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Cultural Histories of Disability

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Abstract

The study of cultural histories of disability examines the past to gain insights into the present. This entry uses the specific example of learning disability to illustrate the contribution cultural histories can make to disability studies. True to the origins of disability studies in the disability rights movement, much of this research is undertaken by activist researchers, including researchers with learning disabilities, often in collaboration with university academics. Also true to the political origins of disability studies, this kind of research has a goal of precipitating positive change for people living with learning disabilities now and in the future. This entry begins by positioning the cultural histories of disability within the broader academic sphere. The specific characteristics of cultural histories of learning disabilities are discussed, and an overview of the origins and development of the field is provided. Methods for researching cultural histories of learning disabilities are then outlined. Key issues and themes in the field are summarized. The necessary relationship between conceptualizations of the human and conceptualizations of learning disability is highlighted. The entry concludes by offering some observations on the modest but important progress made so far in promoting positive change and signals a direction for future work.

Keywords

Culture · History · Learning disability · Intellectual disability · Intelligence · Research · Activism · Metanarrative

Introduction

The study of cultural histories of disability can be conceived of as one aspect of cultural disability studies, located within the broader discipline of cultural studies. In the following sections, an overview of the origins and development of the field is provided. Methods for researching cultural histories of learning disabilities (also often referred to as intellectual disabilities) are outlined as exemplars. Key issues and themes in the field are discussed. These relate to the historical and ongoing exclusion of people with learning disabilities from history; the current metanarrative of learning disability, and how it has been shaped by historical and cultural factors; and the discursive positioning of learning disability in relation to conceptions of the human. Our fascination with learning disability across time and space highlights its significance to culture, and it is argued that a notion of learning disability is necessary to

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make sense of Humanist ideas and ideals of personhood and citizenship. The cultural history of learning disability is a small but dynamic field of research that investigates the past to better understand contemporary responses to, and experiences of, learning disability. Although some of this research is conducted by university academics, much of it is undertaken in collaboration with people with learning disabilities, with the aim of using the findings to advocate for positive change.

Cultural Histories of Disability

The study of cultural histories of disability comprises a subfield of cultural disability studies, which is itself rooted in the field of cultural studies. Cultural studies are an interdisciplinary field that examines and critiques cultural practices, particularly those of ordinary people, while attending to the power structures, which shape those practices. Cultural disability studies are concerned with how disability is represented in culture and what those representations reveal about social attitudes toward disability. Methods used include autobiography (e.g., Grue, 2018) and life-writing (e.g., Couser, 2011)—since a central aim of cultural disability studies is to privilege the voices and knowledges of disabled people—as well as analyses of literary texts and other cultural artefacts such as movies, advertisements, and popular music. Cultural disability studies are exemplified in the work of the Centre for Culture and Disability Studies at Liverpool Hope University, which publishes the *Journal of Literary and Cultural Disability Studies*, widely regarded as foundational to the field. If we conceive of histories as stories a culture tells about itself, the inevitability of cultural histories of disability emerging from cultural disability studies becomes apparent. Cultural histories investigate ideas, beliefs, attitudes, values, and assumptions present in a culture within a given period (Yale Department of History, 2024). As such, cultural histories of disability are concerned with ideas and beliefs about disability; about attitudes, values, assumptions, and prejudices toward disability, and how these might change—or not—over time. In keeping with cultural studies' focus on representation, cultural histories of disability pay particular attention to how disability has been represented in culture. This includes consideration of both how the dominant culture has portrayed disability and how disabled people have fought against such representations, sometimes by creating their own.

A key reference work in the field is the six-volume *Cultural History of Disability* anthology edited by David Bolt and Robert McRuer. Each volume covers a specific period in history, ranging from Antiquity (from 500 BCE to 800 CE) to the Modern Age (from 1914 to present day). Each volume has eight chapters, and those chapters have the same title throughout the set. For example, every volume has a chapter on learning disability, every volume has a chapter on deafness, and so on. This structure means that many themes—in how disabled people have been represented, and the material effects those representations have had, including prejudice, discrimination, and even attempts at extermination—can be traced across hundreds if not thousands of years.

