

**Learn about archives from the perspective of a trained archivist and reflect together on ways archives can both reinforce and subvert ableism.**

# Ableism, Archives, and the Work Ahead

Robin M. Katz - March 20, 2024

UCR Health Humanities & Disability Justice Lab

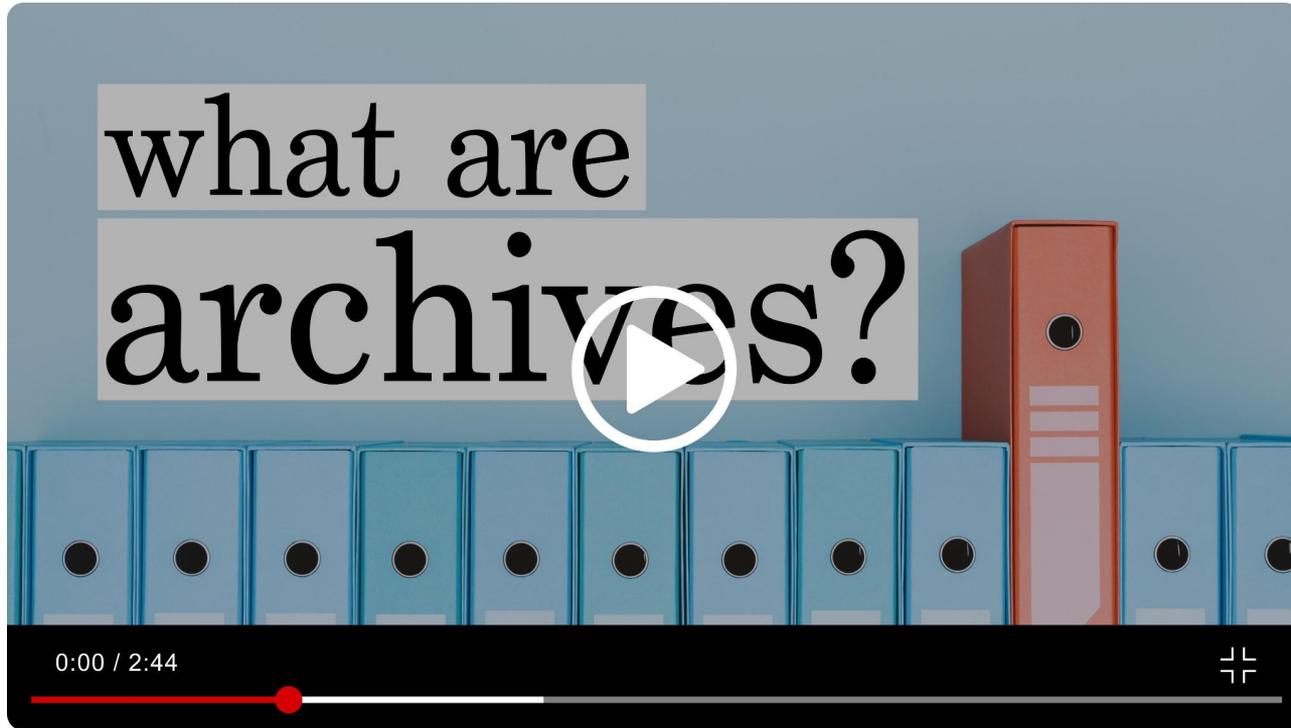
# ASL Introduction



# Introduction

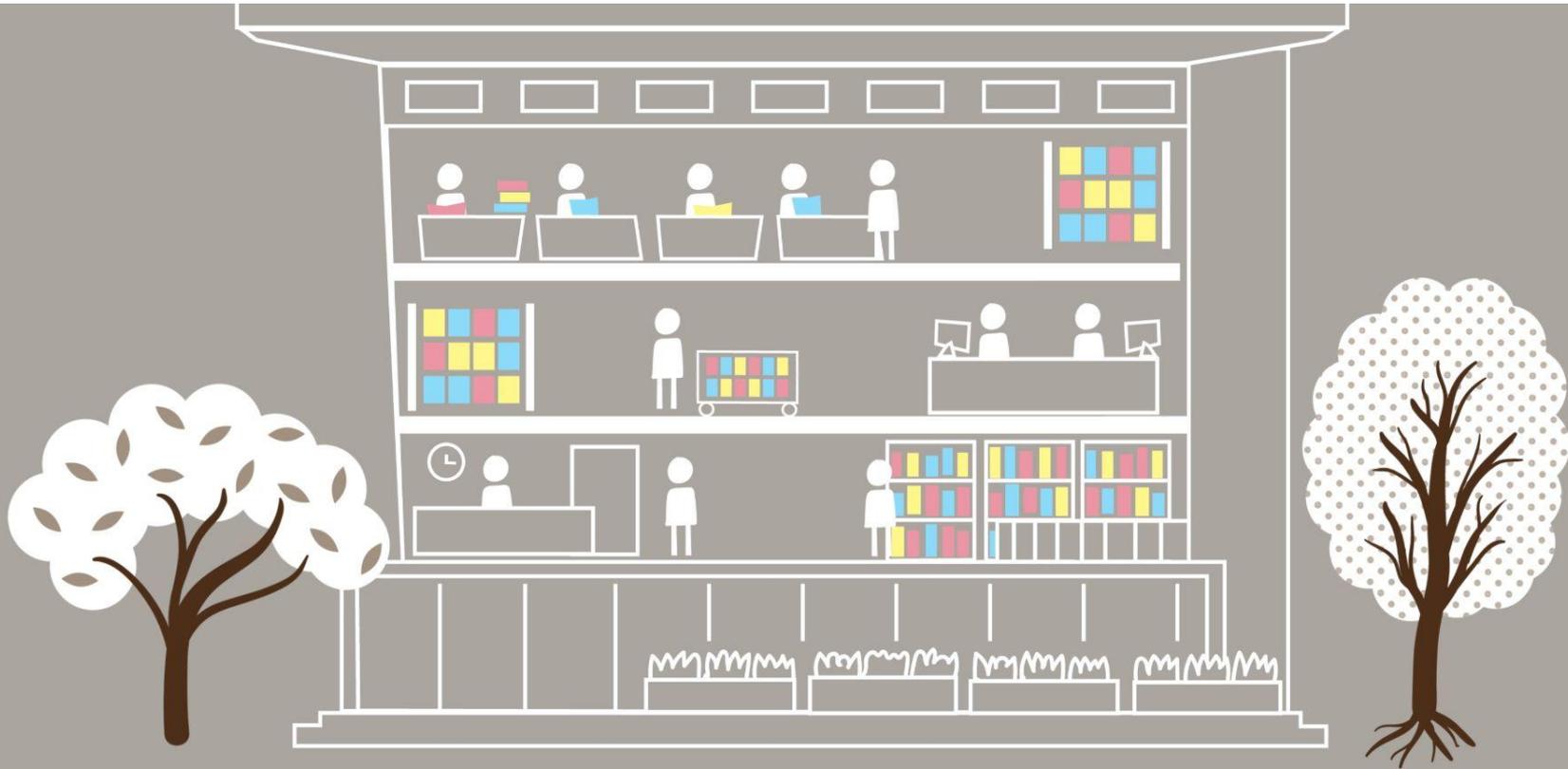
- **Role:** UCR Arts & Humanities Teaching Librarian
- **Training:** archivist and rare book librarian
- **Expertise:** primary source literacy
