

The Spinster in the Attic: Retrieving Disabled Women's Stories from Private Collections

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"Disability History Confronts Women's History: Compliant Daughter or Rebellious Youth?"

I.

I want to take you into some forbidden zones of historical research. Be warned: nothing I'm about to show you will likely get you a book contract, or a fellowship, or an approving nod from any academic department. In fact, there's a real risk that playing with this stuff will get you laughed at by all the wrong people on campus. I don't care. Or rather, of course I care that women who do disability history remain employed and ascend the ranks in their careers of choice, but I think our field has wider responsibilities too, and it's those I'd like to explore with the panel today.

Unlike professional astronomers, who generally have a friendly respect for serious amateur stargazers in their work of documenting the heavens, academic historians have a fraught relationship with historians in the community. We are taught, in graduate school, that sources composed by genealogists and town historians might best be approached as bad fiction; librarians sigh with relief to find a "real" researcher amidst the hobbyists.¹ This disciplinary gatekeeping has some reasonable motivations, but it also has the unfortunate effect of narrowing the range of acceptable sources and venues for presenting research, and ultimately excluding the histories of people and groups without an archival presence.

But disability history, like women's history, is a potent, wonderful thing to make and share in communities. My talk today will give you a tour of several projects I'm involved with, across the drawbridge, beyond the moat, and well out past the pale, among women who are genealogists... and bloggers... and even (gasp) *scrapbookers*... I will argue that not only do such engagements enrich our work as historians, but they make our work more creative, more relevant and more responsive.

II.

Women's historians have done some fine community-based projects. One of the most elaborate and well-documented was the Cambridge Women's Oral History Project in Massachusetts (1980-81), in which high school women were engaged to perform interviews with older working women in the community. Supported by federal and state grants, the town's arts council, and a lot of volunteer hours, the project ran discussion groups and workshops, sponsored a quilt project, and made conscious efforts at accountability, intergroup collaboration, and creating accessible products. "Knowledge of our history can be crucial in understanding the political nature of our seemingly personal problems," a participant

¹ See John Beckett, "Local History, Family History, and the Victoria County History: New Directions for the Twenty-first Century," *Historical Research* 81(212)(May 2008): 350-36?; and Judi Jennings, "My Mama Told Me': Reclaiming the Story in Oral History," *The History Teacher* 30(1)(November 1996): 93-?; some similar experiences are outlined in Penny L. Richards, "Everyone's Story Should be Told, Even the Dead People': The motives, methods, and meanings of doing local history in a small North Carolina town," unpublished course paper, UNC-Chapel Hill, 1993.

explained about the project's activist goals for making and presenting history.² Can the same sense of history's "crucial" role in disability identity and activism bring our work to the community? Can we "capture and facilitate the enthusiasm of all participants towards achieving the greater goal of understanding our past communities?"³ What would that look like? Some glimpses:

III.

Marion Brown (1843-1915) was a multiply disabled woman who lived in rural nineteenth-century Scotland. She wrote dozens and dozens of letters, to her American cousins, for over forty years, sometimes literally while lying in her bed. Those letters were mailed to a house in Dunmore, Pennsylvania, where they remained, sometimes in a desk drawer, sometimes in a closet. They were handed to me by my grandmother in 1994, jumbled in a pink plastic shopping bag. And now they're in an archive box next to my desk in Southern California. These letters have never been in an archive, and we are lucky they have survived at all; Marion was a single woman with no descendants, and her letters were sent to a cousin she never met. The house where they rested for over a hundred years was recently sold, its contents packed up and placed in storage in another state.⁴

I began to see the disability history themes in these letters about seven years ago, and I've published a journal article and a book chapter, and spoken about them at conferences.⁵ A Scottish colleague has helped me understand their cultural context, and has himself referenced the letters in published works.⁶ Marion Brown's letters bear the serious study and consideration we were trained to bring to such documents: they're a rare collection of sustained correspondence from someone left behind in the great wave of immigration to America; they're a rare primary source on nineteenth-century Scottish working women's lives; and they're a forty-year record of a disabled woman's experiences.⁷

² Cindy Cohen, "Building Multicultural and Intergenerational Networks through Oral History," *Frontiers* 7(1)(1983): 98-102.

³ Beckett, 359.

⁴ Stories of how such items survive and reach the author are part of most articles about the writing of one's own family history. See, for example, Johanna Frank, "Bearing Proxy-Witness," *Biography* 25(1)(2002): 58, or Nancy K. Miller, "I Killed my Grandmother: Mary Antin, Amos Oz, and the Autobiography of a Name," *Biography* 30(3)(Summer 2007): 319-341; or Carolyn Wilson, "The Soldier in the Attic," *Western Pennsylvania History* 90(4)(Winter 2007-8): 46-59.

