is present. Professional photographers going back to the early 20<sup>th</sup> century have used acid free or highly resilient protections.
- Paintings of founders, directors and benefactors, as well as renderings of original buildings and grounds, people living in institutions, and special events are often preserved in their original frames and hung for display. Consult with an expert for archiving these materials.
- Other art work includes landscapes, paintings of buildings and installations, restoration work, and artistic examples by people with disability and other stakeholders. Restoration and care of water colors, oils, acrylics and other media require different practices so consult with a curator or expert.
- Consider appraisals to determine the value of collections or specific items for insurance and other purposes.

## Handling Memorabilia

- Memorabilia applies to small artifacts that depict a time, place, or event. Examples include: conference pens, programs, display materials, postcards, shirts, posters, free giveaways, speaker gifts, and handbags.
- Once an item or sub-series is identified, place the material somewhere safe with protection to prevent folding, breakage or exposure to heat and light. Do not over-handle, avoid having others handle, do not repeatedly open and close or turn on and off. Do not place the item back on the pile or in the box where it was discovered. Check out whether battery or other powered items work properly, but be sure to take out batteries before item is placed in archives.
- Damage in transport of items, however minor, sometimes happens. Be as careful as possible in this process, not putting stress on glass, and making sure each item is individually wrapped. Before transport, ensure that items are placed securely in a plastic or water proof carton or traveling container. Use rope and bungee cords to arrange cartons so they will not shift during transport. Avoid packing or unpacking in inclement weather.
- Do not store memorabilia where there is mold, bugs, or potential water damage. If an item has a musky odor, separate it from other items and let it air-out individually in a cool dry place. Keep all items away from direct sunlight.
- Avoid keeping full matchbooks, flammable or explosive items, food items, plants unless dried, and wildlife likely to decompose. Pharmaceuticals like old pill bottles with their original contents can be retained or emptied. Include caution statement on cartons where poisons, sharps, medical equipment and controlled substances are stored. Do not display these items except under locked glass or in an out of reach place.

## Working with Reference Workers

- Reference workers are professionals who offer customer service in museums, large archives and other institutions.
- The domain of reference workers consists of records, staff, and patrons/clients. Researchers and visitors are reminded to respect the responsibilities of reference workers and to be patient and understanding with their protocols and practices. Take the opportunity to learn from reference worker expertise.

- An initial responsibility of the reference worker is registration that generally includes: the person's name, contact information, review of institutional guidelines, and summary of the researcher's purpose. Ongoing responsibilities include accommodation assistance, technical support in finding materials, arranging access to finding aids and equipment, and related information such as use of microfiche, catalogs, and copiers.

## **Creating a Disaster Recovery Plan**

A disaster recovery plan for archival materials is recommended. The plan is designed to protect the collection as well as archival users. The plan can direct that rare and valuable materials be located off site.

The plan details:

- Staff responsibilities
- Location of historic material and emergency supplies
- Emergency procedures for exiting the archive or heritage site
- Methods for accessing and documenting damage
- Salvage priorities
- Listings of conservation centers and alternative sites for relocation
- Instructions on how to preserve and protect different materials in transport.

## **Funding**

- Preservation and archival work is generally not a priority for new funding, although a long accepted administrative expense of agencies providing service. Check with funders on their policies.
- Certain foundations, donors like the National Endowment for the Humanities, business associations; private trusts, funding drives, and charities accept inquiries and requests for proposals. Note that start up grants for new organizations are relatively common with area business associations.
- There are numerous foundations and trusts that have a mission to support community engagement, cultural and community development, and historic appreciation. See your library and consult with colleagues for additional information.
- Donors and grantees have different expectations with regard to the use of their funds. Grant work requires reports and other accountability measures. Informal arrangements and coalitions will generally assign a non-profit 501c3 organization to manage claims and ensure financial accountability.

- Do not make the relationship with grant administrators any more complicated than it needs to be. Do what is expected, and deliver regularly scheduled reports on time. Be well prepared at meetings.
- Keep separate files for each donor or grantee, including award letters, key report dates, and fiscal instructions. Award letters and approved proposals are important documents to keep.
- Consolidations, institutional closures, and administrative changes have affected historic continuity across human service systems. Deeding the collection to a local historical association, sister agency, museum or archive, may be options for organizations that are about to close or which need to retire their collection.

## **Sharing**

Once the collection is established into a heritage center of some form, the organization can begin to make the collection known and useful in supporting people with disability in community life.

Careful consideration of this outreach phase is recommended, with adequate planning that leads to public and other stakeholder engagements with historic aspects of people and disability. The remainder of the report deals with this aspect of the work.

# Chapter 3: Community Outreach

## Introduction

This chapter provides information on sharing history with the community and other stakeholders. The information was gathered over the course of outreach projects conducted in conjunction with sharing a traveling exhibit about the history of Pennhurst State School and Hospital, from March through December 2015.

The traveling exhibit was developed by the Pennhurst Memorial and Preservation Alliance (PMPA) in March after a six month period of design and construction. Funding was provided by the Pennsylvania Developmental Disabilities grant.

This traveling exhibit consists of 12 panels and an iPod kiosk that focuses on Pennhurst's history from 1908 to 1987. The primary parties engaged in the outreach were the PM&PA, Coalition representatives, and individual advocacy agency leads.

The exhibit offers an opportunity for the public and other stakeholders to stroll from panel to panel and learn about the life and times of children and adults placed in the institution, as well as the importance of Pennhurst in changing the course of formalized services and support for people in Pennsylvania, and across the nation.

Exhibit panels depict aspects of institutional life, including brutal and dehumanizing conditions exposed by the Bill Baldini and his reporting team on Philadelphia television in 1968. The exhibit also explains how Pennsylvania came together to address these atrocities through the advocacy of parents and decisions made by political leaders, the legal system, and change agents.

Over 20 community outreach projects were conducted during this period, including 6 projects funded under the grant. Thousands of people across the Pennsylvania and in other states and countries have viewed the exhibit at the time of this writing.

Numerous generic organizations contributed to the outreach by offering their sites for the exhibit to be shared. Generic sites consisted of public libraries, war veteran establishments, government and civic centers, schools and universities, a mall, conferences, community centers, historic sites, and archives.

Funding from the Pennsylvania Developmental Disabilities Council afforded a modest stipend to advocacy organizations that hosted exhibits and planned outreach events. These organizations consisted of county based chapters of Speaking for Ourselves, the Arc of Pennsylvania, and Our Path of Montgomery County.

Special thanks to:

- Janet Herman, Betsy Neuville, Greg Pirmann, Jean Searle, Judy Gran, Jim Conroy, Ed Goldman and other PM&PA board members for determining the exhibit's content, media, and themes, and for managing distribution of the exhibit to the venues.
- Maureen Cronin and Matt Steiner of the Arc of Pennsylvania, along with directors and associates of the Arc of Chester County, the Arc of Philadelphia, and the Arc of Northeast Pennsylvania which hosted the exhibit and outreach events
- Debbie Robinson and Frank Yurich of Speaking for Ourselves and the Speaking for Ourselves chapter project leaders and membership in Chester, Philadelphia, and Montgomery Counties
- Paul Kuglar, the project officer assigned to the Coalition grant's by the Pennsylvania Developmental Disabilities Council
- The Commonwealth Institute, including Betsy Neuville, Thomas Neuville, and board members for the Coalition's financial management and their participation in these and projects
- Chelsey Wirth, an honors college intern and volunteer from Millersville University who represented the Coalition with local advocacy organizations and developed outreach templates and materials. Ms. Wirth was also instrumental in organizing the Coalition's first statewide conference in 2013.

