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1

Disability and Life Writing

Google Search results: “About 3,220,000 results (0.18 seconds).”

How strange, I thought! What a high number of hits on “disability autobiography,” search terms entered to investigate my working research assumption: that individuals with disabilities had long written about their worlds rather than only after such expression was made possible by cultural developments associated with Helen Keller, new technologies, and changing educational and civil rights laws.¹ The surprisingly high number of hits—3,220,000!—suggested that my instinct was not only utterly misguided but also that others had beaten me to my scholarly task. When I anxiously examined the results, they covered a range of issues associated with disabled individuals—disability history, writing by disabled authors, and analyses of these matters in scholarly and popular books, in college courses, lectures, blogs and the like. But, none of the references mentioned any autobiography or life writing by a disabled person before the twentieth century; of those mentioned, virtually all were written in its second half and few individuals were specifically identified other than Helen Keller.² My instinct, thus far, was upheld and leading me in a propitious direction.

Intrigued by these apparent imbalance and omissions, I conducted another search on “disability autobiography before 1900.” This time, the response offered a “mere” 2,630,000 hits. The first 10 entries included coverage of Franklin Delano Roosevelt, Maria Montessori, Helen Keller, eugenics, “famous people with disabilities and dyslexia,” and even Kaiser Wilhelm II. These were clearly less sources about life writing and disability than gauges of popular perceptions of life and disability.

As my initial search, then, this one located references to a history of disabled individuals as well as to life writing by and about disabled
individuals, primarily the latter. But, none of the entries offered a single example of life writing by a disabled individual before Helen Keller.

As an academic, I am aware of the limitations of the Google search; it is not a scholarly site, to say the least. But, my search was not directed at finding scholarly materials. Because my purpose was to poll public interest in life writing about disability, Google was an appropriate choice. As it informed me, these interests were focused on recent writing, on disability history, and on analyzing others’ efforts. Although it seemed reasonable that the public leaned in such directions, it still appeared odd that no individuals with disability wrote about their experiences before 1900.

Next, I conducted a scholarly search. This search confirmed the Google results: almost nothing emerged about life writing by disabled individuals before Helen Keller wrote. Thus, this study was born, a response to the following prompt: when, how, and under what circumstances have individuals with disabilities written from their own perspectives before 1900?

Although the Google results on life writing by disabled individuals was surprisingly limited, the number of hits was anything but unexpected. Life writing is an increasingly popular form of narrative non-fiction, both generally and within the context of writing about disabilities. The genre’s popularity is due, in part, to the increasingly globalized world exemplified by my Google search, one in which individuals connect and communicate by means of multiple media. Because life writing in particular allows authors to represent their own experiences, it has become a favorable medium for disability writing both for personal presentation as well as for educating the broader public about lives often spoken for by others (if at all). However, with assistive shifts in technology, accommodations, legislation, and education (and as my Google search confirmed), many contemporary readers assume that individuals with disabilities did not often write about themselves before the twentieth century, specifically before the publication of Helen Keller’s classic text, *The Story of My Life* (1903). This assumption is reinforced by the seeming scarcity of materials about disability life writing before Keller’s work. Given these circumstances, this study questions that assumption by asking:

- what is disability life writing within the context of the Western tradition;
- how do we understand this genre; what changes has it undergone since its first recorded stories and what links its manifestations;
● what do we discover from those who speak for themselves within a history of marginalization and without the kinds of access and accommodations now increasingly available?

In responding to these questions, my investigation considers how individuals within the Western tradition have identified and represented themselves as disabled. To that end, I use a sociological and historical approach, an approach which considers the sources in their contexts and then relocates them in the present where they might inform current concerns about the body and its representation within disability studies, sociology, medical sociology, the history and rhetoric of disability, and related areas. In so doing, I trace a broad path within the socio-historical study of disability. Following that path reveals that many pre-twentieth century individuals with disabilities succeeded in representing their experiences but their texts have not yet been examined as life writing. When examined as such, these texts demonstrate that their authors were well aware of the stigmas they faced, offer an initial corpus of materials for further study, highlight a tradition of advocacy for the underserved, and contribute to understanding that tradition’s contemporary manifestations. This introductory chapter lays out my plan for the investigation while preparing the way for individual chapters to discuss the specific relevant perspectives as well as the social and historical background.