⁵ Penny L. Richards, "Points of Entry: Disability and the Historical Geography of Immigration," *Disability Studies Quarterly* 24(1)(Winter 2004) ; Penny L. Richards, "Knitting the Transatlantic Bond: One Woman's Letters to America, 1860-1903," in Jeanne Kay Guelke and Dallen Timothy, eds., *Geography and Genealogy: Locating Personal Pasts* (Ashgate 2008): 83-98. Conference presentations (before this one) were at the Association of American Geographers (2005), and the Society for Disability Studies (2007).

⁶ Iain Hutchison, *A History of Disability in Nineteenth-Century Scotland* (Edwin Mellen Press 2007); Iain Hutchison, "Marion Brown," in Sue Innes, Sian Reynolds, and Rose Pipes, eds., *The Biographical Dictionary of Scottish Women* (Edinburgh 2006): 46-47.

⁷ On the rarity of such sources: Jane McDermid, "Missing Persons: Women in Modern Scottish History," in Terry Brotherstone, Deborah Simonton, and Oonah Walsh, eds., *Gendering Scottish History* (1994): 37-45; David Gerber, *Authors of their Lives: The Personal Correspondence of British Immigrants to North America in the Nineteenth Century* (NYU Press 2006); and Elisabeth Bredberg, "Writing Disability History: Problems, Perspectives, and Sources," *Disability and Society* 14(2)(1999): 189-201.

But “academics are not the only arbiters of what is valuable,”⁸ and Marion Brown has other audiences to address. For my family, retrieving her story from the pink shopping bag clarified much about our forebearers’ lingering ties to Scotland--about the Robert Burns grace on the wall in the kitchen, about the black-and-white knitted pattern in the old wool blankets. And knowing that Marion Brown’s physical status contributed to her decision to stay behind, and her need for support from American kin, puts disability history at the center of our coming-to-America story.

I was especially pleased to present Marion Brown’s story, with pictures and excerpts from her letters, for a wellness group at the Marilyn Hilton MS Achievement Center at UCLA, as part of their women’s studies enrichment series in 2005. The members of the wellness group were mostly women, and all were at various stages of multiple sclerosis, a chronic and complex condition not completely unlike Marion Brown’s unnamed condition. They *got* Marion Brown--they laughed and sympathized with her writing, they asked wonderful questions (“did she have a boyfriend? did she go to church?”), and they contributed real knowledge to my understanding of Brown’s experience with relatives, doctors, memory, and her array of impairments. I was told later that it was a popular presentation, in part because it was so interactive, but in part because it invited each of the audience members to claim a place in disability history--if Marion Brown’s story was still being recounted a hundred years later, their stories were also worth telling and recording.

IV.

Vintage scrapbooks are recognized as a “rich source for researchers interested in women’s history.”⁹ Like quilts and personal recipe books, scrapbooks work within the conventions of a feminine genre that at first seems constrained mainly to practical and ephemeral ends; but on closer examination bears a woman’s narrative and creative expression. Also like quilts and personal recipe books, scrapbooks have long been shared projects, bringing together and preserving the experiences of communities of women. For this reason, working with scrapbooks as primary sources isn’t always about documenting one woman’s life, or one family’s, but about the lives of women, plural.

The project I’ve brought to show you from this realm involves a group of women who all have young children with physical, developmental, and other disabilities, who participate in a “circle journal” or collaborative scrapbooking project. Each woman starts a book, sets the theme, and sends her book around the group to get contributions from each. For my book, I invited the others to create layouts about “the personal uses of history” in their parenting experience. Two of them women focused on stories about women in their own family histories. Using private photos, interviews, and family lore, they presented their answers to this invitation. I have their permission to share these layouts with you today.

Lisa wrote about her great-aunt Rachel Ann (1917-1962)--Lisa’s daughter’s namesake. The pages are deep red, floral, reminiscent of old wallpaper, with lace, smudged paint, torn paper and hidden flaps and curvy fonts adding to the story’s feminine and “way-back” atmosphere. We see Aunt Rae’s story on the left page, and young Rachel’s story on the right, with black-and-white photos of equal size and matting. Aunt Rae, we learn, was beautiful and kind and bubbly, according to her sister (Lisa’s maternal grandmother); Aunt Rae barely survived giving birth at 25, when her appendix burst during labor:

They sewed her back up and told her family that she would probably die. By some miracle, she fought the infection and lived another 20 years, until cancer finally took her.

⁸ Beckett, 359.