## **Outreach Organization and Practices**

### **Project Summary**

The purpose of the outreach was to demonstrate whether traveling exhibits would be an effective means to educate the public and other stakeholders about the struggles that people with disability have confronted in Pennsylvania and across the country. Exposure to the exhibits was expected to enhance public awareness and participation in ways that promote the dignity and participation of people with disability in everyday life.

Each outreach event was organized around the display of twelve (12) portable screens or panels, each 7 ft. high by 3.5 ft. wide. This part of the exhibit required a minimum of 60 linear feet to display the 12 panels. A thirteenth screen related to the PM&PA's plans to establish an interpretive center at the Superintendents House

on old Pennhurst grounds was added to the exhibit in the summer, requiring an additional 5 feet of linear space.

Exhibit space was also needed for the iPad kiosk that contains audio-visual enhancements and additional information. The kiosk served as an accommodation for people with visual impairments and different learning styles. Space for an adjustable chair next to the kiosk and a table for earphones are also recommended.

Additional space would also be required for folding tables where local agencies and the PM&PA can share additional historic information. Examples of this information included: scrap books of the disability rights movement, posters, and equipment including a lobotomy machine used in a state hospital, photos, and vendor information.

During the course of the projects, PM&PA purchased an additional set of the panels to satisfy overlapping schedules and requests for the exhibits outside the purview of the Coalition's grant. The kiosks required adjustments over the year to work properly.

## **Project Content and Planning**

Each Council funded outreach project involved a month long display of the exhibit and a community event hosted by a county-based advocacy organization.

- The advocacy organization hosting the event was responsible for scheduling one or more sites where the exhibit would be shown and one or more outreach events.
- The only condition placed on the sites was that they would all be generic and regularly used by the public, such as a library, civic center, community center, government building, or museum.
- Planning activities involved a Coalition representative; the PM&PA outreach leader, and representatives of the local advocacy organization host. Conference call meetings began on a bi-weekly basis, and changed to weekly meetings as events drew near.
- A schedule of exhibit showings and events across different venues was maintained by PM&PA and the Coalition. Multiple projects were in process at any one time. Coalition affiliates discussed exhibits at monthly meetings and reviewed written materials.
- **A table that summarizes the sequence of events that local hosts completed is contained in Attachment 3.** Actual times for planning exhibit showings and events ranged from 8 to more than 12 weeks.

- Samples of public relations and outreach resources were provided to local sponsors for planning and publicity purposes. **These samples are included in Attachment 4.**
- Some organizations moved the exhibit to multiple sites for different audiences during their month. **Coupling the opening event with an art show or American with Disabilities Act (ADA) 25<sup>th</sup> Anniversary celebration was done by a number of sponsors, as noted in director's narrative summary in Attachment 5.**

# Attachments

## Attachment 1

### Outline of Recommended Series and Subseries in the Preservation Process

The following is an outline of series and sub-series that can be adopted by organizations as part of a collection's preservation process. The outline is derived from recommendations by Dr. Margaret Jerrido based on her career in archival work at the Urban Archives in Temple University.

These eleven (11) series and sub-series have been applied to the collections of Coalition affiliates. Each series is identified by number (1 to 11), with sub-series options noted beside a sequence of letters (a-k).

1. Administration. Within each sub-series, sort by year and organizational entity such as a department or advisory board. Organizations that have been influenced by a central event, like a court case, may organize around this.
  - a. Minutes
  - b. Agendas
  - c. Internal Reports
  - d. Subject related
  - e. Personnel
2. Finances. Within each sub-series, sort by year and month. Note that 19<sup>th</sup> and early 20<sup>th</sup> century financial records are bound in ledgers. Do not separate.
  - a. Invoices/bills/payments
  - b. Ledgers and record books
  - c. Budgets
  - d. Audit reports
  - e. Checks organized by month and year
  - f. Other
3. Correspondence. Correspondence between organizational leaders is generally covered here. Also include letters to and from the organization from family members, other clinicians, government entities, officials, and researchers.
  - a. Individual- alphabetical by name of organization writer and chronological within each folder. Include correspondence to and from the individual.
  - b. General – chronologically ordered, or ordered by subject
  - c. Other

4. Organization publications. Books and articles written by organization representatives can also be in a library collection that is separate from the archive. (See Chapter 2, Step 4 for further information.)
  - a. Manuscripts, articles and books authorized by organization for stakeholder and public consumption
  - b. Brochures
  - c. Pamphlets
  - d. Reports
  - e. Reprints of original material
  - f. Program materials published by the organization
  - g. Ceremonial records, like retirement programs and presentations
  - h. Speeches and presentations by organization employees and representatives
  - i. Advertising and public outreach
  - j. Specialty
  - k. Other
5. Outside publications. These publications are about the organization or the field of work.
  - a. Newspaper and magazine articles
  - b. Pamphlets, testimonials and other documents
  - c. Reference works, journals, trade reports and magazines
  - d. Papers written by professionals from other organizations
  - e. Program materials published by an outside organization
  - f. Reprints
  - d. Other
6. Research, Programs and Projects. Projects include collaborative activities such as community outreach, fundraising, and political action.
  - a. Attributed to the organization
  - b. Attributed to a committee, task group, coalition, trade association or other group in which the organization was a participant
  - c. Attributed to a field of study, medical research, and behavioral testing pertinent to the organization's history
  - d. Program materials used in habilitation, training, education, treatment and recovery

7. Branches, Partners and Affiliates

Organize chronologically by branch, partner or affiliate. Where the entity involves the acquisition of significant historical material, the branch collection can be noted separately in the finding aid. Series that have not

already been established in an existing inventory or finding aid would conform to the series identifiers established for the main collection.

Large branch collections can be archived at the branch, or shared as part of the main organization archive/museum. Historic materials gifted to or otherwise owned by the organization from a local chapter, stakeholder group, or prior owner can be allocated to the main or a branch collection as well.

8. Other Organizations.

- a. Correspondence from other organizations
- b. Information about competitors, partners, affiliates, and others
- c. Biographical accounts of colleagues

9. Other Subjects. Use this designation when the amount of material warrants its own series. Otherwise include items in Misc. The following subjects are included as they are germane to many human service organizations.

- Building and landscaping. The layouts of institutions and other human service settings provide important evidence of life conditions and social interpretations of people. This series includes architectural models and blueprints.
- Clothing and textiles. Clothing items are boxed individually in archival quality containers. Avoid folding and place between acid free tissue paper. Hats can be left in their original boxes, with acid free tissue paper added to avoid bleeding of colors or acidity from the box. Blankets, flags, banners, and other textiles are boxed individually and protected by tissue paper.
- Film. Organize each film by date and subject. Keep in original canister or “can”. Store horizontally. Label the container for items that appear fragile, such as mid-20<sup>th</sup> century 16 mm film.

Place warning labels on canister and photo negatives or envelopes emitting a strong vinegar odor, or that present breathing, skin or eye irritation. Store these items separately in a cool dry place and prioritize for restoration and disposal.

- Memorabilia. Place small items individually in a sealable 3 hole punched sleeve or bag with identifier. Generic sealed plastic bags used for freezing and preserving foods can be used to preserve plastic and non-paper materials. Organize by subject name like: ‘conference giveaways’, ‘pens and pencils’, ‘shirts and hats,’ ‘conference

programs', 'speaker notes', 'vendor information', 'conference tote bags', etc.

- Photographs and Still Images. Remove photo from frame and note this separation on a "remove sheet." If loose photos are part of one event, keep together in a bag or other closed receptacle. Pencil in the event on the bag and folder. Do not wrap a group of photos in a rubber band. Be careful in handling individual photos. Touch borders but not the image. Keep in a cool, dry, and unlit space. Store horizontally, not flat. Glass negatives, tintypes, and negatives can require special handling. Keep original negative with the photographer's "proof photo" unless condition issues require that negatives be removed and separated.
- Scrapbooks. Keep scrapbook together if possible and place in a protective folder. Organize by date. Reinsert items that have fallen out of the scrapbook using archival quality fasteners. Repair or reinforce bindings if necessary and include a note on the item's folder or covering when contents are fragile. Separated pages can be reinserted in their original placement. Store scrapbooks upright in protective cover, sleeve, or container.