- **Interpreter of archives**



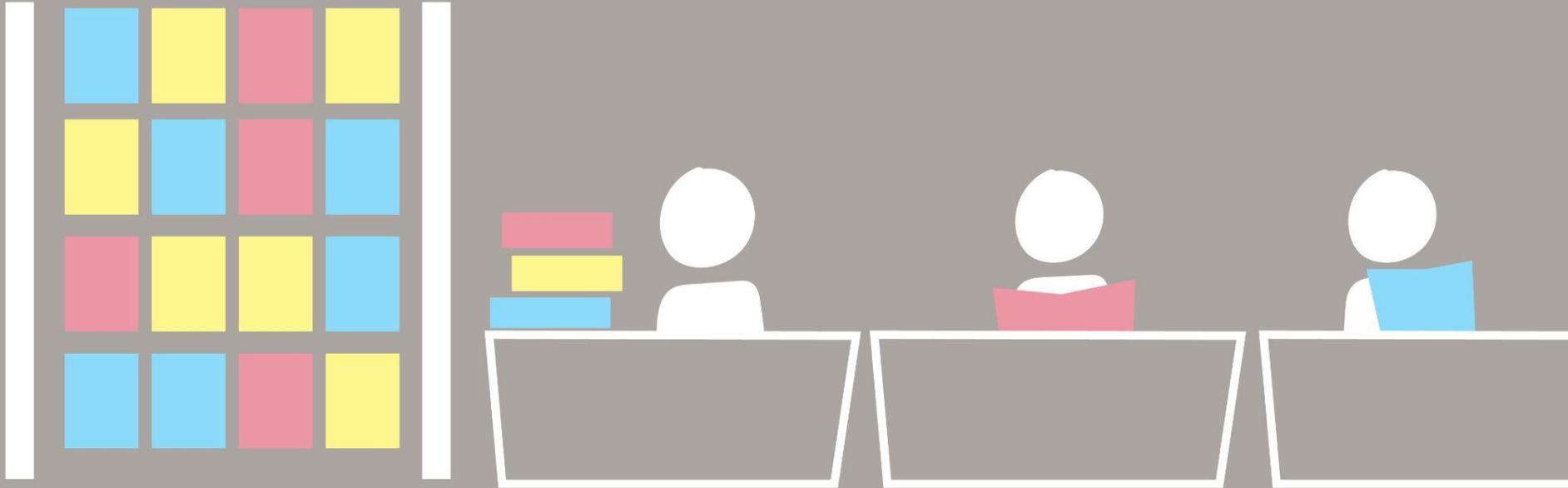


“What are archives?” YouTube video (2:44 min) - [youtu.be/1cewm\\_t9DWM](https://youtu.be/1cewm_t9DWM)

**archives = collections, place, organization**



# Access to Public Spaces (physical & digital)



# Work Ahead

Updated Accessibility  
Guidelines

Society of American Archivists (SAA)  
***Guidelines for Accessible Archives  
for People with Disabilities***

published in 2019, **due for revision**

Deadline for community input  
just passed [\[1\]](#)