Cultural Histories of Learning Disability

The study of the cultural history of learning disability is a relatively new phenomenon. The field has emerged and developed over the last 30 years or so. Much of the initial impetus came from "activist historians" working in collaboration with nondisabled academics to expose living conditions in the institutions in which they had been held and to contest official histories of those places, which they felt were sanitized and inaccurate. Until quite recently, learning disability history research was held to be the preserve of academics such as sociologists and medical historians, or simply neglected altogether (Atkinson & Walmsley, 2010). In the decades since the late twentieth century, activist historians and their allies have conducted their own research. Much of this has challenged the narratives created around learning disability by medics, scientists, and medical historians (Philo, 2014). Learning disability has also emerged as a field of inquiry

within its own right within disability studies, following recognition that it was often overlooked in both the Social Model and the later return to considering impairment effects (Goodley, 2001).

While investigating cultural histories of learning disability, researchers are not interested in what specific individuals or groups of people are or are not learning. Neither do they focus on any one individual's experience of disability. Instead, researchers examine and critique the roles learning disabilities play in culture. A cultural history of learning disability attends to discourses relevant to what we currently call learning disability, how these discourses reciprocally shape relationships between people and ideas, and how they structure opportunities for, and constraints on, action and agency (McDermott et al., 2006). A cultural history of learning disability history is thus concerned with the way people said to have—what we currently call—learning disabilities were thought about, spoken of, and related to, and how these behaviors and attitudes were shaped by the sociocultural environment in the period or moment in time subjected to analysis. For example, from the mid-nineteenth century until the end of World War II (WWII), medical, educational, legal, political, economic, scientific, and racialized discourses constructed the phenomenon of learning disability as we now recognize it. This created a "regime of truth" (Foucault, 1980; Simpson, 2018), which helped to establish eugenics as a mainstream politico-scientific movement in Great Britain, Europe, and the United States of America, until the world recoiled from the abomination of WWII Nazi genocide. This discourse has resurfaced recently in endeavors to screen out and hence eradicate people with learning disabilities through interventions like prenatal diagnosis (Altermark, 2018). What this example shows us—as does the cultural history of learning disability more broadly—is that although the roles learning disability plays in culture may shift somewhat over time, there are certain enduring features, which persist across decades, centuries, and millennia. Contrary to the rhetoric, which claims societies are becoming ever more understanding and inclusive, cultural history shows us that people with learning disabilities are *always* Other. They remain—in Western societies at least—the ultimate outgroup (Goodey, 2016).

Methods Commonly Used for Researching Cultural Histories of Disability

Henri-Jacques Stiker's seminal book *A History of Disability* (Stiker, 1999) employed several methods to analyze Western cultural responses to disability and how these responses relate to representations, systems of thought, and underlying sociopolitical structures. These methods range from close readings of myths and literary texts, to discussions of the etymology of disability terminology, to analyses of taxonomies of impairment, to examination of formulations of contemporary legislation (Kudlick, 2016). These methods and more are currently employed in cultural histories of learning disability. For example, etymology and taxonomy are closely related. Research in the cultural history of learning disability shows how such etymologies and taxonomies evolve over time. Etymologically, *idiot* comes from the Ancient Greek *idiotes*, meaning relating to an individual rather than the State. The related term *idiotikos* meant a private person, uneducated, and unskilled (Barnhart, 1988). Since in Ancient Greece education was the preserve of the privileged few, at that moment in history almost everybody would have been classed as an idiot—it was just another way of saying "ordinary person." By the early nineteenth century, the term had shifted its Anglophone meaning to refer to a minority rather than the majority; it referred to those people deemed to be lacking mental capacity to an extent that somehow marked them out as different to the rest of the population. Come the mid-nineteenth century its meaning had shifted again, as the emerging class of self-appointed medical experts co-opted the word *idiot* as a formal diagnosis. It became part of a taxonomy of the general phenomenon of *feeblemindedness* or *mental deficiency.* In the United Kingdom and the United States, *idiots* were regarded as less intelligent than, and hence

