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## The Construction of Disability through Historical and Modern Perspectives: Literature Review and Personal Reflections

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# The Construction of Disability through Historical and Modern Perspectives: Literature Review and Personal Reflections

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## **Introduction**

Disability Studies is a relatively new field that provides insight into many topics of relevance from a perspective that is too often overlooked. My interest in this area of study was peaked when I decided to research disability labeling in public schools and the various ways that labels can help and harm students of different backgrounds. During the course of this research, I began to recognize that the medical lens through which I (as a student of biology and psychology) had learned to examine disability was inadequate; but more importantly, I learned that there are and have always been many ways to understand and respond to disability.

Disability Studies explains disability as a cultural construct, similar to race or gender; and as the meaning of disability has varied over time and place, so has the disabled experience. As a future medical professional who plans to work with disabled individuals, I realized that expanding my research and investigating both historical and modern perspectives of disability would provide a more complete understanding of the current views, needs, and concerns of disabled individuals. Recognizing the many factors that have led us to our current state and continue to play a role in how we understand disability is an important step in identifying modern injustices and imagining and advocating for an alternative future.

This review is therefore intended to compile and synthesize recent literature pertaining to disability frameworks. By beginning with historical perspectives and moving in to modern ideas, I aim to create a map that identifies the various factors at play and also traces the development of themes that still influence our thinking today. Although several viewpoints on the same or similar topics may be presented, concepts that are of particular relevance to the thinking of medical professionals will be emphasized, and conclusions will be drawn regarding how the medical field might alter its frame of view to become more justice oriented. Finally, specific

connections will be made to my future field of study, Occupational Therapy, as I attempt to reconstruct problematic logics and explore alternative approaches to outdated understandings of disability.

### **Methodology of Review**

This literature review is intended to paint a broad picture of the past, present, and potential future lenses through which people view and interpret disability. The articles reviewed were chosen based on their ability to explain the various factors and themes that have contributed to the current state of Disability Studies, and in particular their relevance to the strengths and weaknesses of the medical model of disabilities. Articles are grouped chronologically, beginning with those that discuss historical perspectives and then examining current models. The final section includes personal reflection and discussion of topics pertaining specifically to the field of Occupational Therapy.

### **Historical Perspectives: Constructing Meaning**

#### *“Deaf and Dumb in Ancient Greece”*

This essay asserts that the medical perspective is useless when investigating disability in ancient societies. M. Lynn Rose attempts to bring the reader outside of the modern lens, to get a glimpse of what disability meant before interpretations were influenced by more recent scientific discoveries. The main difference described is that disability was not viewed as inherent to the individual, but often had an impact relationally. The author uses deafness as an example, explaining that this disability was viewed as a purely relational impairment; to the people of Ancient Greece, the ability to speak mattered far more than the degree of hearing loss. The

inability to communicate verbally was interpreted “not as a physical handicap but as an impairment of reasoning and basic intelligence”, separating the deaf and mute from the political and intellectual arena (21).

The major take away from this essay for the modern medical mind appears to be that today’s interpretation and treatment of disability has stripped away much of its social and cultural meaning. Viewing disabilities as physical phenomena that need to be fixed or changed denies the problems that those with disabilities face which stem from society, not from the disability itself.

*“Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century”*

In this essay, Lennard J. Davis investigates the construction of normalcy, arguing that “...the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (3). Even the word “normal” as we use it today did not enter the scene until the 1840s. Davis explains that the preceding concept was the ‘ideal’, which was a compilation of different parts of living models and therefore by definition did not exist (except within the realm of mythology). In ancient societies, there was no demand that people have bodies that conform to the ideal. The advent of statistics first brought about the concepts of ‘norm’ and ‘average’; in the 1830s Adolphe Quetelet realized that the “law of error” used by astronomers to calculate the positions of stars could be applied to measure human features. The ‘average man’ came to represent both a physical and a moral norm; thus the average became a new kind of ideal, while deviations became undesirable. Davis uses the phrase “tyranny of the norm” to describe how the ‘norm’ implies that the majority of the population must be a part of it - quite the departure from the previous concept of the ideal. He goes on to propose that statistics had ties to eugenics from its inception. For example, he connects the work

of Francis Galton to his cousin, Charles Darwin, by stating that together their theories laid the foundation for "...the idea of a perfectible body undergoing progressive improvement" (7).

Davis's work serves to remind the medical professional that even the concepts of 'norm' and 'average' by which we measure and compare people are relatively recent revelations; for many thousands of years, people existed uninfluenced by the "tyranny of the norm". The main contribution of his work is to tie in the potential harm that these concepts can do, especially by relating them to the uprising of eugenics, which will be explored further in later sections.