10. Miscellaneous: This series provides a space for items in the collection that are not included in another category, including one-of-a-kind examples.

11. Case records. These records are filed at the end of the collection because they are usually closed to the public and stored off site. Organize by year and site, or as explained in the finding aid in Step

## **Attachment 2**

**TABLE: Pennsylvania Repositories with Significant Collections of the History of People with Intellectual/Developmental Disability**

<b>Pennsylvania Repositories</b>	<b>ID/DD Series</b>	<b>Location</b>	<b>Contact Information</b>
Pennsylvania State Archives	State and county Department of Welfare records State School and Hospital records Other facility records Pennhurst and other litigation records Birth and death records of residents of state facilities 19 <sup>th</sup> and 20 <sup>th</sup> century film and photos, manuscripts and records	3 <sup>rd</sup> and Forrester St Harrisburg	717.783.3281 <a href="mailto:phmc@state.pa.us">phmc@state.pa.us</a>
Pennsylvania State Library and Historic Commission	Government records, Publications and journals Genealogical records County histories and atlases Research guides State facility artifacts Dorothea Dix Museum artifacts	607 South Drive Harrisburg	717.783.5950
Urban Archives and Institute on Disabilities at Temple University	Pennhurst history, Pilcop and other litigation history Home and community based services history, Independent Monitoring for Quality Oral histories Historic films, records, and audio recordings	1210 Polett Walk, Philadelphia	215.204.8204 <a href="mailto:urbanarchives@temple.edu">urbanarchives@temple.edu</a>

Heinz History Center	Polk Center Artifacts	1212 Smallman St. Pittsburgh	412-454-6000 Heinzhistorycenter.org
Elwyn	Admission records from the 1850s Scientific inquiries on disability causes and etiology, Papers and correspondence of superintends from the 1850s Museum 19 <sup>th</sup> and 20 <sup>th</sup> journals, periodicals and pamphlets on disability 19 <sup>th</sup> and 20 century films and photos	11 Elwyn Rd Media	610.891.2000 info@Elwyn.org
Pennhurst Memorial ad Preservation Alliance	Pennhurst State School and Hospital materials	COA 426b Darby Rod. Havertown	Preservepennhurst.org
Arc of Pennsylvania	Advocacy history from 1950s Advocacy, training and education films from the 1960s	301 Chestnut St. Harrisburg	717.234.2621 info@thearca.org
Speaking for Ourselves	History from 1970s involving PA. and national organizations operated for and by people with disability ADA photos and programs Karl Williams songs and writings Autobiography of Roland Johnson	714 Market St. Philadelphia	Debbie@speaking.org

### **Attachment 3**

#### **Template for Planning Traveling Exhibits with County Based Advocacy Organizations**

This table provides an overview of actions that county based advocacy organizations have taken in planning for outreach events and exhibits. The packet referred to in the notes section is updated by this outline. The packet is not included in this guide. Contact the Coalition or PM&PA for updates.

<b>Time Frame</b>	<b>Advocacy Organization Planning Task</b>	<b>Notes</b>
Nine and ten weeks before exhibit opening	Select local project leader and assistant.  Review outreach packet from Coalition and PMPA on conference call.	Share contact information with Coalition and PM&PA
Seven and eight weeks before exhibit opening	Select community site(s) for exhibit showing and opening event in conjunction with PM&PA and Coalition.  Establish tentative dates and times for exhibit display(s) and for opening event.  Send save the date notice to network and stakeholder lists  Confirm progress with PM&PA and Coalition on conference call.	Refer to exhibit requirements in outreach packet.  Notify planning team as soon as confirmation is attained  Refer to save the date template in outreach packet
Five and six weeks before exhibit opening	Confirm arrangements with host site.  Forward final invitation to stakeholders  Confirm speakers and facilitators for opening	Include confirmation of display delivery/pickup, display times, layout of exhibit space, seating, accessibility, technical support, security, refreshments

	<p>event</p> <p>Confirm progress with PM&amp;PA and Coalition on conference call</p>	<p>Confirm whether PM&amp;PA representative will speak or introduce the panels</p>
<p>Three and four weeks before exhibit opening</p>	<p>Inform local paper and event media</p> <p>Check in with host site to ensure venue is ready</p> <p>Confirm arrangements on conference call</p>	<p>See public relations samples in packet</p> <p>Refer to host site checklist included in packet</p>
<p>One and two weeks before exhibit opening</p>	<p>Forward reminder notice to stakeholder list</p> <p>Prepare packets, name tags, evaluations, historic materials for display</p> <p>Check in with local and media channels</p> <p>Conference call to confirm final arrangements</p>	

## **Attachment 4**

### **Public Relations and Outreach Materials**

#### **1. Public Service and Save the Date Announcement**

The (local sponsor) is honored to join with the Pennhurst Memorial and Preservation Alliance to host a traveling exhibit and reception about the rise and fall of Pennhurst State School and Hospital, and the impact of this institution on the lives of people with intellectual disability.

The exhibit will be open to the public at no charge at (display site) from (dates and times). The address of the exhibit is \_\_\_\_\_.

A reception is also open to the public and offered at no charge. The reception is being held at (place)\_\_\_\_\_ on (date), from (time). The address of the reception is \_\_\_\_\_.

The reception will feature complimentary light refreshments, (speakers and highlights), and (displays of local history and/or by other organizations).

(Note location and cost of parking and accessibility at the site).

Funding for this exhibit and the reception is being provided under a grant from the Pennsylvania Developmental Disabilities Council.

For additional information please contact: \_\_\_\_\_. Also please visit our website at: \_\_\_\_\_.

#### **2. One Pager for Exhibit Sites and Stakeholders**

The Pennhurst Memorial and Preservation Alliance (PM&PA) is organizing a series of traveling exhibits about the history of Pennhurst State School and Hospital in coordination with local sponsors.

The purpose of these traveling exhibits is to engage the public and other stakeholders in learning about Pennhurst and its role as an institution where people with intellectual disability were sent to live from 1908 to its closing in 1987.

During its existence, Pennhurst became known as an institution where people with intellectual disability were mistreated. Conditions there became so atrocious and inhumane that the Federal court ordered all residents to be removed from the institution into state funded home and community based services.

Pennhurst litigation relating to right to treatment, right to education, peonage, and right to home and community services became important state and national precedents that have become a cornerstone of justice for people in institutional settings. Programs and practices formed at the time of Pennhurst's closing continue to control thousands of people's lives in Pennsylvania and other states.

The Pennhurst experience and its aftermath underscore the crucial roles the community plays in supporting people with disability. As neighbors, friends, classmates, family members, employers and work colleagues, we all have a role in ensuring that individuals are empowered to lead everyday lives, with respect and the resources they need to be successful.

These and other points are brought to light with the Pennhurst exhibit. The public and other stakeholders are encouraged to share in the journey people with disability have taken in becoming respected citizens in our communities today.

There will be people at the exhibit to talk with about Pennhurst and other matters affecting people with disability. Bring your family, friends and neighbors. Thank you for your consideration.

### 3. Additional Talking Points and Information

The exhibit consists of a series of panels that tell the story of Pennhurst State School and Hospital (1908 -1987). The institution housed over 3,000 people and served over 10,000 children and adults over the course of its existence.

People from across Eastern Pennsylvania were placed at Pennhurst. Before the 1970s, public institutions like Pennhurst and private facilities were the only options for families who were not able to care for loved ones at home. Schools would not accept children with disability and physicians encouraged people to be sent away.