⁹ For a wonderful bibliography from this scholarship, see Danielle Bias, Rebecca Black, and Susan Tucker, “Scrapbooks and Albums, Theories and Practice: An Annotated Bibliography,” available online at <http://www.tulane.edu/~wclib/susan.html> (accessed May 2008).

From that story, which Lisa heard often in a woman-centered family, we move to young Rachel's tale. She is the namesake of the great-aunt Lisa never knew in person. She is also described as a "miracle," because she was born a little early and with a rare chromosome disorder. Like Aunt Rae, the newborn Rachel was dismissed by doctors in 1998, who said she'd "probably be a vegetable". Rachel is alive and very well today, as Lisa's layout attests in color photos added in a little booklet to her side of the layout ("writing her own book" is a phrase heard often among families of children with unknown prognoses, and in adding a separate booklet, Lisa makes that expression literal). For Lisa, her aunt's story provided an example of hope when her daughter was born, and continues to help her see the younger Rachel as part of a family that surrounds its members with confidence and care across generations.

RST is the mother who created the second set of pages for this circle journal. She did two content-rich spreads on the topic. In the first, RST first summarizes her situation: her younger sons, Daniel and Andrew, were twins affected by Twin-to-Twin Transfusion Syndrome, an in utero condition where the circulatory systems between the placenta and babies is misrouted; only with a prenatal surgery were their lives saved. Daniel's survival was accompanied by significant impairments. As RST explains,

"while their story is unique, it does not exist independently from the past, or the future....My mother often told stories...ranging back over a century. The family anecdotes recounted by aunts and grandmothers often contained a germ of wisdom or a moral; often they reinforced the potential for disaster. It seemed as if my mother loved the twin tales best--stories of lost twins, the twinless twins, and the motherless twins in our family tree."

Then RST invites us, visually, into her family archive of twin stories. Her paternal grandmother, Lena, had twins too--and RST contrasts her story with Lena's, on facing panels. We see Lena and RST as young women, in their favorite cars, pregnant with twins, and in 1995 together, just before Lena passed away. Lena's story includes such poignant bullet points as "Her babies were born on an old quilt...her four young children played nearby." "Her babies died before the day was out. she buried them herself." Across from that, RST's bullet point states simply, "My babies are alive." RST expresses gratitude in that contrast, which she traces to the changes in medical technology and parent support groups since Lena's day.

The next spread, titled "A Totally Subjective Timeline of Twins," puts both Lena and RST into a larger family history context--they are only two of the women in over a century of Carlsons and Mennies and Syretts who have had twins with medical complications, most of their stories ending in perinatal loss. In 1876, RST's great-great-grandmother died soon after giving birth to twins; a great-aunt delivered twins and a stillborn third, whose configuration was rare enough to be "written up as a medical oddity." RST's timeline is accompanied by looping wire and tiny images illustrating her anecdotes, and each anecdote has a "what I learned" tag in italics, such as "From this I see that life is ironic," or "I see how statistics don't tell the story." In these snippets of text, RST is consciously drawing lessons from her awareness of family history, but she is also visualizing her part in a long line and a grand circle of women, and her last lesson learned is "I think about how history is both linear and cyclical."

(After making these pages for my book, RST's mother read them and had some factual corrections to add, illustrating the point that by creating such pages, scrapbookers are putting women's stories and stories about illness and crisis into play, available for retelling and renegotiation, stirring the history forward in ways that a strictly text version would not so readily invite.)

The value of family scrapbooks in both preserving and presenting private histories of disability is beautifully illustrated in Susan Schwartzenberg's recent book, *Becoming Citizens: Family Life and the Politics of Disability*.¹⁰ Schwartzenberg used family scrapbooks as prompts, in interviews with the women who founded a Seattle parent group in the 1950s. Their group co-

¹⁰ University of Washington Press 2005.

authored “Education for All,” the Washington state legislation that preceded the IDEA in guaranteeing public schooling for all children. Excerpts from those interviews are printed alongside, or even over, images of those scrapbooks, photo albums, clippings, and old calendars, to help the reader visualize the times. In many of the photos, we see family members holding these old pages and volumes and framed images, either in contemplation or for display. The existence of these collages testifies to the impulse to record, which is common among many mothers, but their contents and their survival is also a testimony to the special awareness these women have, that they made history by fighting for the rights of their disabled children, and all disabled children in their state.

V.

