

# Crippling the Archives: Negotiating Notions of Disability in Appraisal and Arrangement and Description

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## Abstract

Have archivists adequately documented people with disabilities? This essay examines how disability studies provide archivists with a framework with which to understand and document disability. After defining the medical and social models of disability, this article analyzes the development of the social model emphasizing the significance of social relationships and identity construction, and recognizes its weakness. As an alternative to the social model, this paper introduces the theory of complex embodiment and demonstrates how embodiment corresponds with archival theory, especially recent literature challenging the definition of provenance. The author concludes that embodiment can be applied to archival practice during appraisal and arrangement and description.

Would archivists be doing an acceptable job if only a handful of archives documented the lives of African Americans, Hispanics, or any other ethnic or racial minority? Think about your answer to this question and consider this statistic: People with disabilities constitute the largest minority group in the United States at 19 percent of the population.<sup>1</sup> Yet, do archives reflect disability in American society?

Historian Catherine J. Kudlick questions the significance of the history of disability in our society in her recollection of conducting research at “one

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<sup>1</sup> Robert Bernstein, “Number of Americans with a Disability Reaches 54.4 Million,” U.S. Census Bureau Newsroom, [http://www.census.gov/newsroom/releases/archives/income\\_wealth/cb08-185.html](http://www.census.gov/newsroom/releases/archives/income_wealth/cb08-185.html), accessed 20 November 2011.

place that had been one of the most important institutions of blind history.”<sup>2</sup> She writes:

I was shown an attic so filthy and neglected that pages crumbled simply because I opened the door. . . . Very few understand the problem. The vast majority of people in the modern world think that history is useless and irrelevant. And fewer still give one iota about the blind. So the history of blind people seems like a Venn diagram that pinpoints the epitome of insignificance.<sup>3</sup>

Kudlick’s account raises the question: Have archivists failed to collect an accurate representation of people with disabilities? For more than thirty years, we have wrestled with ways to document marginalized populations. In his presidential address to the Society of American Archivists, F. Gerald Ham cautioned archivists not to be the “weathervane moved by the changing winds of historiography.”<sup>4</sup> Instead of a collection development strategy based on historical trends, he argued that archivists need to document “the broad spectrum of the human experience.”<sup>5</sup> Responding to Ham’s call to action, a decade later, Helen Samuels introduced the idea of a documentation strategy with the goal of collecting a more complete representation of society.<sup>6</sup> Since Samuels’s article, archivists have continued to examine how best to document diversity.<sup>7</sup> However, disability as a subject has evolved over the past century, and only recently have people with disabilities been recognized as an underrepresented group. As a result, archivists have just embarked upon documenting them, and only a handful of archives in the United States actively do so.<sup>8</sup> Of these archives, the University of California at Berkeley’s Bancroft Library documents the disability rights and independent living movement, and the University of Toledo collects the history of people with disabilities at the regional level. Both archives only recently began collecting the history of disability, and the collections are tied to the independent

<sup>2</sup> Catherine J. Kudlick, “From the President,” *The Disability History Newsletter* 4 (2008): 2.

<sup>3</sup> Kudlick, “From the President,” 2.

<sup>4</sup> F. Gerald Ham, “The Archival Edge,” in *A Modern Archives Reader: Basic Readings on Archival Theory and Practice*, ed. Maygene F. Daniels and Timothy Walch (Washington, D.C.: National Archives and Records Service, 1984), 329.

<sup>5</sup> Ham, “The Archival Edge,” 329.

<sup>6</sup> Helen Samuels, “Who Controls the Past?,” *The American Archivist* 49, no. 2 (1986): 116.

<sup>7</sup> Kathryn Neal, “Cultivating Diversity: The Donor Connection,” *Collection Management* 27, no. 2 (2002): 33–42.

<sup>8</sup> According to my research, the archives that actively document disability are the National Federation of the Blind, Gallaudet University, the Bancroft Library at the University of California at Berkeley, and the University of Toledo. Sara White, “Historiographical Essay on Disability History” (master’s degree essay, graduate historiography, history 600, University of Colorado, Colorado Springs, Fall 2007). While many archives may contain some collections that document disability, it is my opinion that many of these collections are not likely described as doing so.

living movement.<sup>9</sup> Since Berkeley was a focal point for the beginnings of this movement, the Bancroft Library began the Disability Rights and Independent Living Movement Project in 1996 to document disability activism. The University of Toledo started collecting the history of people with disabilities in 2002 with funds from the Ability Center, a local independent living center.<sup>10</sup> Helping archivists meet the challenge of documenting disability would be easier if we had an analytical framework with which to approach the subject.