Thanks to the emergence of Federally and state funded home and community based services, less than a thousand people continue to live in publically funded institutions like Pennhurst across the state. The census of residents in private facilities has also been reduced significantly. Private and public institutions that operate today are monitored to ensure resident health and safety, and compliance to minimum program standards.

Pennhurst was forced to close as a result of litigation by the Arc of Pennsylvania, a parent organization, subsequent to inhuman living conditions exposed in 1968 by a Philadelphia based news team headed by the reporter Bill Baldini.

Over the course of the next 20 years, litigation related to closing Pennhurst was instrumental in ensuring new rights to education, rights to treatment, and rights to home and community based services.

The Pennhurst Memorial and Preservation Alliance has dedicated itself to keeping the story of Pennhurst alive in order to ensure that the inhuman conditions of life in institutions like Pennhurst are never forgotten or allowed to recur.

The Pennhurst Memorial and Preservation Alliance is a 501c3 non-profit organization of volunteers dedicated to preserving the memory of Pennhurst and the people who resided and worked at the institution. More information is available on their website: [presevepennhurst.org](http://presevepennhurst.org).

#### 4. Television and Radio

Check with area public and private media outlets for free announcements of the exhibits and events. Send your contact information and event summaries to contact persons in these organizations and keep in touch, remembering to thank them after the coverage is aired.

Local talk radio and regional public media may be able to schedule time on a talk show to discuss the exhibits in the context of the history of people with intellectual disability.

The Coalition recommends public media alliances especially, due to its collaboration with WITF Media of Central Pennsylvania, which produced the 2016 full length disability history documentary, *I Go Home*, available on its website.

#### 5. Social Media

Utilize web and social networking sites to advertise the events and exhibit. Ask host sites and partner agencies to share the information as well. Post information on Facebook, Twitter, and other sites.

With Facebook or LinkedIn create an event. Promote events on Twitter with a hash tag. Request that readers re-tweet your message.

For more information on using the internet to promote events see:  
<http://wiredimpact.com/library/social-media-nonprofit-events/>.

#### 6. Checklist for Exhibit Areas

- 66 linear ft. for 12 panels; 45 linear ft. for 13 panels.
- Ceiling height of at least 7.5 ft.
- Space for one or two six ft. folding tables for other displays (optional)
- Chair, quiet space, and electrical outlet for iPad kiosk. (only if iPad kiosk is included)
- Desk or table for PM&PA brochures

- Exhibit area locked and secure when not in use
- Kiosk iPad locked in secure space when not in use
- Kiosk iPad monitored by attendant while in use
- Attendant available to answer questions and provide assistance.
- Accessible entrance way to building
- Parking lot location and accessibility
- Accessible bathrooms
- Elevators and ramps in building
- Plan for assisting people with visual impairments
- Contact names and cell numbers for host site, audio visual technician, in case of last minute changes, emergencies.

#### 7. Checklist for Community Event/Premier

- Adequate seating for expected number of people
- Microphone and podium for speaker
- Desk and long table with microphone for panel
- Audio visual technical support for showing a film
- Contact names and cell numbers for key people in case of last minute changes, emergencies.
- Internet access
- Exhibit space, environmental controls, and tables for refreshments
- Parking, entrance accessibility, room accessibility
- Check on interpreters
- Availability of site hosts to provide assistance and resources
- Signage directing people to event
- Caterer advised of place and time for delivery of light snacks
- Other exhibitors and vendors advised of set-up and take down times
- Media schedule, plan for interviews, etc.
- Check that evaluations are in packet and plan for reminder

#### Post Event and Exhibit

- Event evaluations to Coalition
- Post event briefing with Coalition and PM&PA
- Follow-up events and postings scheduled
- Thank you notes to sponsors, planning partners, media, and site hosts
- Claim for grant funding

## **Attachment 5:**

### **Director's Summary**

This account recalls my experience in attending a series of community outreach events hosted by various advocacy and other organizations from February through December, 2015. The events centered on the traveling exhibit created by the Pennhurst Memorial and Preservation Alliance about the history of Pennhurst State School and Hospital described in Chapter 3. Pictures, scheduling and other information are included on the websites of the Coalition, [disabilityhistorypa.org](http://disabilityhistorypa.org) and the PM&PA, [preservepennhurst.org](http://preservepennhurst.org).

The summary recalls the author's experience as the Coalition projects director. First names and an informal language style are used to reflect the character and tone of representative outreach events. The personal opinions expressed in the summary are not necessarily those of others, including Coalition affiliates, or project funders.

### **Chester County**

*The outreach began with venues and events organized by the Arc of Chester County with the Chester County Department of Mental Health/Intellectual and Developmental Disabilities. The presentation of the set of 12 panels marked the beginning of the County's celebration of the 25th anniversary of the Americans with Disabilities Act (ADA).*

*Janet delivered the set of display panels, still in their original wrappings from the printer, to the government center where PM&PA board members were ready to help put them together for the first time. We all read the directions carefully to be sure we did this right.*

*Once the twelve panels were positioned along two walls in the large conference room, we were ready. Added to the tables of historical materials that PM&PA and Arc of Chester County hosts also brought, we created a space surrounded by history. It felt right.*

*The premier was held in the Chester County Government Services Center, a large office building in early March. This kick-off brought together over a hundred people who acknowledged what Pennhurst still means to them. News of the event was carried in the Philadelphia Inquirer and area papers.*

*The Arc of Chester County director Jeanne and her associates, along with colleagues of the county's intellectual disabilities administrative office, organized the event. I had worked with Jeanne and the county personnel over the years. Fittingly, this evening was about times, people and places we all had in common.*

*The over packed room generated excitement and curiosity. It was clear that most of the attendees had been part of this Pennhurst saga that saw the return and integration of hundreds of people with disability into Chester County beginning in the 1970s.*

*What stood out to me as the guests began to tour the line of panels, was a deepness of feeling mixed with unity that the display seemed to evoke. Pennhurst was more than a closed and forgotten institution to the people who attended. It was an experience that defined much of their lives and it showed.*

*For about a half an hour, a procession walked respectfully from one panel to another, taking in the images and narrative. Some guests consoled others at points along this tour, which surprised me.*

*There were warm greetings and conversations interspersed too. A few people checked out the iPad kiosk that offered additional audio/visual content, but the crowded conditions were not conducive to use of this option.*

*During this walk to view the exhibit, I noticed an older couple recalling memories of life with their son. The woman crouched down to make out words that the man could not bow to see. She read them aloud, he responded and looked to their son who smiled and nodded, and then they walked on. Poignant describes this and other interactions that night.*

*This atmosphere in the room contributed to making the event feel less like a premier than an opportunity to reflect and renew commitments formulated from decades ago. The emotional quality of the gathering, together with Pennhurst's association with relationships, struggles, and triumphs, had become most compelling.*

*As the evening progressed, I could not help but marvel how this opening came together because a group of volunteers who believed in the Pennhurst story had the will to make this happen. It was a labor of love and toil, with Janet leading the way.*

*Janet ensured the PM&PA volunteers came together to compose elements of the Pennhurst story onto the set of 12 panels. She and Betsy shaped the final composition around themes, and transferred audio-visual enhancements like photos and film clips onto the iPad kiosk that tied into the panels at various points. Janet then directed the copy business to finish the design work and print the information onto the panels, just in time for the opening.*

*As for first impressions, the panels and stakeholder presentations seemed to have the effect we hoped for. We wanted this work to be taken seriously and it was.*

*While I was not prepared for the deepness of feelings expressed that night, the premier showed promise on a number of levels. It demonstrated that historic displays had a power to remind and unite, even inspire.*