**Historical and Definitional Methodology**

“Disability” is currently used and broadly accepted to frame a long history of perspectives on and practices involving human physical attributes and their many variations. While the term is but one of many (in many languages) within a complex history, I understood the concept against the backdrop of its very presence. Simply put, no two humans have the exact same physical attributes and conditions at birth nor do they experience the same physical fortunes over their life course. But, the presence of physical variations and societal perceptions of them are different issues. On the one hand, as current scholarship puts it, the percentage of problematic physical conditions or disabilities across recorded history ranges somewhere between 10% and 25%. On the other hand, these statistics suggest a certainty about the numbers, categories, and people to whom they apply which closer scrutiny belies. First, the statistics conflate two key concepts, physical variation and disability. Through this elision, the statistics fail to acknowledge that only individuals whose physical attributes have been marked as different
in their social context could be included in the historical documents from which they were culled. As a result, the statistics do not indicate how particular differences became marked as disabilities at any point within the millennia they document. What does it mean to fall into the range between 10% and 25% of individuals with physical differences? How do we account for the different ways in which cultures and individuals conceptualize such categories as disabilities and actualize them in social practices? And, how do we make sense of these ways of conceptualizing physical conditions, both looking back and forward?

Responding to these questions requires dealing with historical and cultural materials and, in turn, a methodology which examines these sources in their original social contexts and as they inform relevant contemporary concerns. Such a methodology also acknowledges the inherently socially constructive status of words, definitions in particular. As such, I look to the work of Edward Schiappa who advises investigators to examine historical documents by differentiating between two goals, historical reconstruction and rational reappropriation, each with its own tool set. The former goal, historical reconstruction, attempts to understand cultural artifacts (printed texts, images, sculptures, and so forth) in their original contexts to the fullest extent possible; without such understandings, no study of society, social behaviors, and disability issues, within this, can or need be sought. Pursuing this task requires recourse to contemporaneous historical materials and attention to the use of language and ideas across them; to those ends, investigators should consider the frequency, resonance and density of key terms among other elements. To study the health of the protagonist of Shakespeare’s Hamlet in context, for instance, the investigator would need to investigate Elizabethan notions of melancholy, along with other historically appropriate concepts.

In contrast, rational appropriation seeks to understand how past principles and practices inform contemporary concerns. The appropriate tools for this task include the past texts and the current theories with which they might resonate. To discover this resonance, the investigator looks for themes, practices, and concepts which are evident on some level in both cultures. Because reappropriation brings the earlier concepts forward, so to speak, the investigator not only interprets past elements in light of current approaches but also acknowledges any anachronistic statements which the act of reappropriation might entail. Otherwise, the reappropriation could be misunderstood as a historical reconstruction and skew current understandings of the original historical context. Continuing with the Hamlet example, an investigator pursuing a rational reappropriation of his mental state, as Hamlet’s condition might
now be called, could diagnose him with an Oedipus complex but with the caveat that no Elizabethan had any familiarity with Freudian analysis (without recourse to a time machine); the diagnosis is an interpretation based on a reappropriation that might inform contemporary concerns with madness, critical theories, and the like, but neither Shakespeare’s conceptualization of Hamlet’s character nor his audience’s reception of it.

As mentioned, this methodology also informs how I define key terms in this study. From this perspective, and again following Schiappa, definitions are socially constructed and hence serve argumentative or rhetorical purposes. That is, definitions are hardly universals inscribed in dictionaries but constructs whose various meanings are shaped by their use in social contexts and, accordingly, change over time and location. Students of disability studies are only too familiar with the argumentative force of definitions; each of disability’s many historical and cultural definitions reflects its originating social context, and all manifestations make culturally specific arguments about the individuals thus identified, arguments which are open to analysis and interpretation.