As shown by Figure 1, the ideas held by ancient societies regarding disability as a relational impairment logically flow into a transition from 'ideal' to 'norm' with the advent of statistics, resulting in the first construction of deviation as undesirable. Several other factors would soon come in to play that would reaffirm and expand this changing view of disability.

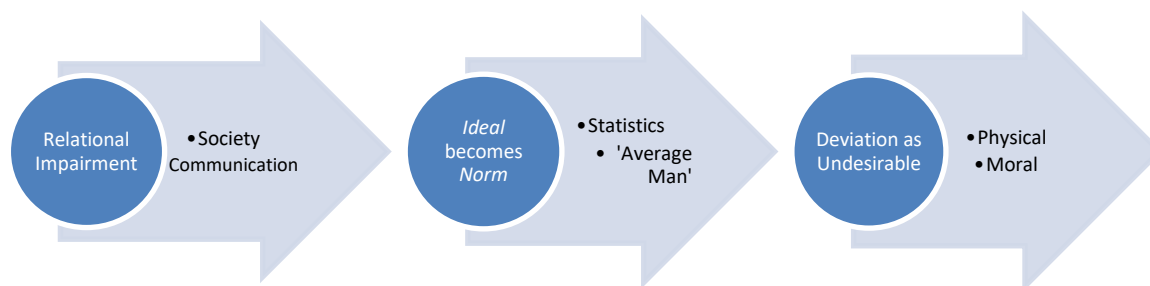


Figure 1. Changing interpretations of disability from ancient societies to the advent of statistics in the 1800s.

*“A Silent Exile on This Earth’: The Metaphorical Construction of Deafness in the Nineteenth Century”*

In this essay, Douglas Baynton again uses deafness as an example of how the meaning of disability is fluid over time. But rather than examine an ancient society as M. Lynn Rose does in

“Deaf and Dumb in Ancient Greece”, Baynton points out a more recent shift in meaning that occurred around the 1860s. He explains that before this time, deafness was characterized by isolation from the Christian community, and as a result sign language was widely used and accepted. But during the 1860s, the rising trend of “oralism” or lip reading declared that sign language led to isolation from the national community and that “...the use of sign language encouraged deaf people to associate principally with each other and to avoid the hard work of learning to communicate orally” (34). Thus promoting oral education was really a tool for assimilation; post-Civil War, national unity and social order were top priorities. Although oralism was widely discredited by research, its lasting effect was the removal of sign language from many classrooms. It is also important to note that although manualism (the use of sign language) appears quite obviously superior to oralism, both ideas originally constructed the deaf as outsiders who depended upon the hearing to “rescue them from exile” (35). However, the widespread use of sign language eventually gave deaf people a space to “...resist the meanings that hearing people attached to deafness, adopt them and put them to new uses, or create their own” (45).

This essay should serve as a reminder that the promise of medicine and technology should never be to “rescue” a person from their current state. This attitude serves to assign suffering where it may not exist, thereby creating new issues rather than solving existing ones. Instead, the opinions of the disabled need to be heard so that greater efforts can be focused on the problems that really matter.

*“Cultural Locations of Disability: Masquerades of Impairment (Chapter 1)”*

The first chapter of this powerful book begins by making a temporal distinction similar to the one Douglas Baynton makes in *“A Silent Exile on This Earth”*. While earlier generations saw

human differences from a religious perspective, the nineteenth century saw disability in terms of dependency and disservice to the nation. The authors add a new contributing factor to the causes of this switch: Charity. During this critical time period, disability became marked by its removal of the individual from the capitalist economy; simultaneously, charity was becoming less the responsibility of the community and more governed by private and government organizations. This new method of enforcing who was deserving of charity allowed for the rise of bodily classification and detection strategies used by medical authorities; thus we see the shift from religious to scientific interpretive frameworks being carried out. The authors call this entire shift the process of “cultural dislocation” (39). Those in need of charity came to be seen as pariahs; the authors explain that “charity in this period was transformed from a matter of paternal relations into a system in which those who received handouts increasingly found themselves punished for their need” (41).

It is quite interesting to consider that the changing way Western cultures viewed disability was not only due to the new age of scientific discovery. On the contrary, the shift involved many cultural components, including economics, religion, and politics. This chapter serves as a reminder of the many forces at play, and uses the enactment of charity as an example of the convergence of many factors that began to reshape the way people viewed disability.