*It also demonstrated the viability of relationships between families, their loved ones with disability, and public officials who supported them over the years. Given the collaborative themes expressed by speakers, I was surprised how provider participation at the event was slim, and made a note to look into this further.*

*After a county commissioner spoke about the long road that this liberation has taken, I felt that this type of recognition around Pennhurst was probably overdue. It was about time that the people who left Pennhurst and the people who helped citizens and loved ones return to community life were acknowledged as part of a bigger picture of liberation and inclusion that continues to unfold.*

*I could not tell whether other people that evening viewed this premier's impact in pioneering terms like I did. While some visitors commented along these lines in the guest log, many did not use this feedback loop as we hoped.*

*As we packed-up the panels into Janet's vehicle that evening for the first of numerous times over the next ten months, PM&PA members lingered in the parking lot. Someone noted how the people at the premier were a composite of what made the Pennhurst saga what it was. Yes, they were heroes, all of them.*

*For the remainder of the month into mid-April, PM&PA, the County Office, and the Arc chapter worked with Janet to ensure that the panels made the rounds from various floors within the government center, to Arc chapter headquarters, and to some libraries in town. Easily hundreds and likely thousands of citizens were exposed to the panels during this time. There was a lot of transporting, setting the panels up, and taking them down, but no one objected. It all went pretty smoothly, thanks much to Janet again, and Chelsey too.*

*Chelsey came to this showing, which was somewhat unexpected. She was unbelievably busy at this time in her life, with responsibilities at the dorm, with the Honor's College, family and her courses. It was great she made it to the opening, having contributed so much to the outreach supports and structures we were just beginning to explore.*

*Chelsey was part of the Coalition's work from the beginning in 2013 when we listened to Dennis about what a great resource state universities and colleges were, and how disability history is still so untapped and in need of exposure.*

### *Soltane Village*

*Janet had to pack the displays and kiosks into her vehicle for the next stop, a village called Soltane outside of Pottstown. This was to be the first outreach event sponsored by an advocacy group run by and for people with intellectual and developmental disability.*

*Speaking for Ourselves is the longest operating advocacy organization in the state, and one of the country's most important. Early members were prior residents of Pennhurst or people living in the community who were part of the "Pennhurst class" covered under a federal and state consent decree. Since it began, Speaking for Ourselves has garnered a national reputation and presence, beginning with Roland Johnson, Octavia Green and now Debbie Robinson who continues at the organization's helm.*

*The Chester County chapter, led by Betsy and Jim, arranged a series of events in the village where some of their membership resided. At the opening in Soltane's community hall in April, villagers from three Camphill communities, along with family members, board representatives, neighbors and friends attended. Speaking for Ourselves members who resided outside the Camphill villages also came.*

*Like the other two Camphill villages in Pennsylvania, Soltane subscribes to principles that embrace people with disability as valued members of community life. Their anthroposophical forms of education, collective governance, and abiding respect for nature and the arts, demonstrate how intentionality really does make a difference in the quality of people's lives.*

*People fleeing emerging Nazi genocide in the late 1930s led to the first Camphill village in Scotland. This village and those that followed embraced people with disability in all aspects of community life.*

*After all, it was people with intellectual disability, along with Jews and Romani people, who were the Nazis primary victims. It was no coincidence that this genocide began with systematic killing of children with intellectual challenges in special schools.*

*Today, Soltane is one of over fifty Camphill villages across the world. In Pennsylvania, the village was established after nearby Kimberton Hills in the early 1970s. Beaver Run, that includes a Waldorf school that is also tied to the Camphill movement, is nearby.*

*Based on the writings of the philosopher Rudolf Steiner in the early 20<sup>th</sup> century, and the later work of Karl Konig, Camphill villages like Soltane have affirmed their founding principles in everyday life. As a friend of the village, I was thrilled to be displaying the panels there because we were engaging one of the world's rare examples of a community that strives to honor and include people with disability as part of its core mission.*

*This night at the community hall had the feel of a 'get together'. Guests dressed casually or in work clothes and mostly walked to the event from one of the village homes. In this way, the event was different from the government center in that the audience at Soltane was mainly composed of neighbors and friends who came together as part of their regular routine of learning and life together.*

*80 to 90 people attended. While most people stayed for the full two hour event, there were comings and goings throughout the night, giving the event a flow and informal air. About half of the people in attendance could be characterized by a disability.*

*Seating was already laid out when we arrived, with a Camphill display and historical materials of village life on tables along the far wall. It was so great seeing old friends, like Clemens, who moved from the village but lives nearby.*

*The set of panels was featured in a long row along the back wall, with plenty of spacing between each display. The hall hosted community events like this regularly, including concerts, lectures, eurhythmy exercise sessions, weekly village meetings, art shows, silent auctions, and graduations.*

*Wonderful cheeses and jellies, fresh breads, churned butter and a variety of cookies, cold lemon juice and herbal teas – all grown, squeezed, baked and canned at Kimberton Hills or Soltane - were deliciously offered. This was village hospitality at its finest.*

*Historic materials of Pennhurst and flyers from the villages were laid out as well. Greg brought Pennhurst items and signed the illustrated Pennhurst history book he authored, recently released by Anchor Press. Greg also continued to attend most of the additional PM&PA openings in this capacity throughout the rest of the year.*

*In the front below the stage, speakers shared a couple of tables. They took turns to reflect on the exhibit and its theme, from oppression to rights. Beth, a board member of the village, gave an inspired keynote, recalling the years she directed closure of a facility like Pennhurst, considered the best private institution of its day.*

*Beth remarked how people who lived in this institution and their families worked with staff in deciding where to live and what they would do. Some residents moved back with their families, others elected shared living with an unrelated family or companion, and some moved with friends to apartments or group home programs.*

*When people found their new living arrangements, the agency closed that institution for good. They achieved this closure in an expeditious manner during the same years that people from Pennhurst were being relocated into the community under court order and consent decrees.*

*The people who left this private institution never returned. While other private facilities of that era were vying to stay afloat with newly minted Medicaid ICF/MR funding, Beth and her staff took direction from people and their claims for everyday lives.*

*They did what was right for people not programs. Beth ended her remarks with a caution that institutional solutions continue to allure families who seek ready-made alternatives in special gated neighborhoods.*

*After this, speakers at the front tables offered remarks. Villagers, parents, and others in the audience then spoke, which took up the remainder of the evening. Most contributors were individuals with disability, speaking for themselves, using a cordless microphone that was passed from hand to hand.*

*People milled around afterwards and checked out the panels again before retiring. I returned to the snack table for more of that delicious tea and a cookie for the road.*

*In contrast to the opening at the government center, those in attendance at the village premier had fewer direct ties with Pennhurst or any large impersonal institution. Whether their families were from Pennsylvania or elsewhere, the villagers were fortunate to have had better choices in life than institutions.*

*While a few speakers expressed relief that they never had to be placed in an institution, I wondered whether villagers who never set foot in a place like Pennhurst could really appreciate the oppression that the exhibit and Beth's presentation depicted.*

*While Camphill's origins in fleeing Nazi genocide explain an enduring connection with the people with disability subjected to systematic oppression, the experiences that many villagers shared that evening seemed removed from institutional ways that persist in Pennsylvania, though in a less malignant form than they were in the 1960s and 1970s.*

*Villagers talked about what they liked about their life and did not seem threatened by institutional demons. Bravo for Camphill communities, I concluded, having made it possible for people to feel secure and be appreciated in community life, no matter the era.*

*I wondered how long it would be until disassociation with institutional oppression would show its face with future generations outside the village, as the horrors of institutional care are already becoming a dim memory with many stakeholders. That cliché about the importance of remembering the past, lest it be repeated, rumbled in my head.*

*One of the two iPad kiosks worked well that night, and it was easy to see how this device could enhance the exhibit experience under the right conditions. I envisioned the kiosk and exhibit being used in a classroom together, so students could discuss the panels with Pennhurst photos and the Bill Baldini film classic: 'Suffer the Little Children', all featured on the kiosk.*