inferior to, *imbeciles*, who were themselves regarded as one rung down the ladder from people diagnosed as simply *feebleminded* (Royal Commission on the Care and Control of the Feeble-Minded, 1908). As new diagnostic labels have proliferated, the word *idiot* has been abandoned by the medical fraternity and is now used as an insult, most often regarded as quite a mild and harmless one. This pattern is common. Many words have evolved from being diagnostic labels for a learning disability to popular insults in everyday culture. This is true for *imbecile*, *moron*, *retard*, and *mong*, which derives from Mongolian Idiot—John Langdon Down's original name for what we now call Down Syndrome (Down, 1866)—and many others. The persistent repetition of this pattern highlights both our uncertainties over what to call those people we perceive as different to us, and the ongoing disavowal of people labelled with learning disabilities (Goodey, 2011).

Scholars continue to undertake close readings of literary texts to analyze the role of learning disability in culture. For example, Christopher McDonough's book *Idiocy-A Cultural History* (McDonagh, 2008) analyzes representations in works by William Wordsworth, Charles Dickens, Joseph Conrad, George Eliot, and many more. Methods not employed by Stiker but now in use include life-writing, autobiography, and storytelling. Rather than analyzing the writing of other writers, these methods often foreground the insider knowledges of people labelled with learning disabilities. For example, Richard Keagan-Bull's book *Don't Put Us Away* (Keagan-Bull, 2022) offers, as the title suggests, an autobiographical account which advocates against institutionalization and other forms of segregation, and for a more inclusive society. The work of the pioneering *Social History of Learning Disability* group (SHLD), based at The Open University in the United Kingdom, has been particularly influential in fostering and supporting the research of "activist historians": people with learning disabilities who use their research into history to advocate for change in the present. Notable scholars include Jan Walmsley and Dorothy Atkinson, who founded the Social History of Learning Disability group in 1994. Of particular significance is their research with Mabel Cooper, who may be regarded as one of the first activist historians. Mabel spent much of her life in a long-stay hospital. Upon release, she became Chair of the learning disability advocacy group Croydon People First and campaigner for learning-disabled people's rights and the closure of long-stay hospitals. The research she undertook with SHLD forms a considerable contribution to the cultural history of learning disability, with this contribution taking several forms including online resources in The Inclusive Archive and at the Open University, as well as a book, *Forgotten Lives* (Atkinson et al., 1997). The cultural importance of Mabel's life with a learning disability is evidenced by the fact that The Guardian newspaper published her obituary (Atkinson, 2013). The research she undertook and inspired was also a catalyst for subsequent projects, which used creative methods to interpret and present learning disability history—such as the short film *No Longer Shut Up*—as well as co-authored journal articles, written in collaboration between learning disabled people and nondisabled academics (Tilley et al., 2021). Creative methods are often regarded as more inclusive for people with learning disabilities and are used relatively frequently. A good example is storytelling, exemplified by the work of Openstorytellers, which includes drama productions and animations.

Yet other scholars have used more orthodox historical methods in producing cultural histories of learning disability. Excellent accounts that draw on documentary methods include Simon Jarrett's *Those They Called Idiots* (Jarrett, 2020), which analyzes evidence from courtrooms, joke books, slang dictionaries, cartoons, and so on to trace attitudes toward learning disability from 1700 to the present day, principally in the United Kingdom. James W. Trent's *Inventing the Feeble Mind* (Trent, 1994) analyzes public documents, private letters, investigative reports, and photographs to chart the discursive construction of learning disability in the United States from the mid-nineteenth century onward. Accounts of individual institutions, while rare, can also be illuminating. An example is Joe Alston's *The Royal Albert. Chronicles of an Era* (Alston, 1992).

This book combines official records with firsthand accounts to provide a detailed history of The Royal Albert Asylum for Idiots and Imbeciles of the Seven Northern Counties, which existed just outside Lancaster in the north of England from 1870 to 1996. Other less common methods include combining archival and participatory approaches to generate insights into the historical experience of learning disability and how it relates to the lived experience of learning disability today (Barden, 2021).