This essay examines how the field of disability studies offers archivists a framework with which to understand and document disability. The paper is divided into two parts. The first section describes the historical context from which disability studies emerged as a field. While it cannot provide an extensive historical analysis, a brief overview of the key historical developments is necessary to understand scholarly approaches to disabilities. In particular, this section defines two models that have been used to evaluate disability: the medical and the social models. After examining the development of the social model and its weakness as it relates to notions of social relationships and identity, this paper introduces the theory of complex embodiment as an analytical framework that can help archivists account for all disability experiences. The second section demonstrates how embodiment can be applied to archival practice during appraisal and arrangement and description. This paper concludes by addressing the challenges that disability poses for archivists when working within the framework of embodiment, and it offers some practical considerations.

### Constructing Disability

In the United States, the history of disability intertwines with the development of and interrelationship between medicine and nationalism. During the nineteenth century, an explosion in scientific development and subsequently medical knowledge changed how health-care professionals addressed disease. Treatment of illness, previously the domain of female midwives, became the responsibility of male physicians as new technologies and instruments including the stethoscope and X-ray transformed healing from a folkway to a science.<sup>11</sup> The categories of “normal” and “defective” resulted from the examination of humans within a scientific framework. Medical doctors first introduced the concept of *normal* as they compared and contrasted the bodies of their patients.

<sup>9</sup> The University of California, Berkeley, Bancroft Library, “Disability Rights and Independent Living Movement,” <http://bancroft.berkeley.edu/collections/drilm/>, accessed 20 November 2011; Diane F. Britton, Barbara Floyd, and Patricia A. Murphy, “Overcoming Another Obstacle: Archiving a Community’s Disabled History,” *Radical History Review* 94 (2006): 213.

<sup>10</sup> Britton, Floyd, and Murphy, “Overcoming Another Obstacle,” 216.

<sup>11</sup> Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 50.

Physicians described disease using words such as “intensity” and “excitement,” while they viewed the normal body as “silent.”<sup>12</sup> Lennard Davis argues that diseased and defective people were seen as a threat to nationalism because the formation of the United States required a normal citizenry. White Anglo-Saxons were considered normal Americans; African American slaves, immigrants, and poor whites were categorized as defective, whether or not they had functional impairments. Disability and disease were seen as characteristics of defective Americans that could spread to normal Americans.<sup>13</sup> For instance, officials called Down Syndrome “Mongolism” because they understood it to be the regression of Caucasians to the Mongoloid race.<sup>14</sup> Afraid that disability would destroy the nation-state, American leaders looked for a means to protect U.S. citizens. Prior to Charles Darwin’s theory of evolution, the human species was seen as God’s creation. Darwin’s work changed the American view of the human species from a static race to one that can be manipulated to eliminate disability. Eugenics, which states that the human species can be modified and improved through controlled breeding, offered a biological defense against people with disabilities. During the early twentieth century, politicians passed laws prohibiting the immigration of people with disabilities to protect American citizens. Although politicians gradually repealed these laws in the mid- and late twentieth century after scientists debunked eugenics as pseudoscience, their legacy helped solidify Americans’ perception of people with disabilities as defective.<sup>15</sup>

While the development of medicine and nationalism defined people with disabilities as defective, capitalism and Americans’ belief in progress framed disability as a personal tragedy narrative. Since, as historian Douglas C. Banyton argues, “Normality was intimately connected to the western notion of progress,” the perceived inability of people with disabilities to complete work was seen as an impediment to progress.<sup>16</sup> Employers viewed people with disabilities as economic risks because they thought they would be less productive and sought to avoid making needed accommodations. In short, people with disabilities jeopardized capitalism because they threatened the idea that the industrial worker should be interchangeable.<sup>17</sup> In the United States, addressing the problem of how to care for and manage those labeled “defective” resulted in the charity system. During the nineteenth century, the “defective” included the poor, the

<sup>12</sup> Lennard Davis, *Bending Over Backwards: Disability, Dismodernism, and other Difficult Positions* (New York: New York University Press, 2002), 112.

<sup>13</sup> Davis, *Bending Over Backwards*, 105–18.

<sup>14</sup> Michael Davidson, *Concerto for the Left Hand: Disability and the Defamiliar Body* (Ann Arbor: University of Michigan Press, 2008), 10.

<sup>15</sup> Douglas C. Banyton, “Disability and the Justification for Inequality,” in *The New Disability History: American Perspectives*, eds. Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), 45–50.

<sup>16</sup> Banyton, “Disability and the Justification for Inequality,” 36.

<sup>17</sup> Davis, *Bending Over Backwards*, 105.

alcoholic, the ill, the criminal, and the disabled. Political leaders and government officials further divided this diverse grouping of people into the “worthy” and the “unworthy” poor. While the unworthy poor were those individuals whose own behavior was deemed to have resulted in their destitution, the worthy poor were those whose impoverishment resulted through no fault of their own. People with disabilities who found themselves classified in the latter group were confined within a charity system.<sup>18</sup> Although deemed not at fault for their disabilities, the success of capitalism demanded that their conditions be understood as personal tragedies. According to Davis, “Charity ensured that those who did not work were not enticed by the ease of pauperism.”<sup>19</sup> Moreover, charity served to benefit the rich by maintaining their economic and social power through charitable benevolence that functioned as a form of paternalism that kept people with disabilities dependent on the wealthy. This pattern continued into the mid-twentieth century. Disability historian Paul Longmore suggests that donating to the disabled through such venues as telethons helped reinforce the stature and worth of nondisabled people by distinguishing them from both “takers and invalidated.”<sup>20</sup> This further illustrates that framing disability as a personal tragedy served to sustain the inferior status of people with disabilities.