— — —

# Ableism by Employers



## **Required Qualification**

**“The ability to lift boxes of materials weighing 40 lbs and to climb a ladder and bend over to retrieve materials.”**

# Work Ahead

SAA Accessibility  
& Disability Section

Inclusive hiring practices:

- avoid “unnecessarily exclusionary ‘essential functions’ that rely on physical ability”
- “anticipate potential accommodations for qualified candidates who may have challenges with ‘typical’ archival tasks such as lifting, bending, or climbing to reach high shelving.” [2]

— — —

# Are Documents Prioritized over Workers?

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“Most studies about fungi and archives deal with the conservation of manuscripts and documents, and few discuss [archives] workers’ health problems.” [3]

“Conservators/restorers” are “an often neglected sector of our society... despite the many health issues reported by these professionals.” [4]

# Occupational Hazards

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While “archives do not represent a highly contaminated environment,” symptoms were “linked to direct contact with moldy documents.”

“Work with moldy documents was associated with significantly more headache, fatigue, eye irritation, throat irritation, coughing, and rhinorrhea.” **[3]**

# Accommodations and the “Interactive Process”

# Work Ahead

“One Health approach”

“an innovative approach...

simultaneously targeting workplaces, workers (and users) and the cultural heritage...

[to] map the potential risk... and then, if needed, define an appropriate remediation strategy

to simultaneously protect the health of workers and users

and prevent further biodeterioration on the cultural heritage artefacts.” [3]

— — —

# Work Ahead

Adapting “One Health”

Human-**Collections**-  
Environment interface

Archivists already  
similarly balance

- use and access
- preservation

Like “complex embodiment?”

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**Decay is inevitable.**

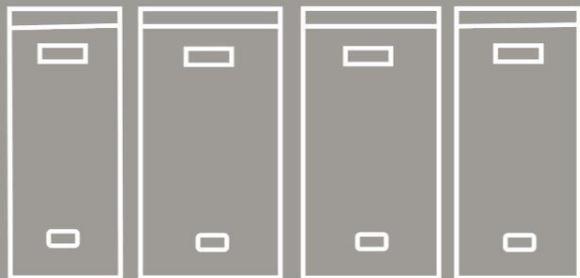
**Archives can have very long lives.**



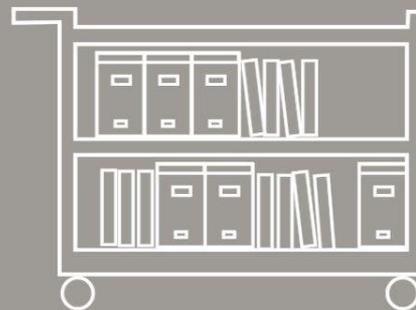
Collected



Preserved



Managed



Accessible

# Access!



**Archives are meant to be used.**

# Ways to Access Archives

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- Closed stacks
- In person or remote interaction
  - Reading rooms
  - Virtual reading rooms
  - Reproductions
  - Proxies
- Request procedures
- Correspondence, assistance



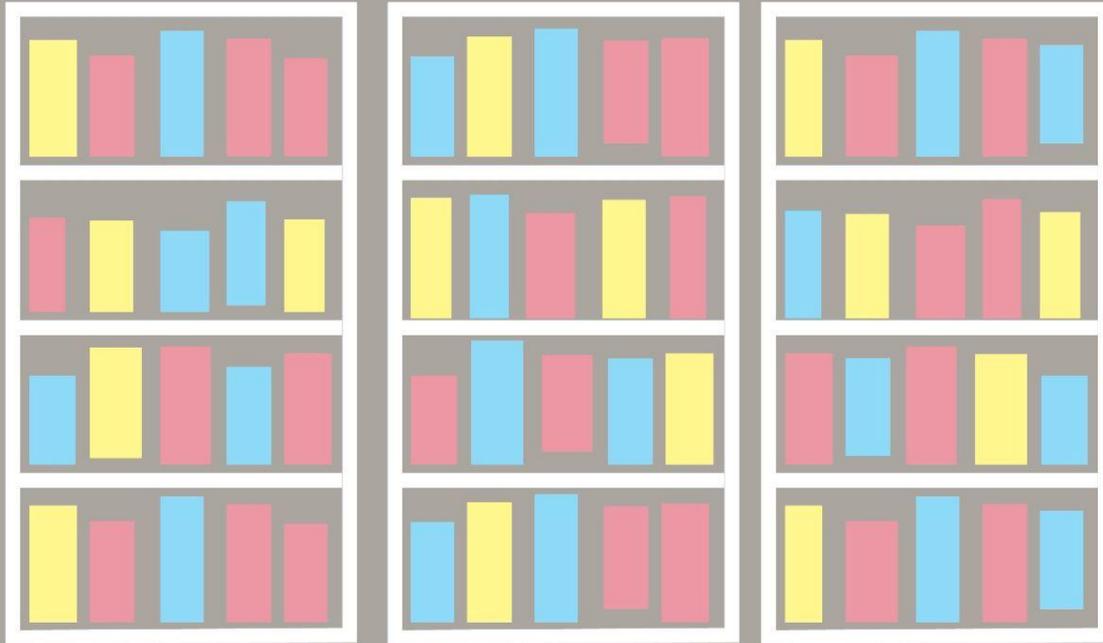
# Using Different Formats

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- Analog or Digital?
  - Physical
  - Digitized
  - Born-Digital
- Mostly unpublished  
(Marrakesh Treaty does not apply)