Although this methodology embraces two different goals, the approach does not preclude conducting research to both ends within a single effort if the goals are pursued consistently and framed as such. With both goals in mind, then, this study analyzes life writing texts in conjunction with appropriate contemporaneous historical materials to determine how these individuals represented their identity as disabled. Based on these historical reconstructions (and when relevant), I reappropriate the historical representation into the contemporary context; by understanding the historical reconstructions in terms of recent theories and constructs involving class, gender, and the like, and acknowledging any changes or anachronisms such extension entails, my reappropriations of these concepts inform current work on disability issues. Maintaining these distinctions between past and present is not only critical to any study involving historical concepts and practices but also conforms with recent work in disability studies which addresses the complexities of assigning meaning, creating categories, and naming terms and concepts.

To illustrate this approach while introducing the background necessary for the study, let me next sketch a history of the concepts and terms surrounding disability over the periods and locations my study covers (as indicated, individual chapters offer in depth detail where appropriate). It is against this history of Western cultural conceptions of disability—this history of assumptions associated with the concept regardless of the particular terms employed to name it—that my study
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examines and compares how individuals thus constrained have represented themselves as disabled. As that discussion makes clear, the term “disability” was only recently coined and is obviously an English term; nonetheless, I use it throughout the study for expository clarity and to trace an historical path for the concept associated with human physical variation.

Although the term “disability” is newly coined, the concept of disability has existed at least as long as recorded history. As many studies have discussed, the concept has by and large been understood in the Western tradition in terms of exclusion and deviance, understandings which separate “normal” individuals from those who are physically or mentally “deviant.” For ancient Greeks and Romans, problematic physical conditions were an everyday presence in a cultural landscape lacking, at the least, sanitation and antibiotics. Based on the available humoral medical system, which was relatively abstract rather than categorical, those cultures judged humans and their physical variations in idealized terms of balance and proportion. Against these canonical norms, individuals were typically characterized as beautiful, strong, virtuous, and superior or as ugly, weak, maimed and inferior. Because these terms were also applied along lines associated with citizenship, they aligned disability issues with what we now call gender, race, and class. Throughout the middle ages, such matters of physical and intellectual/moral fitness were reframed within the scriptural guidelines of the Church. In this context, the presence of problematic physical conditions was associated with spiritual matters, acquiring salvation especially. Within this model, imperfect, weak, and often womanly earthly bodies were obstacles, i.e. disabilities, to be removed from blocking the path to salvation, a goal which required perfect bodies and souls. In these ancient and medieval societies, then, disability had everything to do with the daily presence of physical variations in human lives and with the ways in which these variations aided or prevented individuals from living up to societal expectations.

From the sixteenth century forward—and obviously I am putting this broadly for now (see individual chapters for detailed discussions—social perspectives and practices as well as the notions of disability which they reflected were subject to standardization prompted by new technologies, especially print and medical technologies. The advent of mechanical printing is concurrent with the appearance of the actual word “disability” as well as with the ability to spread emerging categorical cultural conceptions of it more widely and systematically. In shaping these understandings, scientific and medical practices categorized how the body operated in mechanical terminology, contrasting the proper,
effective, and smooth operation of body parts and systems with those that were defective, jerky, or convulsive. At this time, the presence of physical problems, and their reconceptualization as disabilities, acquired an air of the automaton; one’s body either operated correctly or was broken, disabling, and required repair. By the eighteenth century detailed medical taxonomies and associated practices named particular physical problems as disabling and framed them now as categorical illnesses to be cured. With the medical model born and mass printing disseminating its sentiments, notions of impairment, diagnosis, and cure were more fully inculcated in cultural practices. During the nineteenth century, physical deviations from the norm were often understood as deformity, a term which focused on extreme bodily abnormality; disability had become spectacle. To obscure (and yet enhance) their visibility, disabilities were categorized in the twentieth century along more medically specific lines, in some cases, explicitly including sexual orientation, class, and race; the fact that homosexuality appears as a mental pathology in the Diagnostic Statistic Manual of Mental Disorders (DSM-III-R), but not in subsequent editions, illustrates how concepts of disability shift in concert with socio-political issues. Although it retains its early associations with social issues, disability has also acquired an exceptional presence in the twentieth century which categorical naming seeks both to reveal and yet conceal.