During the late 1960s and 1970s, people with disabilities influenced by the civil rights movement challenged the ideas that they were defective and that their situation was merely a personal tragedy. Collectively known as the disability rights and independent living movement, people with disabilities organized protests and other demonstrations to obtain accommodations to enable them to participate actively in society. The disability rights movement includes a variety of disability-specific submovements, of which the independent living movement is one component. The independent living movement’s objective to achieve self-directed independent living for adults with disabilities reflects the goal of the larger disability rights movement. A critical first step for the movements occurred at the University of California at Berkeley when students with severe disabilities challenged the status quo. Led by Ed Roberts, these students, known as the Rolling Quads, protested the fact that the university forced them to live at Cowell Hospital, the student infirmary, because of their disabilities and consequently segregated them from the rest of campus life. Although the university was one of a handful of colleges to establish a disability services center

<sup>18</sup> Walter I. Trattner, *From Poor Law to Welfare State: A History of Social Welfare in America* (New York: Simon and Shuster, 1999), 86.

<sup>19</sup> Lennard Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London and New York: Verso, 1995), 23.

<sup>20</sup> Paul Longmore, “Conspicuous Contributions and American Cultural Dilemma: Telethon Rituals of Cleansing and Renewal,” in *The Body and Physical Difference: Discourses of Disability*, ed. David T. Mitchell and Sharon Snyder (Ann Arbor: University of Michigan Press, 1997), 137.

years earlier, the dorms and classroom buildings remained inaccessible to people using wheelchairs. As a result of the students' protests, Roberts traveled to Washington, D.C., and met with officials from the United States Department of Health, Education and Welfare (HEW). They asked Roberts to design a university program to help students with disabilities achieve self-sufficiency, which served as the model for Berkeley's Center for Independent Living (CIL).<sup>21</sup>

While people with disabilities increasingly succeeded in living independently as CILs began opening across the country, they still faced discrimination in the job market. Section 504 of the 1973 Rehabilitation Act intended to remedy this situation by prohibiting state and federal agencies as well as contractors and institutions from receiving government funding if they discriminated against workers with disabilities. However, when HEW officials estimated that it would cost billions of dollars to institute, politicians delayed its passage. In 1977, determined to enter the workforce, people with disabilities staged sit-ins at the HEW Washington, D.C., headquarters and eight local offices. After nearly two weeks of sit-ins, the demonstrations ended when HEW officials and politicians agreed to finalize the passage of Section 504. Borrowing from the ideology of the civil rights movement, the disability rights movement redefined disability as a social and political issue rather than a medical problem and helped pave the way for legal reform culminating in the 1990 Americans with Disabilities Act (ADA).<sup>22</sup> This shift in how people with disabilities view disability is a key factor in the development of disability studies.

### From Disability Rights to Disability Studies

Drawing on the rhetoric of disabled activists, disability studies began in the early 1980s as an outgrowth of the disability rights movement. Composed as an interdisciplinary field, it responds intellectually to the medical model, which locates disability within individuals with functional limitations or illnesses such as blindness. To counter this inferior status relegated to people with disabilities, disability studies scholars developed the social model, which draws a distinction between disability and impairment. Impairments are the physical, sensory, or cognitive conditions that cause functional limitations, while disability is how nondisabled people respond to people with functional limitations in relation to

<sup>21</sup> Joseph Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement*, 1st ed. (New York: Times Books, 1993), 47–53.

<sup>22</sup> Shapiro, *No Pity*, 64–70; Paul K. Longmore, "The Disability Rights Movement: Activism in the 1970s and Beyond," in *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University, 2001), 111. See also Sharon Barnartt, *Disability Protest: Contentious Politics 1970–1999* (Washington, D.C.: Gallaudet University Press, 2001); and Jacqueline Vaughn, *Disabled Rights: American Disability Policy and Fight for Equality* (Washington, D.C.: Georgetown University Press, 2003) for a more detailed analysis of the disability rights and independent living movement.

economic, political, and cultural aspects of society.<sup>23</sup> Understanding disability as a form of oppression empowers people with disabilities to confront *ableism*, or discrimination based on functional limitations because restrictions are seen as denial of rights rather than merely the result of their physical, sensory, or cognitive impairment. Through the 1990s, this was sometimes referred to as the civil rights model because of its continued use as a tool to end discrimination. In an effort to fight oppression, early works define people with disabilities as a minority group denied rights. According to Simi Linton, “disability studies challenges the idea that the social and economic status and assigned roles of people with disabilities are the inevitable outcomes of their condition.”<sup>24</sup> As a means to rewrite the personal tragedy narrative and take identity out of the hands of the “oppression regime,” scholars interpreted disability as a positive characteristic borrowing from the celebratory rhetoric of multiculturalism. Researchers’ embrace of disability echoed African Americans’ assertion that “Black is Beautiful” and gays’ and lesbians’ use of the phrase “gay pride.”<sup>25</sup> These tactics reflect the understanding that worth must be established before obtaining rights. While the social model is still used to fight oppression, in recent years, scholars have begun to critique its usefulness as a framework for understanding all disability experiences.