# Why Use Sources?



**Document. Evidence. Stories.**



# E. Bredberg's classifications of disability history sources

## **Institutional**

- “expert,” “official,” “authoritative” [5]
- “agency of dominant institutions” [7]  
(medical, legal, educational, etc.)
- more homogenous [7]
- “over-represented” in scholarship [7]
- more explicitly identified as relevant

## E. Bredberg's classifications of disability history sources

### **Institutional**

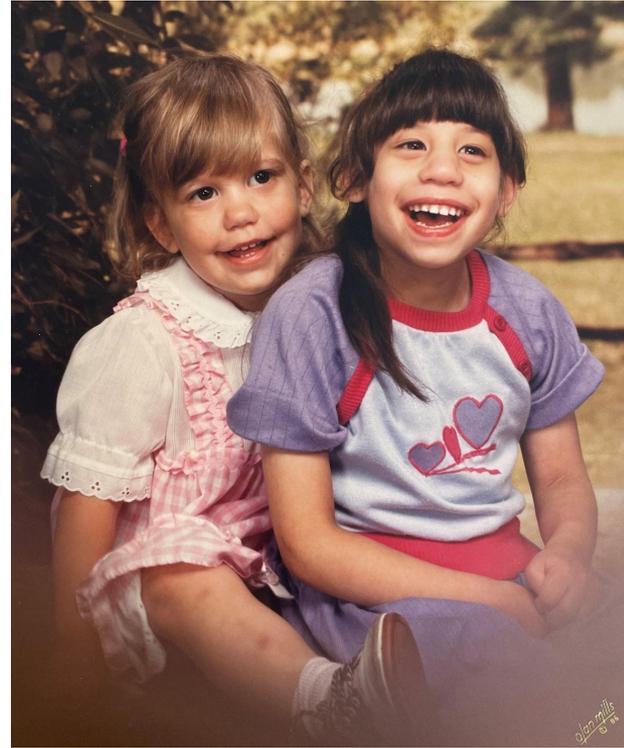
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### **Vernacular**

- “non-institutional responses” [7]
- “community or lay understanding” [5]
- more diverse [7], more personal [5]
- may “vary from or reflect” institutional responses [7]



**Photograph from my family's private collection.**



Photographs from my family's private collection.



INDIVIDUALIZED EDUCATION PROGRAM

Name Sara Katz School Year 89-90 School [redacted] Grade SEP  
Parent/Guardian [redacted] Address [redacted]  
Student I.D.# [redacted] Birthdate 1/9 Age 8  
Recommended District or Educational Agency [redacted] Attendance CH-114 Cuy. Cty.

NAME: Katz, Sara  
DATE OF [redacted]-79  
SCHOOL: [redacted]  
YEAR: 1988-1989

STATEMENT OF SPECIFIC EDUCATIONAL PROGRAM Developmental Education Program

	Check Needs	Date to be initiated	Anticipated Duration	Extent of participation in regular education
Regular Class	<input checked="" type="checkbox"/>			
Special Class/Learning Center	<input checked="" type="checkbox"/>	5/9/89	1yr	
Home Instruction				
Ind./Sm.Group Instruction				
Speech/Language Therapy	<input checked="" type="checkbox"/>	5/9/89	1 year	Consultation
Transportation	<input checked="" type="checkbox"/>	5/9/89	1yr	
Occupational Therapy	<input checked="" type="checkbox"/>	5/9/89		
Physical Therapy	<input checked="" type="checkbox"/>	5/9/89		
Adaptive Physical Ed.	<input checked="" type="checkbox"/>	5/9/89	1yr	
Vocational Sp.Ed. Service				
Work Laboratories				
Aide	<input checked="" type="checkbox"/>	5/9/89	1yr	
School Psych. Service				
Other				

Sara presents as a nonverbal compliant child. She tolerates treatments and the introduction of new activities well. Flucuations in mobility are noted inconjunction with changes in medication.

Sara's range of motion is within normal limits with tightness noted proximally at bilateral hip adductors, flexors and hamstrings. Bilateral external rotation limitation is seen with left over right involvement, exhibiting apparent discomfort with stretch to her left leg. Increased tone is displayed with resistance to passive movements. Scapulo-humeral tightness with internal rotation posturing of upper extremities is noted.

Erratic movement patterns are noted with all postures and postural transitions. Flucuating quality of muscle tone with quick, often jerky movements is demonstrated. Scapular adduction and elevation with poor upper extremity function, seen as an effect of this posturing. She primarily holds her arms flexed and close to midline with hands fistled.

In sitting, Sara consistently will "W" sit. With attempts to promote side

Statement of Present Levels of Educational Performance, including academic and social functioning. Sara demonstrates the following self help skills: finger feeds, attempts to grasp a glass, bring the spoon to her mouth to independently feed herself, removes a jacket when she is hot, pulls socks off when placed on her feet. She is scheduled for PT. trained. Sara also provides eye contact when a person is at a distance. Mobility - dynamic balance has improved, where Sara is able to move about with increased independence.