Medical thinking still resonates in the public mind, but its normative understanding of disability has been complicated in the latter twentieth and early twenty-first centuries by the efforts of advocacy and academic communities to better understand and improve the lives of those marginalized for their perceived bodily differences. As an influential alternative to the medical model, the social model turns from the individual to society and from normalization to rehabilitation. “Unlike people who are ill, individuals with disabilities do not need to adopt the norms of the non-disabled majority or need to ‘get well,’ rather it is society that needs to accommodate their difference.” Further, the social model distinguishes between “impairment” and “disability.” An impairment is a physical fact, but a disability is a social construction. For example, immobility impairs while a building without a ramp disables.

As is generally the case with dichotomies, the binary on the social model is built, specifically between “impairment” and “disability,” reifies the very categories it seeks to destabilize. Some scholars have replaced that binary with a spectrum which moves away from opposing impairments and disabilities to considering the reception and construction of such differences. To populate this spectrum, disability
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has been considered in such transdisciplinary terms as embodiment, oppression, and identity. Quite recently, sociological scholarship has explored how globalization and technology have affected contemporary disability issues by developing new models and concepts, among them: disability orientation and identification as they affect the life course; affirmation models which offer a “non-tragic” model; and aesthetization perspectives which pick up on recent concerns with designer bodies. Such thinking publicly questions and challenges the ways in which the medical model continues to reconstitute itself in social norms and, in so doing, explicitly aligns disability issues with those of other marginalized groups.

At present, contemporary theories and practices hold that physical disability has no universal inherent meaning; instead, disability is defined by a given community’s understanding of member’s roles within it. From this perspective, one which grounds my description above and my analysis below, social constraints impose notions of normality and ability on individuals within a range of mental and physical variations and differences.

As the previous sketch also suggests, a “one-size fits all” approach to defining and understanding disability cannot embrace the fluidity within which social roles and associated notions of disability have been erected, maintained, and/or shifted over time. Such circumstances support my choice of approach, the socio-historical approach described above. Thus equipped, my study moves from its method and definitions to analyses based on the following assumptions. All humans deal with the brute facts of physical conditions. Lacking a social context, however, a particular physical condition is neither good nor bad. Something as simple as a spasm, for instance, has been characterized over time as anything from invisible to a sign of a violent and uncontrolled mind, of sin, or of involuntary neural function. To transform physical variation into disability, societies can be said to rely on values involving success; that is, when a society’s values frame a condition as limiting an individual or group’s ability to be successful (i.e. independent, flourishing, happy—these of course depend on the culture), than that individual is perceived as disabled.

But, an individual’s perception of and response to his/her disability status may differ from its construction in her/his broader culture; marginalized individuals or groups may not accept how others define them. Thus, my study not only examines the social perceptions imposed on disability; it also distinguishes between those social perceptions and the ways in which the individuals themselves recognize and express that identity within their socio-historical contexts. In distinguishing between
others’ perspectives and the individuals’ own, my study treats illness, impairments, and developmental differences in broad yet culturally specific ways within the Western tradition as well as the construction, recognition, and reception of that difference. For such a study of disability, life writing offers a distinctive perspective which other genres cannot provide.

**Definitions: Life Writing**

Although life writing is a new name, it is not a new practice. To acknowledge this circumstance while defining life writing in its past and present manifestations, I look to the work of Caroline Miller. 24 Miller rejects the conventional notion that genres are absolute categories identified by fixed features of form and content, as is the case with novels, poetry, plays, etc. Instead, Miller suggests that genres are kinds of social practices; this perspective recognizes that form and content change over time in response to writer and audience expectations (the novel is relatively recent form, for example). In contemporary business practice, for instance, a memo is a genre but so is, increasingly, a tweet.

Using Miller’s perspective, I define life writing as writing by individuals about their own lives rather than writing by others about those individuals and their conditions. By extension, life writing about disability refers to texts by people who identify with their disabilities and write about their embodied conditions. Thus defined, life writing encompasses a range of formats in which individuals write about themselves, for example, autobiography, letters, diaries, pathography, visionary prophecies, poetry, and memoirs; fictional biography would not be a type of life writing. 25