Scholars challenge the social model primarily because it fails to account for all disability experiences by merely responding to the medical model. According to feminist scholar Carol Thomas, the social model is merely a variant of the medical model because it suggests that impairment causes restrictions and these restrictions result in social barriers for people with disabilities. In so doing, it risks implying that impairment and not oppression is the source of the exclusion of people with disabilities.<sup>26</sup> Furthermore, emphasizing social barriers, the social model excludes disabilities that do not cause physical restrictions such as epilepsy or dyslexia.<sup>27</sup> For this reason, Thomas reframes the social model as social-relational, arguing that “impairment effects” or how people with and without impairment interact is “the medium for the enactment of disability.”<sup>28</sup>

<sup>23</sup> Mairian Corker and Tom Shakespeare, eds., *Disability/Postmodernity: Embodying Disability Theory* (London and New York: Continuum, 2002), 3.

<sup>24</sup> Simi Linton, “The Disability Studies Project: Broadening the Parameter of Diversity,” in *End Results and Starting Points: Expanding the Field of Disability Studies*, ed. Elaine Makas and Lynn Schlesinger (Boston: Society of Disability Studies; Portland, Maine: Edmund S. Muskie Institute of Public Affairs, 1996), 325.

<sup>25</sup> Davis, *Bending Over Backwards*, 10.

<sup>26</sup> Carol Thomas, *Female Forms: Experiencing and Understanding Disability* (Buckingham, U.K.: Philadelphia: Open University Press, 1999), 24.

<sup>27</sup> Thomas, *Female Forms*, 25–26.

<sup>28</sup> Carol Thomas and Marian Corker, “A Journey Around the Social Model,” in *Disability/Postmodernity: Embodying Disability Theory*, ed. Marian Corker and Tom Shakespeare (London and New York: Continuum, 2002), 20.

Other scholars argue that disability is social-relational and in so doing emphasize power relationships, as do scholars in the field of gender studies.<sup>29</sup> According to Joan W. Scott, “gender is a constitutive element of social relationships based on perceived differences between the sexes, and gender is a primary way of signifying relationships of power.”<sup>30</sup> Building on this paradigm, other scholars emphasize the importance of the individual’s internal perception of his or her impairment in creating social arrangements.

Thus, scholars now argue that disability should be understood through the theory of complex embodiment, which locates disability in the interactions between people with and without impairments recognizing power as only one component.<sup>31</sup> According to Tobin Siebers, disability is socially located, and the way people with disabilities perceive the world differs from the perception of nondisabled people because their impairments serve as the vantage point from which they view society. Furthermore, how they interact with a social setting influences how they view their impairments. For instance, how people with impairments interact with their doctors differs from how they interact with friends.<sup>32</sup> Moreover, people who live with chronic pain may not encounter oppression because they live with an invisible disability, but the pain they experience may cause them to feel disabled. Embodiment extends discussion of disability beyond the bifurcation of the medical and social models by demonstrating that social relationships cause disability as both internal and external perceptions influence them.

Identity is one area where people with disabilities negotiate among notions of disability, which further necessitates the need to adopt the framework of embodiment. Since the disabled identity developed differently within each model, the medical model’s defective individual is juxtaposed alongside the social model’s empowered activist. However, both identities oversimplify the disability experience. While many people with disabilities neither consider themselves defective nor seek a cure, they would not necessarily remain passive as their condition worsens. Furthermore, a person who loses his or her leg in an accident may feel disabled despite the promise of a prosthetic leg. Should it be understood that the person identifies with the medical model’s defective individual because he or she does not overcome the disability?<sup>33</sup> Or should it be

<sup>29</sup> Paul K. Longmore and Lauri Umansky, eds., *The New Disability History: American Perspectives* (New York: New York University Press, 2001), 16; also see Catherine J. Kudlick, “Disability History: Why We Need Another ‘Other,’” *American Historical Review* 108 (2003).

<sup>30</sup> Joan Scott, “Gender: A Useful Category of Historical Analysis,” in *Gender and the Politics of History* (New York: Columbia University Press, 1988), 42.

<sup>31</sup> Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008), 3–4.

<sup>32</sup> Janet Price and Margit Shildrick, “Bodies Together: Touch, Ethics and Disability,” in *Disability/Postmodernity*, 62–63.