*The panels remained in the great hall for the rest of the month and provided a backdrop at graduation ceremonies in May. After that, an account of the opening event was featured in Soltane's quarterly magazine, 'Pathways', with lovely photos and a fitting narrative on the cover.*

*The presentations and comments from participants were also filmed that evening and there were plenty of photos taken. The film is like a home movie, and I have enjoyed it a couple of times already.*

*Jim and other members of the Chester County Speaking for Ourselves chapter continued to participate in other outreach events hosted by Coalition affiliates through the rest of the year, and are registered for The Coalition's 2nd statewide history conference in Millersville coming up in a couple of weeks.*

*It is great that this pursuit of history is something the group has chosen to stay with for some time. There has been a lot of this 'good stuff' happening.*

### *Philadelphia City Hall*

*The exhibit at the Arc of Philadelphia Art Show was next. Tanya, the chapter Executive Director and her associates organized the event. The Arc organized the showing with a conscious link to upcoming ADA anniversary events scheduled that summer.*

*The Philadelphia debut was point-on for the country's world renowned cradle of liberty. The venue was City Hall, a remarkable Italianesque edifice on Broad and Market Streets, with its iconic statue of Ben Franklin towering over the landscape.*

*The opening reception combined the PM&PA display and the art show. It was held in the grand legislative caucus room, a treasure in its own right with fine carvings, statuary, a wonderful rotunda ceiling, and splendid murals recalling classic themes. Again, the feeling of "finally" came to mind, but on a completely different scale.*

*Here we were, using this modest exhibit to declare, like women did at emancipation marches in the 1920s and people of color did as they established the first black churches generations before the Civil War, that people with disability have a claim for honor and self-determination too.*

*The Pennhurst panels were placed along the hallway outside the great hall. Six panels on the early days of Pennhurst were on one side of the chambers and six panels about the institution's downfall and aftermath were placed along the other side.*

*Artwork and some historic examples from the Arc of Philadelphia were interspersed in large glass cases along this hallway too, forming an interesting montage. While most of the art was shown on the floors below, attention to the Pennhurst panels shared top billing in the rotunda that night.*

*Speakers included political leaders, advocates, a curator and representatives of the art community. Tanya spoke and Jim did too, graciously thanking the Council for its grant to construct and share the panels in this way.*

*There were a couple of hundred people in attendance, including Philadelphia political leaders, artisans, and advocates. The gathering represented a powerful force for rights and inclusion of people with disability in the state, movers and shakers.*

*In this context, the display served as a reminder that the Pennhurst saga was part of a revolutionary tradition in the minds and hearts of people. The change agents and power brokers that attended that night made it their business to take social responsibility to heart, like we all must to keep freedom alive. The exhibit stood on a liberation tradition that is Philadelphia at its finest.*

*Refreshments included chilled wine and beer, with a variety of finger-foods neatly arranged on silver trays, served with delicate forks and cloth napkins by wait staff in black ties. Maureen and others from Harrisburg and across the state came, making it all seem most auspicious.*

*It was fitting that the PM&PA invited early Pennsylvania leadership to this opening, including past Pennsylvania Arc Executive Director and Deputy Secretary for Mental Retardation Peter Polloni, and early PARC Presidents Pat Clapp and Jim Wilson. These pioneers championed family advocacy in the state and orchestrated the closing of Pennhurst and other institutions during the 1970s and 1980s. Their advocacy for home and community services continues to the current day.*

*A number of guests commented how the Pennhurst display and the artwork of people with disability worked well together. The diversity of themes demonstrated not only how far people with disability have come in expressing themselves, but also how far the community has come in recognizing individual talent, so long hidden and denied.*

*Honoring people for their creative expression would not have been possible without the families and individuals who made the Pennhurst litigation and community dispersal possible. Art and life, life and history, history and art: fitting pairings in a telling nexus.*

*The attendees that evening personified this interconnection. Without these stakeholders declaring that people with disability had value as deep and everlasting as anyone, none of this would have been possible. Contemporary openness to artistic expression would not have been born without honoring people and freedom first.*

*Some participants at the Philadelphia opening may have included prior Pennhurst residents, but not nearly proportional to the hundreds of people from the facility who continue to reside in the city. I sensed again that provider representation was low if it existed at all.*

*Was this absence endemic of an important segment of the human services system losing touch with their history? What were the factors affecting this apparent lack of participation and most importantly, what will it take to ensure workers and people receiving services become engaged?*

*Political, cultural and historic dimensions of life came together brilliantly that evening, reminding me of how Philadelphia leadership has remained in the forefront of home and community services development across the Commonwealth. Philadelphia, the seat of American liberty, the place where the Declaration of Independence was crafted and the Constitution signed: how fitting a venue for this groundbreaking display celebrating the liberation of people with disability.*

*The legal firms and parents that collaborated to introduce landmark Pennhurst litigation came from this city and surrounding counties. Judge Raymond Broderick's hearings were held in Philadelphia Federal District Court. Pennsylvania's first Medicaid funded home and community based waiver in 1984 began with 80 people returning to their city of brotherly love from Pennhurst.*

*Talking with guests that evening took me back to earlier times and my friend Miguel, his family, and the men from Pennhurst, living together at their Mt. Airy group home in the early 1980s. Though some of the men have passed away, their return to community brought with it real jobs, long-term relationships, and valued roles.*

*That is what the Pennhurst saga and its aftermath led to, making it that much more important to share, and pertinent to our lives today.*

### *Elwyn Symposium*

*After Philadelphia, the PM&PA became ever more engaged and identified with the exhibits, authorizing additional showings and events at the 25<sup>th</sup> ADA Celebration and freedom march, the National TASH Convention in Oregon, and the US Constitution Center. The PM&PA purchased a second set of panels to manage growing interest and demand.*

*The displays were emerging at a critical time for sharing the organization's other plans, including its agreement to take possession of the old Superintendent's House at Pennhurst from the Pennsylvania Department of Military and Veteran Affairs for a museum/interpretive center. Outreach events were becoming opportunities to raise funds for the center from sales of Greg's illustrated Pennhurst history.*

*One of the venues that summer was a Coalition sponsored Symposium at Elwyn called 'Magic Happens'. The project was launched at Elliott's favorite Chinese restaurant after a morning of work at the archive with Amanda. The symposium and its name came to us over soup, rice, and hot tea; reflecting a collective delight that the archival work had blossomed and spread in so many unexpected directions.*

*Located near Media after its establishment in Philadelphia in 1852, Elwyn is the oldest continuing operating organization dedicated to supporting people with intellectual disability in the country with an archive that contains a collection of 19<sup>th</sup> and 20<sup>th</sup> disability history unmatched anywhere in the world.*

*One of my favorite series is a set of large photos depicting life at Elwyn that was featured in the 1876 Centennial Exposition in Philadelphia. These images clearly reflected an era when the institutional model evoked almost universal acclaim, with young adults learning trades and enjoying sports.*

*From its inception in 1852, Elwyn established itself as an international leader in studying the causes and treatment of intellectual and developmental disability. Its directors and professional personnel became leaders in formulating educational practices, treatment models, assessments, and forms of habilitation and care that influenced the living conditions of people with disability for a century and a half.*

*Established to celebrate the completion of the initial preservation work at Elwyn through the Council's grant, the symposium offered presentations about disability history by those who know it best: Elliott and Dennis primarily, and then the rest of us who were working on various Coalition projects and basically learning as we went.*

*Charlie, our lead history professor from West Chester University, facilitated a discussion about forming historic narratives. Brent, a visiting professor at the university, presented on his research with Elwyn records to determine what 19<sup>th</sup> century families considered to be the causes of their loved one's disability and need for placement.*