The undersigned agree that we are fully knowledgeable about the contents of this form, agree that information provided was considered in the multifaceted evaluation, and agree to the implementation of the program/services described herein. We understand that the student could not be placed in a special education program until after the completion of this document and that this program is reviewed annually. The undersigned parent agrees to a complete re-evaluation in three years if the child is still enrolled in a special education program.

Conference Participants:  
Date 5/16/89 Parent  
Date 5/16/89 Distri  
Date 5/16/89 Teache  
Date \_\_\_\_\_ School  
Date \_\_\_\_\_ Specia  
Date \_\_\_\_\_ Langua  
Date 5/16/89 SAS/Co  
Date 5/16/89 Other

Individualized Education Program (IEP) and Physical Therapy Evaluation, my family's collection.

Student will will not participate in competency testing.

Sara displays good proximal trunk control when sitting and kneeling and abdominal control with transitions from sitting to supine and kneeling positions. Little truncal rotation is seen with movements, primarily relying on hip rotation. She has been observed to



Statement of Present Levels of Educational Performance, including academic and social functioning:

*Sara demonstrates the following self help skills: finger feeds, attempts to grasp a glass, brings the spoon to her mouth to independently feed herself, removes a*



A spoon from my family's private collection.

# E. Bredberg's classifications of disability history sources

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## **Experiential**

- “disability as it is experienced at first hand” [8]
- “personal accounts” and “other representations” [7]
- “direct accounts of the experience of disablement” [7]

## E. Bredberg's perspectives as a tool for source analysis

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But Bredberg [8] recognizes “complex interactions:”

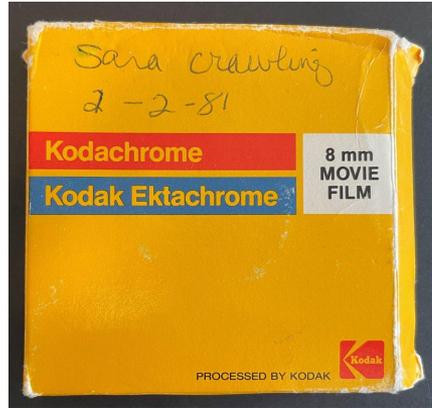
- “inter-relationships”
- “Directionalit[ies]” between perspectives
- “inter-perspective differences”

Worth noting that all of these perspective can be classified as ***primary sources*** as historians define them (from the time period).

Distinction of “experiential” implies that what should be ***primary*** is the lived experience of the disabled person.

Sara presents as a nonverbal compliant child.

Sara presents as a nonverbal compliant child.



*Sara*  
*Kabz*

School Days

7:00	wakeup, get dressed eat breakfast. medicine
8:10	School bus comes
2:15	Tuesdays } Sara comes
3:15	M, W, Th, F } home on
3:15	Medicine School bus.
	Use toilet
	work on skills, play & relax till dinner

Items from my family's private collection.

**Archival gaps and silences. [9]**

Or...

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Is a “belief that any traces of disabled people’s lives would be obscured, or worse yet, obliterated by the presence of more dominant (able) people in their lives”

an “**equally discriminatory belief** that disabled people... were incapable of leaving behind traces of their lives?” [10]



**Photograph from my family's private collection.**

# Type of collection

# Bredberg's "perspective"

**Records** / archives

**Institutional**

**Manuscripts** / papers

- Personal papers
- Family papers
- Corporate (group) collections

**Vernacular**

**Experiential**

# Provenance

— — —

- “Chain of custody”
- Who created
- or compiled?
- Collection naming conventions

## A

Academic Senate Office records (University of California, Riverside)  
Affiliates records (University of California, Riverside)  
African Student Programs records (University of California, Riverside)  
Alcalá (Hugo R.) papers  
Alpha Kappa Alpha Sorority, Incorporated Kappa Theta Chapter records  
Alumni and former students collection (University of California, Riverside)  
ARTSblock records (University of California, Riverside)  
Aschmann (Homer) papers  
Ashmore (Wendy) papers  
Associated Students of the University of California at Riverside records

## Which sources were...

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- Created?
- Survived?
- Made accessible?
  - in archives,  
or elsewhere!





# The archive of Stephen Hawking has been saved for the nation

Professor Hawking pictured outside the Department of Applied Mathematics and Theoretical Physics, University of Cambridge. Credit: Andre Pattenden

> Home > California State University, Northridge > Special Collections

## Collection Guide

https://oac.cdlib.org/findaid/ark:/13030/c80p1286/

Collection Title: Lapin (Harvey and Connie) Collection

[View entire collection guide](#) ?

Collection Number: SC.HCL

 [Printable Guide \[HTML\]](#) **[34 hits]**

Get Items:  **No online items**

 [Contact California State University, Northridge::Special Collections](#)

### Search this collection

Entire Collection Guide  Online Items

## Collection Overview

[Table of contents](#) ?