<sup>33</sup> Siebers, *Disability Theory*, 25.



acknowledged that internal feelings can also shape such a viewpoint independent of the medical model? According to Siebers, complex embodiment allows people with disabilities to acknowledge the difficulties of their situations without claiming to be defective and/or defining their situations as personal tragedies. Through this process, they can accept their bodies for what they are and not for what others believe they should be. The theory of complex embodiment recognizes that how one identifies as disabled is an individual decision, and it acknowledges the importance of both internal and external forces in how one identifies. On the other hand, the social model forces one to identify as disabled as a result of external conditions. Thus, embodiment accounts for how the individual understands his or her disability.

Analysis of disability as an individual identity necessitates an examination of disability as a category. The ADA expanded the category of disability to include hundreds of conditions ranging from obesity to carpal tunnel syndrome. Indeed, given its expansiveness as a category, Lennard Davis raises the question as to who is not disabled.<sup>34</sup> He answers by suggesting disability should not be understood as a category, but instead examined within the framework of what he calls “dismodernism,” which recognizes that people are all different and cannot be categorized. He further refers to disability as the “neoidentity” that has the potential to replace all other identities because all people are limited by their bodies’ functions.<sup>35</sup> Indeed, most Americans will experience a disability at some point in their lives. In this sense, disability should be valued as a form of human variation. As a form of difference, it cannot be neatly categorized, because, as Davis argues, someone could be disabled one day and cured the next day.<sup>36</sup> Rather than understand disability as a category, the theory of complex embodiment evaluates disability as an experience, recognizing how and when a person identifies as disabled as part of the experience. As a theory that values disability as a form of human variation, embodiment complements archival theory, especially provenance.

### **Considering Approaches to Disability in Appraisal**

During the appraisal and selection of records, archivists begin creating a disability identity when they decide to preserve or destroy records. As Tom Nesmith points out, during appraisal and selection, archivists alter records’ meanings by reshaping their context. Building on Nesmith’s analysis, Randall

<sup>34</sup> Lennard Davis, “Identity Politics, Disability and Culture,” in *Handbook of Disability Studies*, ed. Gary L. Albrecht, Katherine D. Seelman, and Michael Bury (Thousand Oaks, Calif.: Sage Publications, 2001), 536.

<sup>35</sup> Davis, *Bending Over Backwards*, 23–25.

<sup>36</sup> Davis, *Bending Over Backwards*, 23–25.

C. Jimerson argues that, during appraisal, archivists construct memory sometimes without an awareness of their actions.<sup>37</sup> To resolve this problem, some archivists suggest involving creators in the appraisal and selection process, or what Katie Shilton and Ramesh Srinivasan describe as “participatory appraisal.” They state that working alongside creators to appraise collections enables them to gain a greater understanding of the practices, knowledge, and beliefs of marginalized groups and subsequently what records best reflect a community’s narrative.<sup>38</sup> Participatory appraisal complements embodiment by focusing on the knowledge and experiences of the community while appraising disability collections. However, before archivists engage in participatory appraisal, we first need to examine how we define disability, how that definition is related to a collection’s provenance, and how it shapes the disability narrative.

How should archivists define disability? On the one hand, if we perceive disability as merely a functional limitation, we not only risk excluding hidden disabilities, but we also risk medicalizing disability. On the other hand, if we view disability within the framework of the social model, we might describe disability only as a form of oppression that people with functional limitations or health impairments respond to with social activism. Both models are problematic because they oversimplify disability. The question then arises: How should archivists define disability? According to Tobin Siebers, disability is an “elastic social category” and, unlike race or gender, disability can change depending on the social context.<sup>39</sup> A person will not go to bed black and wake up white. However, this same person could leave for a road trip able-bodied and become disabled the following day after losing both legs in a car crash. Furthermore, this person adapts to living without legs. In fact, he or she declines the option to receive prosthetic legs. Although a physical challenge, his or her functional limitation has provided new opportunities. For instance, he or she now participates in the Paralympic Games and has formed many new friendships through this participation. Consequently, disability is an individual experience influenced by the social context. As a result, no one definition exists for archivists’ usage. For archivists to successfully document disability, we will first need to re-evaluate our definition of provenance.

During the last decade, archivists scrutinized the meaning of provenance. In the Society of American Archivists’ glossary of archival terminology, Richard Pearce-Moses states: “Provenance is a fundamental principle of archives, referring to the individual, family, or organization that created or received the items

<sup>37</sup> Tom Nesmith, “Seeing Archives: Postmodernism and the Changing Intellectual Place of Archives,” *The American Archivist* 64 (2002): 31; Randall C. Jimerson, “Archives and Memory,” *OCLC Systems and Services* 19 (2003): 93.

<sup>38</sup> Katie Shilton and Ramesh Srinivasan, “Participatory Appraisal and Arrangement for Multicultural Archival Collections,” *Archivaria* 63 (2007): 93.