*“A Social History of Disability in the Middle Ages: Cultural Considerations of Physical Impairment”*

Stepping back in time, this essay is included in order to expand upon the history of charity and explain what it meant in relation to disabled individuals before the dramatic changes of the nineteenth century. During the Middle Ages, the term ‘poverty’ referred not only to economic standing, but also to physical incapability resulting in a lack of social influence. ‘Poor’ was commonly contrasted not only with ‘rich’ but also with ‘powerful’ (155). Economic poverty



was combated by almsgiving, and hospitality towards the needy was considered an essential Christian duty. The poor person who received such charity was not marginalized from society, but was instead considered an integrated member; after all, it was believed that without the poor, no one could be forgiven his sins through acts of charity (156). However, the late Middle Ages saw the development of the first forms of institutionalized charity, and changing perceptions regarding who was deserving of alms began to challenge previous opinions about indiscriminate charity. Thus the stage was set for the massive shifts in framework that would take place during the nineteenth century.

*“Cultural Locations of Disability: Subnormal Nation (Chapter 2)”*

Concrete changes in laws and social structures soon appeared as evidence of the new opinions about disability that were taking shape. Laws were passed to ban vagrancy and begging, thereby linking disability to criminality. Simultaneously, the first hints of the eugenics mindset began to infiltrate thinking. Eugenics basically began as a “scientific” method of blaming social inequalities on human deficiency (69). Once again, many factors contributed to its uprise near the end of the nineteenth century; according to the text, “this change in the meaning of cognitive difference was informed by deep-seated economic and social pressures that fed an increasingly medicalized approach to problems plaguing newly urbanized locales” (70). Rather than an adaptation, variation quickly came to be viewed as an expression of the natural gone awry.

This chapter goes on to describe the many unfortunate impacts and outcomes of eugenics. Asylums became more like prisons than rehabilitative institutions; those marked with pathology suffered from stigma; IQ tests allowed for even more extensive classifications; immigration laws restricted the movement of the “deviant”; heredity became a diagnostic tool for labeling “an array of social Others” (74); and “defective” bodies were banished from view. Public institutions

no longer needed to consider accessibility issues, and the wider culture did not need to confront “the nature of human variation across communities” (91). An extremely important query for medical professionals is raised in this powerful statement: “The larger question at stake here is whether better diagnostic tools lead to identification of those who escaped classification previously, or whether diagnosis itself invents the prevalence of the object it purports to measure” (77-78). The authors challenge the faith that we place in Western medicine, asking the reader to consider the outcomes and effects of eugenics that still prevail within the current model.

*“Cultural Locations of Disability: The Eugenic Atlantic (Chapter 3)”*

In this chapter, the authors further discuss eugenics at the pinnacle of its terror: the Holocaust. They state that the slaughter of the disabled in Nazi Germany has only very recently been studied, and that it is possible to draw many “...parallels between race and disability as dehumanizing formations” during this time period (101). The fact that the disabled have been largely ignored in past studies of this era does not go unnoticed. The authors view this as continuing proof of Western ambivalence towards the value of disabled lives, even suggesting that if the Nazis had only attempted to exterminate the disabled and had not turned their focus to other minority groups, “...the imaginary line between ‘medical intervention’ and murder would not have been crossed” (102). When historians ignore disability in theories of racial eugenics, they reinforce the idea that race is the socially constructed location of insufficiency, while disability is the site of ‘real’ or ‘true’ human incapacity (111). Instead, the many factors that contributed to the social construction of racism can and should be applied to the construction of disability as well.

Therefore, the authors reject disability as a ‘material’ basis for inequality as opposed to the socially constructed platform of racism, instead proposing that both groups were suffering from the ever-narrowing continuum of human variation developed post-Enlightenment (112). Eugenics was particularly appealing because it consolidated this variation even further, categorizing all humans as normal or defective; this power of classification infiltrated many of the professions that still manage the disabled (medicine, therapy, charity, psychiatry, etc.). Although it is easy to dismiss the atrocities of eugenics as relics of the past, it is impossible to deny that classification is still widely used in the management of the disabled. It is important for those who hold such power to understand the historical context at play; medical professionals should seriously question the potential harm of binary logics and constantly question the necessity of classification in medicine and therapy. The ever-increasing number of diagnoses available in the Diagnostic and Statistical Manual of Mental Disorders is a perfect example of how our society has made the branding of human bodies with labels both common and necessary. While labels are generally regarded by those in the medical field simply as requirements for treatment, outside of the doctor’s office, labels can enact harm through agents such as societal stigma and removal from certain spaces.

Along with the development of deviation as an undesirable departure from the norm, Figure 2 demonstrates the flow of various factors that played a role in the major switch from religious to scientific perspectives. Many of these themes, which originally played into the rise of the eugenics mindset, still represent persistent problems facing disabled communities today.