Autobiography is commonly used to designate texts which people write about themselves, but the form is a subset of life writing. 26 In fact, the term autobiography only appeared at the end of the eighteenth century first in German and then in English literature; no one knows who coined the terms. 27 I call life writing before that time “autobiographical.” A similar relationship exists between life writing and pathography. The latter, which refers to narratives written about illness, is a recent term based on equally recent definitions of illness. 28 Because it does not pertain to my pre-twentieth century life writing texts, I use the term only to refer to recent examples of that form. Similarly, for consistency and acknowledging formal inconsistencies within the works I cover, I call them life writing as a whole and use historically appropriate terms in context.
The Data and Analysis

As any historical study, my corpus is limited to texts which survive and to the cultural and sociological comparanda now available with which to examine them. But, scarcity is another relative term, especially in the context of life writing about disability.\textsuperscript{29} For one thing, historical materials are particularly hard to find if no one looks for them. To remedy that situation, I have recovered materials belonging to such traditional genres as history, epistolary writing, and sacred text, and relocated them according to my methodology and definitions within the genre and social practice of life writing about disability; this is the case with Seneca’s letters regarding Stoic philosophy which appear in the upcoming chapter. In addition, I have acquired materials in archives and other locations which have not received much scholarly attention from a disability studies perspective, among them, the medieval and early modern women visionaries the study covers. Finally, survival issues also involve another matter. Scholarship currently favors print linguistic materials, and, so, I call attention to visual life writing, self-portraits, for instance, although they cannot be treated in this study except in some cases as historical comparanda.\textsuperscript{30}

Despite my initial concerns, I found more materials than one study could cover. To select particular texts from this bounty, I relied on my methodological and definitional frameworks and sought interesting themes and patterns portrayed in complete texts. After collecting sources and contemporaneous historical materials, I examined the life writing texts in their contexts to determine if they were authentic instances of the genre and if they represented salient, recurrent, or diverging themes within their contexts and as they might inform a history of the genre. In so doing, I also attempted to present a coherent and compelling argument within an interesting narrative. Once my texts were selected, and keeping my criteria for historical reconstruction in mind, I divided and arranged the materials into chapters to reflect the broad historical periods with which readers are familiar. Because I could discuss only some of the documents I found, I challenge others to view these as exploratory case studies, to be extended, augmented, and changed through continued work.

I used a composite analysis to investigate the texts, or an approach incorporating two methodologies. In this way, I hope to provide a richer analysis than a single methodology alone can convey as well as to triangulate my research, especially since the works I treat are relatively diverse in several respects. Naturally, each period has different cultural conventions for writing and representation; at times, for example,
experimentation is the norm and at others convention the more common practice. These writing conventions intersect with those constraining concepts of disability; some individuals represent their identity as disabled in conformity with accepted writing conventions and some in contrast to them. Thus, the choices authors make in representing their experiences reflect individual responses to various cultural expectations and, in so doing, offer insights into the interplay between disability and normality as well as between individual in society in their contexts. To analyze the choices authors made, I first and primarily employed textual analysis; this approach allowed me to focus on content level issues, on the argumentative force of the texts, as it were. From close textual readings, interesting choices about word use, arrangement, and form, choices including metaphor and repetition, in particular, emerged.

At times, certain patterns appeared not only within individual texts but also across the texts in the particular historical periods under consideration. To investigate these patterns, I used corpus linguistics for two purposes: to determine how key words and phrases appeared and functioned in the text, primarily through forms of word repetition and collocation; and to provide context for the textual analysis of the life writing. For example, in Chapter Three, I examine the ways in which certain phrases associated with pain, suffering, and love appear across the chapter’s corpus; this corpus analysis reveals broad patterns of transmission and usage which inform how these high medieval individuals came to represent themselves in the terms they did. As such, this more quantitative tier offers insights into how words and concepts were socially constructed and disseminated as well as quantitative evidence regarding validity and reliability, even in this admittedly qualitative study.

Despite its variations, all life writing relies on personal testimony and thus raises several methodological issues involving authenticity. How can a story’s content be verified and interpreted? Because my approach is sociological and historical, my interests lie in how the authors represent themselves as disabled to their audiences and what they are attempting to persuade those readers to think. This approach renders issues of precise historical accuracy regarding the events in the writers’ lives less important than what writers choose to say and how they choose to present that material.