<sup>39</sup> Siebers, *Disability Theory*, 4.

in a collection.”<sup>40</sup> Central to the idea of provenance is that archivists respect the origin of collections to preserve their integrity. In maintaining a collection’s origin, its context is also preserved. As any archivist knows, this is core to archival theory. However, as most archivists also know, preserving the true context of collections is difficult. As humans, archivists have personal opinions and biases. Some of us will unintentionally and unknowingly regard disability as a functional limitation. If we lack theoretical framework with which to approach the subject, we risk altering a collection’s context. In the context of disability collections, we first need to re-examine our understanding of provenance. Joel Wurl’s analysis of provenance in relation to ethnicity can also be applied to disability. According to Wurl, “ethnic groups are the product of complex social interaction” and ethnicity is “constantly being shaped and reshaped.”<sup>41</sup> If ethnicity is not viewed as “embodiments of provenance,” archivists risk documenting ethnic groups in pieces and not as a “dimension of society.”<sup>42</sup> Since disability is also an unstable feature of society, archivists should also view disability through the lens of the theory of complex embodiment. Appraising disability from the angle of embodiment will help preserve and respect the context of collections and, consequently, accurately represent how individuals or groups experience disability.

To demonstrate how participatory appraisal and embodiment can help archivists provide a more complete record of how a person experiences disability, let us consider a hypothetical example on how to appraise disability. The collection we will use are the papers of John Doe, a paraplegic man, consisting of three series: correspondence, subject files, and visual materials dating from 1972 to 2004. The collection as a whole clearly reflects his identification as a man disabled after a 1983 car accident. To illustrate why the theory of complex embodiment is the appropriate model through which to appraise disability, we will appraise this collection using both the theory of complex embodiment and the social model. In both instances, we will also use participatory appraisal.

As I work with Doe to appraise his manuscript collection, I learn that the materials collectively reveal his interest in disability activism. However, further discussions with him reveal that Doe’s identification as a man with a disability is complex. For instance, many of his papers do not deal with medical or social problems he encountered because of his disability. Instead, they relate to everyday activities such as weekly poker games and details regarding volunteer work for his church. While I would not in reality appraise at the item level, I

<sup>40</sup> Richard Pearce-Moses, *A Glossary of Archival and Records Terminology*, s.v. “provenance,” Society of American Archivists, [http://www.archivists.org/glossary/term\\_details.asp?DefinitionKey=196](http://www.archivists.org/glossary/term_details.asp?DefinitionKey=196), accessed 12 November 2011.

<sup>41</sup> Joel Wurl, “Ethnicity as Provenance: In Search of Values and Principles for Documenting the Immigrant Experience,” *Archival Issues* 29, no. 1 (2005): 68.

<sup>42</sup> Wurl, “Ethnicity as Provenance,” 69.

nonetheless recognize that his identification as disabled is more complex than merely focusing on his medical problems and their social implications. The theory of complex embodiment can help archivists recognize disability as a multifaceted experience. As it pertains to records, embodiment complements archival theory that suggests records be appraised in the context of understanding the creator's purpose for producing them as well as on their content.<sup>43</sup> The question then arises: Why does the social model conflict with the same archival theory?

Appraising disability from the vantage point of the social model creates a potential problem. Returning to Doe's collection, what types of materials would I be interested in if I only viewed disability through the lens of the social model? How would my outlook influence my work with Doe during appraisal and selection? As mentioned, Doe was enthusiastically involved in activism and participated in a variety of groups that struggled against discrimination. If I look at disability as an impairment or functional limitation that hinders a person's involvement in society, I might encourage him to donate materials that document his work as disability advocate. The problem with looking at disability solely from this angle is that such an approach fails to document disability as a form of human variation.

Manuscript collections, however, are only one piece of the archival landscape. Organizational records, which come to the archives after their disposition by the agency or government department that created them, pose problems for archivists who must also consider legal issues pertaining to health records. The Health Insurance Portability and Accountability Act (HIPAA) prevents archivists from providing access to medical records or other health-related records created and maintained by institutions such as hospitals, medical clinics, and insurance companies. Congress passed HIPAA in 1996 to prevent people from accessing individuals' health records in the wake of new technologies and media such as the Internet.<sup>44</sup> Archivists in particular are affected by two HIPAA restrictions: the Privacy Rule and the Security Rule. In 2000, the United States Department of Health and Human Services issued the Privacy Rule (formally known as the Standards for Privacy of Identifiable Health Information) to ensure that paper health records are kept private while enabling sharing and use of paper health records for medical treatments and payment of health-care services. While the Privacy Rule governs paper health records, the Security Rule restricts the use and sharing of electronic health records to treatment and payment. Both rules preempt less restrictive state laws

<sup>43</sup> Verne Harris, "Postmodernism and Archival Appraisal: Seven Theses," *S.A. Archives Journal* 40 (1998): 49–51.