Current Themes and Issues in Cultural Histories of Disability

The most significant issue in the cultural history of learning disability is that of exclusion. It is common for disabled people, and especially people with learning disabilities, to be excluded from their own histories. There are three forms this exclusion takes. The first is where disability and disabled people are underrepresented or omitted from the historical record; issues of disability and disabled lives are hidden, disguised, or ignored. For example, great lengths were taken to conceal the fact that Franklin D. Roosevelt, 32nd President of the United States, was a wheelchair user because of childhood polio. Only very rarely was he photographed in this wheelchair (Berish, 2016). Secondly, a corollary of the truism that history is written by the victors is that histories tend to be written by nondisabled people. Disabled people are not usually the authors of recognized histories. As a result, emic knowledge and perspectives are excluded from our historical imagination. Thirdly, sociocultural and environment barriers mean that disabled people are excluded from being active researchers investigating their own histories, heritage, and things that matter to them. For example, the material in many archives is inaccessible. This is for a range of reasons including physical location and architecture; travel arrangements and costs; arcane cataloguing systems; staff attitudes and lack of training; and many more.

Where cultural histories of learning disability do exist, they illustrate shifting conceptions of learning disability and hence varying roles for learning disability within cultures. Stretching back to Antiquity, for example, there is evidence that the Meso-American Olmec culture worshipped children with Down Syndrome as divine beings, regarding them as the offspring of unions between women and their main totem, a jaguar deity (Milton & Gonzalo, 1974; Slorach, 2016). This is not a role we see today. In Europe in the Middle Ages and through the Enlightenment, people with learning disabilities might well have been regarded as different and perhaps somewhat lacking in mental faculties but essentially harmless. They may have been mocked but would have lived and participated in their communities (Jarrett, 2020). By the early nineteenth century, the current metanarrative of learning disability had begun to take shape. A metanarrative is the dominant story circulating in a culture about a given phenomenon. The metanarrative suppresses emic accounts and propagates stories derived from hegemonic discourses. It is a globalizing or totalizing cultural narrative schema, which claims authority of knowledge and experience. Over the last 200 years, the role learning disability plays in Western culture may appear to have shifted, from being an object of pity, sympathy, and Christian charity, to a menace requiring eradication, to a target for inclusion in education and society, yet certain stable features persist. Three tropes characterize the recent metanarrative of learning disability: that people with learning disabilities are vulnerable, unworthy of full personhood, and requiring control (Barden & Walden, 2021). Firstly, people with learning disabilities are cast as vulnerable: needing protection from the hazards of the physical world, from exploitation by unscrupulous others, and from harming themselves. This can be seen in the definitions given in the 1908 Royal Commission (Royal Commission on the Care and Control of the Feeble-Minded, 1908) through to current legislative and ethical frameworks (Snipstad, 2022). The second trope is dehumanization. People with learning disabilities are conceptualized as barely human (Carlson, 2023). This is evident in consistent comparisons—often unfavorable—with nonhuman animals in the historical record, including

in the work of Charles Darwin (Gelb, 2008). The harmful belief that people with learning disabilities are unworthy of education, opportunities, or even life has persisted throughout history. The Nazis labeled them as "useless eaters" to justify the Aktion T4 genocide. After the war, some children were wrongly considered ineducable. Many care homes, such as Willowbrook State School in the United States, Winterbourne View in England, and Muckamore Abbey in Northern Ireland, became sites of severe abuse and neglect. Even today, people with learning disabilities receive poorer health care, die prematurely at disproportionately high rates, and were treated as disposable during the COVID-19 pandemic (Arrieta, 2022; Barden et al., 2023; Bates et al., 2017; Care Quality Commission, 2022; Heslop et al., 2013; Inclusion London, 2021; LeDeR, 2017; Walmsley & Jarrett, 2019). The third trope of the metanarrative of learning disability is that people with learning disabilities need controlling. Paradoxically, this is justified both on the grounds that they are exceptionally vulnerable and on the grounds that they pose an unacceptable threat to nondisabled people. This trope has had the real, material effect of justifying the incarceration of people with learning disabilities in an archipelago of confinement (Spivakovsky, 2017) comprising penal, medical, and educational settings. Historically, these settings included asylums, madhouses, special schools, colonies, and hospitals. More recently, prisons, immigration and detention centers, and care homes have become nodes in this network. Within such institutions, people with learning disabilities have often been subject to coercive control through punishment as well as surgical and pharmacological interventions. In these settings, people with learning disabilities are frequently denied their rights and freedoms, often under the euphemistic guise of "care" (Altermark, 2018). These moves to control speak back to the other two tropes of vulnerability and unworthiness.