*After lunch, West Chester University history interns Amanda and Kelly described their work in preserving and organizing the Speaking for Ourselves and Elwyn collections. They also led a brief tour of the newly renovated archive, showing off its new displays, neatly arranged cartons of historic material on shelves, and other highlights. Visitors marveled at the finding aid, still in a draft form.*

*Back in the auditorium, Jim and Jean spoke about Pennhurst and the PM&PA's plans for the museum and interpretive center. Then Rose from Elwyn spoke about their supported employment program, and introduced Bert, a person who participated in the program.*

*Bert described categorizing letters of Elwyn's 19<sup>th</sup> century superintendents, Drs. Kerlin and Barr. He enjoyed the work once he was able to distinguish the handwriting styles of the time.*

*Bert contrasted the views of these early luminaries to his own experience, noting the "king like" authority these directors seemed to possess. He connected beautifully with the audience, composed of West Chester University students, Elwyn personnel, representatives from the area advocacy organizations, academicians from Drexel, and guests including a representative from the Council.*

*Sadly, this event was one of Frank's last public speaking appearances before he passed away a few months later. Representing Speaking for Ourselves, Frank spoke about how*

*advocates have an important role to ensure that special interests are kept from hijacking this history or keeping it hidden.*

*Frank emphasized that this history belonged to people first and foremost, not programs or even teachers. The history he wanted to share was not about brick and mortar, or theories about treatment methods to address “special” needs. It was about how people were treated and how they rose from oppression when given a fair shake and the right support.*

*Given the rich amount of information shared during this event, it seemed that the Pennhurst panels had a muted effect compared to other venues. It may have been that the symposium was so focused on earlier ages, but there was something else at least for me.*

*I admit to holding different opinions about Pennhurst and Elwyn, though they can both be classified as institutions. For starters, Pennhurst began in the 20<sup>th</sup> century as a “world apart” where people with disability were viewed as social burdens. Elwyn Institute, as it was called originally, was created in the mid-19<sup>th</sup> century in order to assist people with disability in becoming accepted as valued adults within civil society.*

*In view of this predisposition, I reminded myself that it is entirely proper to have installed the Pennhurst panels at the symposium as a reminder that uncomfortable truths coexist in places and at times where ‘Magic Happens’. After all, the best intentions of 18<sup>th</sup> and 19<sup>th</sup> century reformers were no match for the oppressive realities that people in public and private institutions experienced throughout the 20<sup>th</sup> century.*

*Dennis spoke to this dichotomy beautifully in his presentation about Eugenics and the systematic dehumanization of institutional life during the modern era. Discussion on the Pennhurst film narrated by the actor Henry Fonda brought oppressive underpinnings home to roost as well.*

*It was not that 19<sup>th</sup> century leaders like Drs. Kerlin and Barr were disingenuous any more than leaders that followed. Nineteenth century practitioners believed in the treatments and the science they applied. As spokespersons that reflected their eras and esteemed professions, they viewed their institutional model as a practical and humane means to provide appropriate study, care, and support.*

*Whether these early leaders considered people with intellectual and developmental disability to be fully human is another question, especially as ominous opinions about disability became more and more fear based during the 1880s. I wonder about these qualities even today.*

*The sad fact is that the goals of 19<sup>th</sup> century reformers to employ specialized resources as a means to teach people for their return to community life never materialized. As*

*facilities like Elwyn became self-sustaining colonies in the 1880s and more like a world apart, they also became accepted fixtures in American life.*

*So I wondered: how would this be so different today with complex human service systems that have taken the place of the institutions in managing people's lives? 'History will have something to say about that too,' I thought with some relief and more than a little frustration.*

*All things considered, the symposium was successful in celebrating the Coalition's work and ability to draw in other stakeholders. I totally enjoyed learning about the Europeans who set the stage for ideological struggles that emerged in the United States, and the role that the Enlightenment played in freeing people with disability from institutions in France and Belgium.*

*Another observation I would offer applies to the symposium and other outreach venues. In retrospect, I sensed we must take care to ensure that audiences that experience the exhibits have adequate time beyond the casual stroll after lunch.*

*Using the Pennhurst exhibit responsibly calls for individuals to consider why Pennhurst is relevant to a history marked by different places, times, and perspectives. People need time to walk with the panels, take in their own meanings, and have opportunity to process their impressions with others.*

*In this way, the panels, like so many other qualities of the Pennhurst experience, are a memorial, like the Vietnam memorial in ways. They are a place to reflect, feel, and share what we can. That takes time and a certain state of mind.*

*While the exhibit speaks to oppression, it also explains the impact of changing attitudes, expectations and ideals. It touches on heroism and resilience in the midst of despair.*

*These themes bring the Pennhurst saga to life and keep the struggles of people with disability relevant through ever changing times. In this sense, Pennhurst and the hundreds of closed and dilapidated institutions across America will always be with us as something more than a chapter in Pennsylvania history.*

*The legacies of untethered institutional control that nested in these places are rooted in the lives and interpretations of people with disability which continue to unfold. That's the emotionally difficult part of this history, the part that demonstrates how long it can take people to have valued everyday lives, and overcome disability related barriers that society continues to impose.*

## Coventry Mall

*The displays continued their journey in the summer months and early autumn. Janet and other PM&PA board members transported the panels to a variety of new venues: VFW halls, state and national conferences, colleges, and the atrium at the Capitol in Harrisburg. The exhibit even accompanied Jim to an international conference in Seoul South Korea where he gave a keynote. While all of these opportunities were important, the caper for me was the Coventry Mall outreach in September.*

*Both Speaking for Ourselves of Montgomery County and a group called Our Path were the sponsors. Debbie and Frank were instrumental in introducing us. Our Path's organizer, Dave, did yeoman's work in putting the installation together, with assistance from Sharon, a long-time family advocate.*

*Composed of people with intellectual and other disability, including individuals who lived at Pennhurst, Our Path takes on projects that give back to the community. The members of the organization also enjoy each other's company at social events, including lunch trips to the Coventry Mall where the shopkeepers have come to know members on a first name basis.*

*During Pennhurst's heyday, the Coventry Mall was thriving. While the public has newer and larger shopping centers to choose from today, people who worked and lived at Pennhurst considered the Coventry Mall to be one of the best in its time.*

*Our Path arranged with the mall's management to be granted complimentary access to the old Gap Store each and every day in September. For each of the 30 days the mall was opened that month, Our Path and the PM&PA displays were on duty.*

*Dave and some of Our Path members have been together from the time Pennhurst closed in 1987. In fact, Dave lived with three of the men going back to the late 1980s when he was a residence manager at what was the medical director's house on grounds.*

*It is a little known fact that a handful of men who were residents of Pennhurst refused to leave the institution when it officially closed in 1987. The court approved of the men living in a supervised arrangement at the medical director's house on grounds for years until they found another location.*

*Today, Dave and two of these same men live together in a shared living situation known as "lifesharing", which is supported by public resources funded under Pennsylvania's Medicaid home and community based waiver. Both men are in their retirement years, and one man needs Dave's assistance to walk.*

*The success of the Coventry Mall outreach surprised everyone. Apart from the people who worked and lived at the institution and settled in the Pottstown area, there were hundreds of other visitors, both children and adults, who knew of Pennhurst's history,*

*had family members that worked at the institution, or were just curious about the installation at the old Gap store.*

*Throughout the month, former residents and workers brought memories to share to the setting: slides and pictures, family albums and snap shots, stories, program descriptions, and professional papers too. Our Path set up many additional tables to display these items, including a display of the Speaking for Ourselves collection that Amanda and her friends brought from Elwyn.*

*During the times I was there; the store space was occupied with Dave and Our Path members and a stream of visitors. Sharon and her family, along with Speaking for Ourselves members, were regulars too.*