<sup>44</sup> Susan Lawrence, "Access Anxiety: HIPAA and Historical Research," *Journal of the History of Medicine* 62, no. 4 (2007): 435–37; Menzi L. Behrnd-Klodt, "The Brave New World of 21st-Century Medical Records Privacy in the U.S. and Canada, Contrasted with European Data Privacy Model," in *Privacy and Confidentiality Perspectives: Archivists and Archival Records*, ed. Menzi L. Behrnd-Klodt and Peter J. Wosh (Chicago: Society of American Archivists, 2005), 285–87.

and apply retroactively, requiring that researchers obtain the written consent of the patient to use his or her health records for historical or any other research.<sup>45</sup> Archivists can provide access to limited, nonidentifiable data, but only if the researcher signs a data-use agreement. Nonetheless, because many organizations that work with people with disabilities fall under the purview of HIPAA, archivists have little desire to acquire collections if they cannot provide users with access. Despite HIPAA, connecting with local United Way agencies and other nonprofit groups offers archivists potential sources of disability collections and an opportunity to engage in participatory appraisal.<sup>46</sup> Although archivists will need to remove or restrict the client case files, these collections will increase documentation on disability. Thus, despite legal restrictions, archivists can begin to expand disability archival collections.

### **Considering Approaches to Disability in Arrangement and Description**

Beyond appraisal, archivists need to consider how to arrange and describe disability collections. Since disability intersects with a variety of topics, one could argue that the subject is already widely documented, but not adequately described. Consequently, how we describe or fail to describe disability is instrumental in how researchers interpret the subject. We must consider how our own feelings and beliefs about disability color our description. Wendy Duff and Verne Harris caution archivists to be mindful of our own biases. They state that archival description is a form of storytelling, and, as storytellers, we privilege some voices while oppressing others.<sup>47</sup> For this reason, embodiment provides archivists with a useful tool to describe collections because it complements archival theory that focuses on the creator and the context of record creation.

Traditional archival theory states that provenance and original order work together to enable archivists to remain neutral and objective while letting the records speak for themselves. Provenance dictates that records from different creators be kept separate to preserve their context, while original order maintains that records be preserved in the creator's arrangement to retain relationships among the materials.<sup>48</sup> During the past two decades, postmodernism

<sup>45</sup> Behrnd-Klodt, "The Brave New World of 21st-Century Medical Records Privacy," 286–90.

<sup>46</sup> Barbara Floyd, Kimberly Brownlee, and Arjun Sabharwal, "Invisible Cultures: Engaging the History of People with Disabilities" (paper, 2010 Midwest Archives Conference, Chicago, Illinois, 24 April 2010).

<sup>47</sup> Wendy Duff and Verne Harris, "Stories and Names: Archival Description as Narrating Records and Constructing Meanings," *Archival Science* 2 (2002): 276, 278.

<sup>48</sup> Pearce-Moses, *A Glossary of Archival and Records Terminology*, s.v. "original order," Society of American Archivists, [http://www.archivists.org/glossary/term\\_details.asp?DefinitionKey=69](http://www.archivists.org/glossary/term_details.asp?DefinitionKey=69), accessed 12 November 2011.

has challenged the meaning of these long-established archival principles. A postmodern viewpoint of archives changes our understanding of both provenance and original order. Joseph Deodato writes that the complexity of provenance also includes “the context in which the records were created, the functions they were intended to document, and the record-keeping systems used to maintain and provide access to them.”<sup>49</sup> Postmodernism reconsiders the archivist’s role in arrangement and description. No longer neutral or objective, it instead recasts archivists as the mediators of archival records. Tom Nesmith states that provenance includes “the societal and intellectual contexts shaping the actions of the people and institutions who made and maintained the records.”<sup>50</sup> As part of the societal and intellectual context, archivists shape the provenance of archival materials. In short, as mediators, we mold archival collections through our arrangement and description.

As mediators of collections, the model through which we view disability influences how we arrange and describe collections. To illustrate why the theory of complex embodiment is the best model to utilize when describing disability collections, let us return to Doe’s manuscript collection and illustrate the difference between processing his collection from the vantage point of the theory of complex embodiment and the social model. As previously noted, Doe’s disability identity is complex. In the biography, I would not only detail when his accident occurred, but how it changed his perspective on life. Processing Doe’s collection through the lens of embodiment allows me to be more open-minded regarding the description. Indeed, I focus on Doe’s perspective rather than on my own thoughts on disability. I recognize Doe’s identification as disabled as more complicated than simply a medical problem or social barrier. For example, Doe chooses to remain paraplegic and not have prosthetic legs implanted. If I viewed disability from the angle of the social model, I might be inclined only to describe disability as a source of oppression that he fought against rather than as an experience. I would potentially overlook such complex particulars and, as a result, misrepresent Doe’s view of his disability in his papers’ finding aid. As mediators, archivists need to be aware that how we describe disability affects how researchers analyze the topic.

The questions now arise: Is the theory of complex embodiment worth the time and investment? How are disability collections currently described and indexed? While a detailed answer to these questions warrants its own paper, a brief analysis will demonstrate why archivists need to consider how we define and describe disability. According to my research in WorldCat, archival collections that comprise disability manuscripts contain primarily medical materials.