In sum, because each instance of life writing about disability is contingent on the context from which it emerges, this study examines the sources in their original cultural context; in particular, I focus on the ways in which the authors create arguments, implicit or otherwise, about their life experiences by means of metaphors, formal characteristics, and
patterns of repetition which emerge from the text. In addition to investigating what these writers say and how they express themselves, I consider how they were viewed in their time period, especially in comparison with contemporaries who did not identify as disabled and against cultural conventions those contemporaries would value.

Book Overview

Based on the method outlined above, the body of the study moves chronologically between key periods and populations in the Western traditions, focusing on representative and/or provocative texts. Chapter Two examines ancient Greek and Roman representations of disability within what I call the civic model, a perspective associated with concepts of citizenship and belonging. Following the model from the time of Pericles to Hellenism reveals societal shifts from groups engaging in public debate concerning disability issues to crafting personal written reflections on such matters. Chapter Three connects the civic model with Wheatley’s religious model of disability. From this Church based perspective, the texts of five women visionaries manifest as a form of life writing which shares and challenges cultural norms associated with their bodies by communicating about those very bodies. In contrast to the medieval women, the early modern visionary women described in Chapter Four enact their disabilities, one in public, with spiritual and political ends, practices associated with the appearance of the modern notion of the “self.” During the long eighteenth century, as Chapter Five suggests, the concept of disability is increasingly subject to standardization, a circumstance enabled by the spread of printing and medical technologies; with these developments, the notion of personal identity begins to separate from a collective perspective, calling attention to disability in new ways. By the nineteenth century, as Chapter Six discusses, the force of new social standards attempts to remove disability from the public view. Those perceived as disabled are often hidden in asylums; institutionalized, they begin to identify and advocate in more radical ways. Given my goal of recovering pre-twentieth century life writing, Chapter Seven considers Helen Keller’s story as a watershed in life writing about disability, especially since other life writing about disability was known and available at the time. Chapter Eight turns to a genre of life writing that is both underrepresented but representative of life writing about disability at the turn of the twenty-first century, the online stories of wounded American war veterans. The concluding chapter draws together what I have found
and yet to know regarding such matters as the everyday and the extraordinary, form and function, writing and the body, and more.

At present, scholars have written about disability and disability writing from many perspectives but not from the socio-historical viewpoint on life writing my study takes. By focusing on self-representations of disability, I hope to place these texts and my discussions of them in dialogue with existing scholarship, all of which consider the ways in which marginalized groups experience difference. “Thus, far from being marginal to modern society, disabled people have been central to its most important intellectual projects—invisible but highly visible.”

1 Because of the popular nature of Google, I used “autobiography” rather than “life writing” for my search.
2 As Frank confirmed in 1993, “There are virtually no academic studies of nonfiction, first person, published illness narratives; the sole exception I know is Hawkins (1984). This omission is of sociological interest, given the number of publications on ‘literature and Medicine.’ ‘Literature,’ however, refers invariably to fiction and poetry. Contemporary nonfiction exists in a scholarly void. The journal Literature and Medicine has not even reviewed nonfiction illness narratives” (“The Rhetoric of Self-Change: Illness Experience as Narrative,” p. 50, Note 1).
6 Schiappa, Protagoros and Logos: A Study in Greek Philosophy and Rhetoric; Schiappa, Defining Reality: Definitions and the Politics of Meaning.
7 Schiappa, Protagoros and Logos: A Study in Greek Philosophy and Rhetoric, pp. 32-35.
9 Wilson and Lewiecki-Wilson, Embodied Rhetorics: Disability in Language and Culture, p. 4, for example.
10 I am neither suggesting that subsequent medical and public health practices are simply better than ancient ones or that these practices always have positive consequences. But, developments in sanitation and antibiotics have improved the overall quality of human life.
15 Linton, *Claiming Disability: Knowledge and Identity*.
18 Shakespeare, “The Social Model of Disability.”
22 Siebers, *Disability Theory*.
26 Ibid., pp. 6 ff.
27 Ibid., p. 6.
29 Eyler, Ed., *Disability in the Middle Ages: Reconsiderations and Reverberations*; Metzler, *Disability in the Middle Ages: Thinking about Physical Impairment during the High Middle Ages, c. 1100-1400*; Stiker, *A History of Disability*.
31 Smith, *Behind the Scenes, or, Life in an Insane Asylum*, p. 3.