**Description** Harvey and Connie Lapin's son Shawn was diagnosed with severe autism as a child. In the 1970s, they became activists in advocating for autistic children and adults, and Shawn became national poster child for the National Society for Autistic Children shortly after. The Harvey and Connie Lapin Collection documents the couple's advocacy work with various agencies beginning in 1971 and continuing through the 2000s. The collection consists primarily of manuscript materials, some of which are available online.

[34 Search hits](#) [Clear search hits](#)

### Collection Overview

[Collection Details](#) **[16 hits]**

[Family History:](#)  
[Scope and Contents](#)  
[Arrangement of Materials:](#)  
[Conditions Governing Access:](#)  
[Conditions Governing Use:](#)  
[Immediate Source of Acquisition](#)  
[Preferred Citation:](#)  
[Processing Information:](#)

**Background** Harvey and Connie Lapin, residents of Northridge California, have three children, including an autistic son, Shawn Lapin. Shawn became the national poster child for the National Society for Autistic Children in 1973, at age 5. Over several decades they have founded or worked with various organizations promoting awareness and advocacy for the people and families affected by **autism**.

**Extent** 10.58 linear feet

### Collection Contents

Series I: Sanchez v. Johnson, 1997-2005  
Series II: Activism, 1969-2006 **[10 hits]**  
Series III: Photographic Material, 1977-1999 **[6 hits]**  
Series IV: Scrapbooks, 1977-1987  
Series V: Audio Visual Material, 1977-1996 **[2 hits]**

**Restrictions** Copyright for unpublished materials authored or otherwise produced by the creator(s) of this collection has not been transferred to California State University, Northridge. Copyright status for other materials is unknown. Transmission or reproduction of materials protected by U.S. Copyright Law (Title 17, U.S.C.) beyond that allowed by fair use requires the written permission of the copyright owners. Works not in the public domain cannot be commercially exploited without permission of the copyright owners. Responsibility for any use rests exclusively with the user.

**Availability** The collection is open for research use.

> [Home](#) > [UC Berkeley](#) > [Bancroft Library](#)
**Collection Guide**

 ∞ <https://oac.cdlib.org/findaid/ark:/13030/c82v2mng/>

Collection Title: Center for Independent Living records

Collection Number: BANC MSS 2000/43 c

 Get Items:  **No online items**   
 [Contact UC Berkeley: Bancroft Library](#)
[View entire collection guide ?](#)
 [Printable Guide \[HTML\]](#)
**Search this collection**
 
 Entire Collection Guide    Online Items

**Collection Overview**
**Table of contents ?**

**Description** Records of the Center for Independent Living, a Berkeley-based organization dedicated to supporting and advocating for issues related to independent living for the disabled community.

**Background** The Center for Independent Living (CIL) had its roots in the 1960s as the Physically Disabled Students Program at the University of California, Berkeley. The organization was officially founded in 1972 by Edward V. Roberts, Hale Zukas, and Jan McEwan Brown. CIL provides support services that allow people with disabilities to live independently and advocates for social and legal changes on behalf of the disability community.

**Extent** 34 linear feet (27 cartons, 1 box, 1 oversize folder)

**Restrictions** Materials in this collection may be protected by the U.S. Copyright Law (Title 17, U.S.C.). In addition, the reproduction of some materials may be restricted by terms of University of California gift or purchase agreements, donor restrictions, privacy and publicity rights, licensing and trademarks. Transmission or reproduction of materials protected by copyright beyond that allowed by fair use requires the written permission of without permission of the copyright owner. The copyright for unpublished manuscript material in this collection is held by the donor. Responsibility for any use rests exclusively with the user.

**Availability** Collection is open for research.

**Collection Overview**
[Collection Details](#)
[Conditions Governing Access](#)
[Conditions Governing Use](#)
[Immediate Source of Acquisition](#)
[Processing Information](#)
[Preferred Citation](#)
[Biographical / Historical](#)
[Scope and Content](#)
**Collection Contents**
**Director's Office**

Correspondence

American Coalition of Citizens with Disabilities files

Administrative files

Rehabilitation Advisory Committee files

Development

Community Services Administration files

Program contracts

Projects and reports

Assorted disability materials and publications

**Board of Directors**

Hale Zukas/Kitty Cone accessible architecture and transportation materials

Publications

Legal sources

21st Century Conference on Independent Living

Newscippings

**What isn't in archives?  
What should be?**

# Work Ahead

Collect (identify, cultivate, acquire) more “experiential” sources

“The emergence of disabled people in disability history...is **potentially emancipating**”

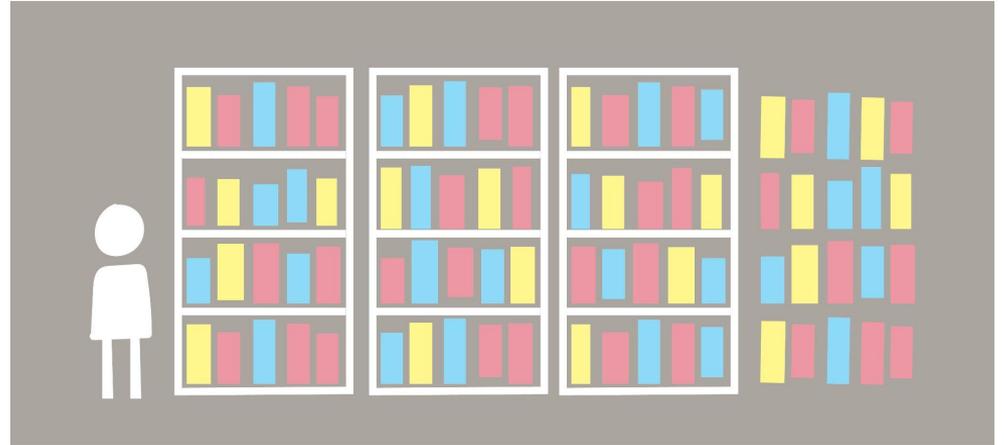
“history has broadened... to include [the] formerly invisible” as “an **active and personal presence in history**” [7]