<sup>49</sup> Joseph Deodato, “Becoming Responsible Mediators: The Application of Postmodern Perspectives to Archival Arrangement and Description,” *Progressive Librarian* 27 (2006): 56.

<sup>50</sup> Nesmith, “Seeing Archives,” 35.

For example, a search of “epilepsy” in WorldCat turns up mostly materials from physicians or hospitals that treat people with epilepsy or developed early anti-seizure medications. For example, Harvard University holds the papers of William Gordon Lennox, an epilepsy researcher during the mid-twentieth century. According to the catalog record, the papers consist of his research notes and translations of literature written by medieval and Renaissance physicians who studied epilepsy. Consequently, one could argue that these collections do not document disabilities, but instead scientific research and medical discoveries.<sup>51</sup> Do archives currently house disability collections that are not described? Are these collections undocumented because the archivists who processed them understood disability as a medical problem and not an identity or experience? After all, as this paper demonstrates, the definition of *disability* has evolved over time. In addition to being more sensitive in describing our incoming collections, we should consider re-indexing collections we currently house. Archivists used this approach in the 1970s and 1980s to document the history of women. In the early 1970s, archivists worked alongside women historians to survey archival holdings to uncover and describe “hidden” women’s sources.<sup>52</sup> The same approach could be used to find collections documenting people with disabilities. Viewing disability from the vantage point of the theory of complex embodiment would allow archivists to find more collections than does understanding disability through either the medical or the social model. Consequently, archivists could help illustrate disability as an experience and not simply as a medical problem or a social barrier.

## Conclusion

In an attempt to get archivists to think more critically about how to document disability, this paper offers an analytical framework with which to evaluate disability and a few practical considerations. The theory of complex embodiment asks archivists to look beyond the social model and consider disability in all its complexity. Using embodiment during appraisal and arrangement and description, we can ask how a person experienced disability in different settings and in the presence of various individuals, and determine what records best document the disability. Regarding organizations, embodiment asks archivists

<sup>51</sup> My searches in WorldCat using the keyword “disability” and limited to archival sources and the English language returned 810 results. Further research revealed many of these documents to be medical records or original scientific research. This was also the case when I limited my search to a specific disability such as epilepsy. For example, see William Gordon Lennox Papers 1926–1953, Harvard University Medical School, [http://www.worldcat.org/title/papers-1926-1953/oclc/231042883&referer=brief\\_results](http://www.worldcat.org/title/papers-1926-1953/oclc/231042883&referer=brief_results), accessed 12 November 2011.

<sup>52</sup> Honor R. Sachs, “Reconstructing a Life: The Archival Challenges of Women’s History,” *Library Trends* 56, no. 3 (2008): 661–62.

to consider how an organization understands disability. Yet, for this reason, embodiment is also problematic since its implementation could result in privacy concerns, including disclosure of another person's medical condition. Consequently, archivists need to work closely with donors during appraisal and arrangement and description to gain a greater understanding of the types of documents within their collections. In the absence of a creator's participation, archivists need to pay close attention to the natural language used in the records. These few strategies can help us begin to document disabilities.

To consider how archivists can begin to confront the challenges that arise when documenting people with disabilities, let us return to the question posed at the beginning of this essay as to whether archivists would be doing a good job if only a handful of archives collected the history of racial or ethnic minorities. Undoubtedly, many archivists, if not all, would answer no. After all, it has been over a generation since F. Gerald Ham called on us to document the history of marginalized groups.<sup>53</sup> Since then, we have made strides in documenting racial and ethnic minorities. Yet, with a few exceptions, people with disabilities have been largely overlooked. How different would the archival landscape look if archives included the records of schools for the blind alongside manuscripts of disabled activists? Certainly archives would contain a more complete record of disability. However, further research and work is still needed before a more complete record becomes reality. Among the areas that need to be explored are how disability fits within archives' existing collection development policies and what documentation currently exists on disability in both traditional and community archives. Archivists also need to consider outreach to the disability community and how to overcome any potential communication barriers standing between us and people who may not communicate as we do. United Way agencies and other disability organizations offer archivists potential resources to assist in reaching out to people with disabilities. Beyond outreach, archivists also need to critically examine how to arrange and describe disability collections in an age of minimal processing without losing their context. Finally, we need to advocate for revisions to HIPAA's Privacy Rule and Security Rule as they pertain to historical research so that we can provide access to medical records of the deceased after a specified number of years.<sup>54</sup> Although the theory of complex embodiment as a framework for appraising and describing disability is just a starting place, archivists must take further steps in documenting disability. After all, if we do not remember people with disabilities, who will?

<sup>53</sup> Ham, "The Archival Edge," 329.

<sup>54</sup> Mark Greene, "The Power of Archives: Archivists' Values and Value in the Postmodern Age," *The American Archivist* 72, no. 1 (2009): 35.