The historical record shows that, across time and cultures, people with what we now call learning disabilities have been variously portrayed as gods, animals, monsters, servants and slaves, and incapable noncitizens who tend to induce fear and anxiety in the nondisabled population (Haraway, 2013). The way that learning disability is characterized in a given culture at a particular time may be context-specific, but what seems to be universal is that people with learning disabilities are regarded as "other"; they are "them," not "us." Whatever the culture and era, people with learning disabilities remain the ultimate outgroup (Goodey, 2016).

Conclusion

Inevitably, the cultural history of learning disability is also the cultural history of intelligence. C. F. Goodey has charted this history extensively in *A History of Intelligence and 'Intellectual Disability': The Shaping of Psychology in Early Modern Europe* (Goodey, 2011). This history again illustrates that although what counts as intelligence changes over time, intelligence remains central to evaluations of a person's worth. It also shows that you cannot invoke intelligence without implicating its opposite or lack. Intelligence needs something to measure itself against. It is often forgotten, for example, that intelligence quotient tests are relative and not absolute measures of intelligence. When somebody takes an intelligence quotient test, the score they get is not an independent measure of their intelligence; it is a measure of their intelligence relative to the rest of the population. Thus, calling some people "intelligent" or "of average intelligence" means labelling others as "not intelligent" or "of below average intelligence," irrespective of what they are able to think, learn, and do. This is an illustration of the way learning disability and intelligence are mutually constitutive.

The cultural history of learning disability is also the cultural history of humanity. Conceptions of learning disability reciprocally shaped conceptions of what it means to be human. In this way, the cultural history of learning disability shows us that learning disability can be regarded as what the Canadian philosopher Ian Hacking called an *organising concept* (Hacking, 2004). Organizing concepts are those which radically transform our sense of what it means to be—or not to be—a person. Learning disability achieves this in

Western culture by providing the benchmark against, which normalcy is measured. People without learning disabilities are citizens, persons with full moral standing: they are human, and they are normal. People with learning disabilities are often denied the rights their citizenship should grant them, are often not regarded as worthy of full moral standing, and are perceived as not normal and so not fully human.

More positively, current research in the cultural history of learning disability indicates that there may be grounds for cautious optimism. The fight for recognition and civil standing instigated by the disability rights movement is producing some victories, for example, in the provision of Higher Education opportunities for people with learning disabilities in the Republic of Ireland. Collaborative partnerships and networks of researchers with and without learning disabilities are challenging the metanarrative through acknowledging, celebrating, and publishing the insider knowledges and perspectives that lives with learning disabilities bring. However, learning disability communities are often rather insular. While this itself a manifestation of the metanarrative, it highlights the ongoing mission of shifting attitudes outside learning disability spheres not only in other disability communities but also in culture more generally.

Cross-References

- ▶ Capital Punishment, Intellectual Disability, and the Courts in the United States
- ▶ Current Challenges in Addressing Intellectual Disability: Global Perspectives and Strategies
- ▶ Disability History
- ▶ Inclusive Education for Children with Intellectual Disability
- ▶ Intellectual Disability Rights: Implications for Research, Policy and Practice
- ▶ Intellectual Disability-Past, Present, and Future
- ▶ Representation of 'Disability' in Cultural Narratives
- ▶ Representations of Disability in Shakespearian drama
- ▶ Representations of Disability in the Frankenstein Narratives

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