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# Collecting

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- How acquired?
  - Records Transfer
  - Donation
  - Purchase (rare)
- Cultivate relationships
- Appraisal
- Strategies or policies



**“archival value”**

**“value” may change**

# Work Ahead

Documenting as Activism

“Capturing and transmitting stories of this long-overlooked population... assume[s] political significance by **empowering groups** who never thought of themselves as having histories.” [15]

— — —

# “discrimination diaries”

helped pass the Americans with Disabilities Act in 1989

*This collection of personal testimonies, newspaper articles, and official communications played a critical role in making the American with Disabilities Act of 1990 possible.*

For centuries, people with disabilities lived without rights, were oppressed by social stigma, rejected by wide swaths of culture, and were denied access to life, to liberty, and to the pursuit of happiness. It took a dedicated band of advocates and activists to create the cultural change needed to ensure such ostracization would no longer be deemed acceptable.

These advocates and activists deserve to be honored and memorialized as veterans of democracy. Here are just a few of the many historical insights within the ADA Diaries that await your discovery



Alabama



Alaska



Arizona



Arkansas



California



Colorado



Connecticut



Delaware

ADA Diaries Gallery

[www.itsourstory.com/be-inspired/ada-diaries/ada-diaries-gallery/](http://www.itsourstory.com/be-inspired/ada-diaries/ada-diaries-gallery/)

# Many Ways to Proactively Document Disability

— — —

- “Oral” Histories
- Exhibits + displays
- Documentaries + podcasts
- Social media + the internet

**Archivists want to ensure these are collected and preserved.**



# E. Bredberg's perspectives in archives

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## Institutional records

- the archives life cycle
- “most likely to be preserved in archives” [8]

## Vernacular & Experiential sources

- may be “less likely to... announce their subject matter” [5]
- “very small but telling detail” [7]

# Work Ahead

Describe available  
sources better

“Unusual to find disability-related topics mentioned in a collection guide, even when the papers themselves record decades of experiences.”

“A detailed finding aid might contain passing reference”

“still mostly on a treasure hunt for the ‘inadvertently collected but largely ignored’ evidence”

[5]

— — —

# The Nature of Archives

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- Bulky
- Hierarchical
  - Collection
  - Series
  - Box and folder
  - Items



The Archives at Gallaudet University



GallaudetU  
14.2K subscribers

Subscribe

385



Share

Save



YouTube video (7:05 min) - [youtube.com/CTjmZvUTvbA](https://youtube.com/CTjmZvUTvbA)

**“Once historians started looking, sources seemed to abound with references to disability and disabled people, including those with mental disabilities.”**

**[10]**

# Archival Processing

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- “Arrangement & Description”
- “Original order”
- Re-housing, storing
- Finding aids



# Finding Aids Will Greatly Vary

- “More Product, Less Process” (2005) [11]
- Introduced the idea of processing levels
  - Minimal
  - Unprocessed

**Collection Guide** <https://oac.cdlib.org/findaid/ark:/13030/c8zs340x/>

Collection Title: Frank (Gelya) papers

Collection Number: 5286

Get Items: No online items  [Contact University of Southern California: University Archives](#)

**Collection Overview**

**Description** This collection consists of the papers of Gelya Frank (born 1948), an American author and anthropology professor at the University of Southern California.

**Background** Gelya Frank is an author and professor at the University of Southern California. She teaches in the USC Clayton Division of Occupational Science and Occupational Therapy and the Dorisette College Department of Occupational Science and Occupational Therapy. Her books include "Venus on Wheels: Two Decades of Dialogue on Disability, Biography and Being Female in America," "Defying the Odds: The Tule River Tribe's Struggle for Sovereignty in Three Centuries," and "Making Betty..."

**Extent** 53,292 Linear Feet 44 boxes

**Restrictions** Finding aid description and International (CC BY 4.0)

**Availability** Advance notice required for access

**View entire collection guide**

[Printable Guide \[HTML\]](#)

**Search this collection**

Entire Collection Guide  Online Items

**Table of contents**

Search hits [Clear search hits](#)

**Collection Overview**

[Collection Details](#)

[Conditions Governing Access](#)

[Immediate Source of Acquisition](#)

[Biographical / Historical](#)

[Preferred Citation](#)

[Processing Information](#)

[Statement for Archival Description](#)

**Materials added to the collection** 2021 [minimally processed] 1970-2017

**Processing Information**

These materials were donated in large plastic bins with a label on each bin. The material was rehoused into acid-free boxes and the bin labels were used as titles for each record under this series.