*One Saturday, I led a talk with a group of 20 men and women. All of the members of the group were blind or had visual impairments, including a man who was one of the first therapists employed by the institution after the scandals hit in 1968.*

*I was especially interested in meeting this group and obtaining their views about the display and the kiosk. Instead of another form of accommodation, group members preferred it when a person, like Dave, would lead them as a tour guide, reading from the panels, describing the photos, and taking questions.*

*I thought this low-tech, personal, and highly interactive method of accommodation to be instructive. Group members appreciated the kiosk during this tour too, especially the narrative portions offered by Bill Baldini, the TV news reporter who broke the Pennhurst story in 1968.*

*There were other 'take-aways' from the Coventry Mall experience. While Dave made a point to take notes about conversations he had with exhibit visitors, plans to have a private space for recording oral histories never materialized. With the advancing age of people who remember Pennhurst first hand, I made a note to make more of an effort to capture personal stories before this last generation of people who left the institutions is gone. Fortunately, the Institute on Disabilities at Temple University has embarked on an oral history campaign affecting Pennhurst and other institutionalized residents known as 'Visionary Voices.' (See Attachment 2 for contact information).*

*The mall site was also instructive as a place where the public was open to hearing about Pennhurst and its history. What others perceived as a struggling shopping center, Dave recognized as a viable platform to invite public participation.*

*Another quality of this venue was how it amplified understandings. This started from the first night for me, with Roosevelt, a prior resident at Pennhurst who lived at the old medical director's house after the institution closed.*

*Roosevelt was the master of ceremonies for the Friday night events. Dave said Our Path always did it that way, with Roosevelt as host.*

*As I understand it, Roosevelt like so many others was placed in Pennhurst as a teenager because the family had been struggling with his behaviors, which reached a breaking point after incidents forced his mom to make a choice between Pennhurst and a juvenile facility. There were no community alternatives at the time and a private institution was beyond the family's limited means.*

*At a break in the schedule that evening, Roosevelt shared a story about Pennhurst with me. It was about taking a secret pathway from the men's to the women's colony where he met up with his woman friend. The two regularly snuck away to a tavern down the hill for beers and dancing, sometimes by themselves, and sometimes with another couple or friends.*

*I appreciated the story because it underscored how the human spirit prevails in finding relationships and adventure, regardless of the conditions. It also introduced me to an aspect of being an inmate at Pennhurst that I had not imagined to be possible.*

*Here were two young adults sentenced to a "world apart" with strict rules about so called elopements, who regularly participated in an aspect of community life. I wondered how many more stories Roosevelt and others placed at Pennhurst had to share.*

*The other three Friday night events at the Coventry Mall were a smash, as was the opening with PM&PA that I could not attend. These events included presentations about supported employment, advocacy, Pennhurst today, and services for the blind and visually impaired.*

*The audiences were diverse, engaged and appreciative. The stories that the exhibits evoked provided a stream of information and insights. By the end of the month, the space allocated for display tables more than tripled.*

*Innovations were tested that month too. Our Path introduced various music styles on a CD player to draw visitors into the exhibit space and accompany them on their tour of the panels. Refreshments were made available from a big blue cooler in the back. Subtle lighting changes were attempted.*

*There were pens and other giveaways, and candy in a bowl next to the guest log where Dave liked to do interviews. The book store at the mall featured the illustrated Pennhurst history and other copies were sold by Our Path and Greg. Nearly 50 copies of the history sold at the exhibit installation, not to mention book store sales.*

*Vendors from the food court provided complimentary samples of their wares, ice and utensils. Management posted information about the events on its website and Facebook.*

*Some of these enhancements worked better than others. The point is that the exhibit kept getting better and others pitched in. The kiosks were improved and updated too. We were all a little sad to see it end in October.*

*Much more needs to be done in utilizing community resources like the Coventry Mall to engage the public. There is probably a mall space that serves every community across the state with an empty store that could be adapted in this manner.*

*One question we need to ask is why this or other forms of creative down to earth outreach have taken so long to be discovered let alone used? What is there about the history of people with disability that keeps it yet hidden and repressed? What are we all so afraid of?*

*Above all, the Coventry Mall project demonstrated that outreach in generic places is feasible and cost-effective. Our Path showed us how history shared where the public gathers can be a win-win for management, merchants, the public, and advocates.*

*As an example of demonstrated benefit, visitors to the Our Path installation decided to talk with area leaders who spoke in turn with the press. Within a couple of weeks, articles appeared in two area newspapers, culminating in a hard-hitting Sunday editorial decrying the use of Pennhurst as a haunted house attraction since 2010, drawing in thousands of fee paying people during the Halloween season.*

*The editor claimed that this use by the owner of the men's colony portion of the institution has cast damaging aspersions on people with intellectual disability, their families, and support workers, perpetuating misconceptions that people with disability are objects of dread, fear, and disease. While horrid things happened at Pennhurst, the editor noted that the use of these decaying buildings into a profit making attraction without historic context or other considerations was unjustified and basically a disgrace.*

*Letters from prominent citizens followed, mostly in agreement with the editor. Not long after this, the Pennsylvania Department of Military and Veteran Affairs which holds title to certain Pennhurst property decided to demolish some of the buildings that constituted the men's colony, and offer the Superintendent's house to the Pennhurst Memorial and Preservation Alliance for an interpretive center. The Department has operated a veteran's home and National Guard armory on site since 1986.*

*I am not saying that this editorial or the synergy created at the Coventry Mall that September influenced this turn of events at Pennhurst. There is no apparent correlation between the Coventry Mall and the receptivity of public agencies to support PM&PA's efforts to transform the superintendent's house into a museum and interpretive center.*

*The PM&PA has also been trying to end the Halloween debacle ever since it began. In this respect, the organization has taken strides to have Pennhurst identified as an international site of conscience and memorialized with a Pennsylvania keystone marker. Having Pennhurst transformed to a museum was always part of the organization's mission too.*

*Despite this, I liked to think that the editorial spawned from the Coventry Mall experience made a difference. Maybe it was a tipping point, a rekindling of community awareness, or something subliminal. All I know in light of this year of outreach projects is that 'magic happens', and that's good enough for me.*

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*As a postscript, Janet and the PM&PA are continuing to book the panel showings and events. Hardened traveling cases have been procured so the exhibit can be taken on flights, busses, and trains.*

*The organization is also focusing its outreach on students in colleges and high schools, and finding receptivity with advocacy organizations outside the Philadelphia area. At the time of this writing, the panels are booked for the Coalition's 2<sup>nd</sup> history conference at Millersville University in March, where over 200 people are expected. Janet has a breakout session to talk about the outreach that is already totally full.*

*Also, Speaking for Ourselves is planning to develop a series of panels about its work in advocating with people with disability with new funding the Coalition received from the Pennsylvania Developmental Disabilities Council that will extend the Coalition's grant for another 18 months.*

*The Coalition plans to continue its work with our 2015 affiliates, as well with new players and new projects. John, Mary, Ann, Tina, Nancy, Paul, Shirley, Guy, and so many others have formed a history and action consortium in Western Pennsylvania. So much of the state's rich past with people with disability rests in these 28 counties, along with a history of outstanding leadership and more.*

*The Consortium's new emphasis on the history of people with all forms of disability is important too, and a sign of our movement's maturity. The Council is also supporting the development of the Consortium, along with a generous grant from the Judith Trees Charitable Trust.*

*Going into 2016, I am pleased to report that donors and affiliates alike appreciate the role that history plays, not as an academic exercise, but as a critical teaching tool and call for social action. The work of preservation and sharing continues.*

*Respectfully submitted by Dana Olsen, Projects Director, the Pennsylvania History Coalition Honoring People with Disability*