To some academic historians, blogs are strictly the domain of gossip and cat photos. But more and more, historians are embracing the possibilities of creating websites with blogging software that are linked to other sites, linkable, searchable, open-access, and open to comments.¹¹ Jeremy Young recently pointed out that historical blogs aren’t anyone’s replacement for journal articles or books. “Instead,” Young writes, “blogging is about something else: distilling historical knowledge into something juicy, fun, and intelligible, and sharing that richness with laypeople and with one another... it is to reach out into the community and begin a discussion on historical issues of importance.”¹² And, as with scrapbooking and family history, non-academics are also telling histories in blog format--so, again, we’re talking about a medium that’s got potential both as a source of otherwise untold disability histories, and as a place to share what we know and wonder with the broader community.

Who’s blogging about disability history? Well, to give you a sense of the vastness of the blogosphere, there are at least three blogs focused on medieval disability history.¹³ Heather Munro Prescott, who’s here at the Berks, has a blog, *Knitting Clio*, which includes discussions from her own work on the history of campus mental health programs and campus violence. And I post about disability history several times a month at Disability Studies, Temple U., usually in biographical posts marking a historical figure’s birthday, or drawing from the exciting online image collections being made available by the Library of Congress, the National Medical History Museum, and other repositories. We find that these posts are popular, in part because they expand the range of life stories available to tell about disability: teachers and students must get awfully tired of the same old Helen Keller and Louise Braille reports, after all. By participating in virtual symposia and blog carnivals, I can easily have hundreds of hits on these posts, and a string of comments adding details or disputing conclusions.

Another important group of bloggers posting on disability history are those who write about autism. Advocates of the concept of neurodiversity read autism as an ordinary variation in neurological processing, not as a disorder to be cured or prevented. Against the idea of autism as something new, autistic bloggers write about the “hidden horde” of people from the early 20th century and before, who might today have an autism diagnosis (a label coined in the 1940s, and only recently bestowed widely).¹⁴ They go well beyond the “did he or didn’t he”

¹¹ For an already-dated but still useful history of the genre of history blogs, see Ralph Luker, “Were there Blog Enough and Time,” *AHA Perspectives* (May 2005): online here: <http://www.historians.org/perspectives/issues/2005/0505/0505tec1.cfm>

¹² Jeremy Young, “Blogging and Peer Review,” at *Progressive Historians: History for our Future* (27January 2008): online here: <http://www.progressivehistorians.com/2008/01/bloggng-and-peer-review.html>

¹³ Medieval disability history blogs include Greg Carrier’s *Medieval Cripples, Crazies, Imbeciles, and a Service Dog*, Alison Purnell’s *The Furnace of Doubt*, and the group blog *Society for the Study of Disability in the Middle Ages*, in which Carrier and Purnell are also involved.

¹⁴ The blog *Autism Diva* (run by Camille Clark, who was recently featured in *New York Magazine* article on neurodiversity) had a series of posts called “Antique Autistics” in 2006-7, which are good examples of this genre.

parlor-game style of retroactive diagnosis, by posting photos and videos, translating medical records, and otherwise bolstering their claims. These examinations not only counter the notion of autism being a recent phenomenon, but open up questions about language and diagnosis and the changing expectations of education, skills, social lives, and work lives that have affected the lives of autistic children and adults across history.

There's a vast range of others who are writing disability histories small and large, and whose work calls to us. Military historians, professional and amateur enthusiasts alike, recognize disabled veterans in their purview (the monthly Military History Blog Carnival has linked to several posts by Simi Linton, for example). Family history bloggers (mostly women) post fascinating, well-researched profiles, complete with photographs from family albums. Colleen at Orations of OMcHodoy is a genealogical blogger who has made loving, detail-rich posts about her two great-aunts with Down syndrome, full of family anecdotes and priceless images: aunt Marianne in cowboy gear, singing at a church party; or aunt Anna holding a doll. Far from continuing traditional stigmatization, a new generation of family historians is actively probing the sources for the forgotten stories of institutionalization, exclusion, and loving family strategies toward support and inclusion.

VI.

It's easier than ever to jump in and be part of the bridging across campus and community. Starting a blog takes less than five minutes (unless you fuss over what to call it, that's extra time); putting images up on Flickr or a video on YouTube is equally easy. Can you make a podcast? Sure! Link and comment and read the Carnivals (digests of blogging in various fields), and your bridge is built. But it's a two-way bridge, so be prepared for visitors, conversations, and input from well beyond the usual audience for journal articles and university press books.

I know this stuff is beyond the comfort zone and prestige zone for many academic historians, but like women's historians before us, we have a wider responsibility, beyond our careers, to a community history: to seek and preserve and present evidence of its existence and all that entails. Of course there are different standards of evidence for this kind of historical activity, and it must be approached with that understanding--but it needs to be approached, instead of ignored--it's going to continue as a popular exercise, so it's best to engage with it. The challenge is to get over the prestige gap, ally with the broader community, improve our presentation skills, and demonstrate the value of our work for more than footnotes.