Box 19, Box 20	G. Frank Author Consultant Correspondence
Box 20	Grace Nicholson coll. / Mormons in California / Reconstruction of Salt Lake Pete Abduction / Frank Laha papers / Yosemite
Box 21	Mini DV Tapes 2004 / cassettes of interviews (transferred) circa 1970s
Box 22	NARA - D.C. Sources on TRR Retrieved circa 1972-73 including U.S. v. Whaley and censuses
Box 23	Sources on Yokuts: Gayton, Merriam, Dick Bisschette, Jeff Edwards
Box 24	Sources used to Reconstruct Whaley case and characters
Box 25	Sources used to Reconstruct Whaley CG Belknap et al.
Box 26	TRR Irrigation Water Rights Research for NARF: Madden Farm Irrigation Inspection Repts.

# Finding Aids Will Greatly Vary

- “More Product, Less Process” (2005) [11]
- Introduced the idea of processing levels
  - Minimal
  - Unprocessed

### Collection Guide

Collection Title: Exceptional Children's Foundation records

Collection Number: 0494

Get Items:  No online items   Contact University of Southern California::California Social Welfare Archives

### Collection Details

**Conditions Governing Access**  
Advance notice required for access.

**Conditions Governing Use**  
The use of archival materials for on-site research does not constitute permission from the California Social Welfare Archives to publish them. Copyright has not been assigned to the California Social Welfare Archives, and the researcher is instructed to obtain permission from the copyright holder to quote from or publish manuscripts in the CSWA's collections.

**Preferred Citation**  
[Box/folder# or item name], Exceptional Children's Foundation records, Collection no. 0494, California Social Welfare Archives, USC Libraries, University of Southern California

**Processing Information**  
The collection is unprocessed.

**Subjects and Indexing Terms**  
Children -- Services for -- California -- Archival resources  
Mental retardation -- Archival resources  
Social service -- California -- Los Angeles -- Archival resources  
Social work with people with mental disabilities -- California -- Los Angeles -- Archival resources  
Annual reports  
Minutes  
Newsletters  
Exceptional Children's Foundation -- Archives

# Access!



# Reparative Metadata Suggestions [12]

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# Reparative Metadata Suggestions [12]

- *Disability Language Style Guide* & preferred terms
- “Participatory appraisal”
- No euphemisms
- No harmful language “victim of,” “-bound”
- Notes about terms “we can’t replace,” especially when in a name or title

**“It’s our responsibility as archivists to ensure disabled subjects and creators are given dignity in our collections.”**

# Work Ahead

Highlighting collections

## *Sample project:*

A public historian (Prithi Kanakamedela) and an archivist (Larry Weimer) spent years combing through one archive's collections to identify all traces of Black folks.

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**Remsen and Schenk family papers, 1698-1837**

Call number: 1985.017

0.30 linear feet.

[Link to finding aid.](#)

Three wills referring to enslaved people, Brooklyn, 1785 and 1794 (folder 1) and one unspecified (folder 2).

**Terhune and Wyckoff families papers, 1747-1932**

Call number: ARC.279

0.8 linear feet.

[Link to finding aid.](#)

Bill of sale for an enslaved person, Flatlands/Gravesend, 1794, and receipt for sale, 1798 (folder 1); will, Gravesend, 1797 (folder 2); receipt for sale, New Utrecht, 1812 (folder 4).

**Conkling family papers, 1782-1798**

Call number: ARC.284

0.25 linear feet.

[Link to finding aid.](#)

Account book with reference to Black people in Southold, Suffolk County (1784-1797).

**Kings County census of 1786**

Call number: 1981.012

0.08 linear feet.

[Link to finding aid.](#)

Contains information regarding the number of families, men and women in various age groups, number of enslaved people by gender, and total number of white people and enslaved people in Kings County. The data is also broken down by township. Compiled by Peter Vandervoort, Sheriff.

[13]

## *In Pursuit of Freedom*

was a public history project at Brooklyn Historical Society

funded by the US Department of Education's Underground Railroad Program.

# Technical Challenges of Digital Materials

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- Appraisal
- Item-Level Description
- Researcher Access
- Digital Preservation  
[14]



# Work Ahead

Imagining New Ways

Is there “a distinct disabled perspective or perspectives that **challenge(s) standard ways of thinking** and of doing things for everyone?” [15]

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# Community Archives Practices

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- Post-custodial [16]
- Community ownership [16]

“What is our motivation in collecting materials about people with disabilities? Are we the right home for these collections?”  
[12]

# Work Ahead

Publishing Opportunity

**Call for Abstracts [17]**

*Preserving Disability: Disability  
and the Archival Profession*

Eds. Gracen Brilmyer & Lydia Tang

**due April 1, 2024**



# Questions? Discussion? Experiences? Thoughts?

— — —

- What sources do you created every day?
- Why collect? What? Goals / projects / needs? What gaps?
- Traditional repositories or community archives?
- How to better describe or highlight collections?
- Accessing and using collections?
- Compare themes of stewardship, custody, caretaking, and labor?
- How are archives connected to disability justice?

# References

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- 1** <https://saadisabilityarchivists.wordpress.com/2024/02/02/seeking-community-input-guidelines-for-accessible-archives-revision/>
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