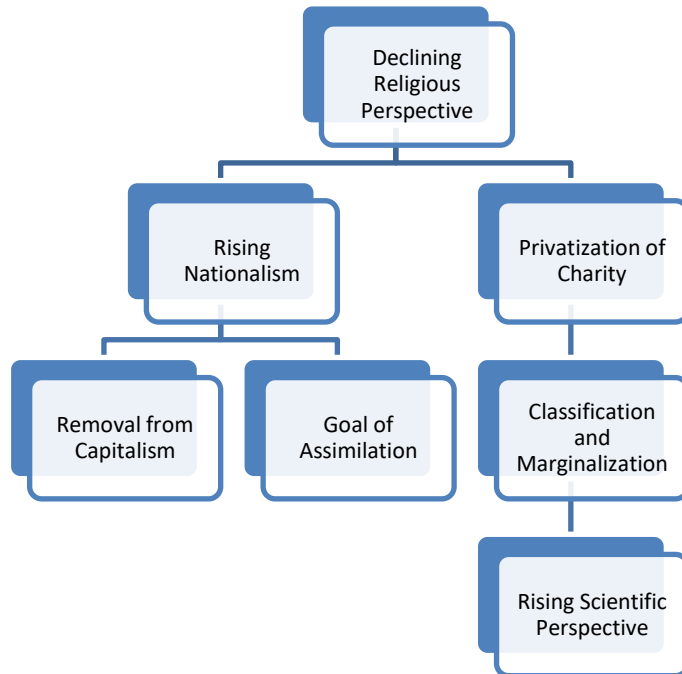


Figure 2. The construction of various factors that set up the eugenics mindset during the nineteenth century.

### *“The Other Arms Race”*

Post - World War II, issues surrounding disability surged to the forefront as disabled veterans returned home. This might have presented an ideal opportunity for America to reckon with its prejudices. Unfortunately, normative models of masculinity also took on great significance at this time as gender roles were challenged by women entering the workplace. Bioengineering and materials science breakthroughs allowed for prosthetics to be reimaged; however, new designs focused on returning the amputee to the ideal “normal, able-bodied workingman” (51). Propaganda campaigns idealized the disabled veteran who was able to “overcome” his situation by finding individual solutions; the main strategy of therapists at the time was to help the able-bodied “deal” with their biases rather than to empower the disabled.

This time period represents a massive missed opportunity where medical professionals could have used a better understanding of historical views of disability to avoid a repeat of past mistakes. Unfortunately, no large-scale efforts attempted to establish acceptance or redesign the social structures that made living with a visible disability so challenging for returning veterans. Therefore, the same themes that had already been developing regarding the idealized “norm”, the importance of contributing to a capitalist economy, deficit and individual tragedy, and societal stigma persisted into more modern times.

### **Modern Perspectives: Recurring Themes and New Challenges**

#### *“The Social Model of Disability”*

During the last few decades, people have rallied to challenge the oppression and exclusion of the disabled, often converging around a new ‘social model’ of disability which claims that “it is society which disables physically impaired people” (198). By this view, disability is actually in addition to physical impairments; the term is completely redefined. Because it is easily explained and identifies actual barriers to be removed, the model is effective politically and instrumentally; it has also built up a collective sense of identity among disabled people. However, some believe that the model ignores the importance of impairment by disregarding the medical approach; additionally, it is hard to distinguish impairment from social barriers in everyday practice. Removing every barrier is all but impossible as different disabilities often require opposing solutions. In order to adequately understand the complex interactions of the disabled individual and the environment, a more developed theory may be necessary.

While the social model of disability may not represent a comprehensive solution to every problematic societal belief surrounding disability, it does offer a valuable starting point which I believe medical professionals ought to become more familiar with. The social model is a valiant attempt to recognize and account for the complex historical factors discussed previously that have made and continue to make disabled life uniquely challenging. Its other great strength is its call to action, which demands societal change rather than reinstating old themes regarding assimilation and individual solutions. However, important questions still remain. Is it possible for the strengths of the social and medical models to interact or even work in harmony? What alternative theories have been developed to address the weaknesses of the social model?

*“What Disability Studies Has to Offer Medical Education”*

This article presents excellent ideas about why medical students should be educated in disability studies. G. Thomas Couser explains the medical model as only one of three paradigms that are prevalent currently; the other two are the symbolic and the social model (22). The symbolic paradigm, characteristic of traditional cultures, views disability as the product of a moral/spiritual condition; although widely discredited, this theme still appears in popular books and films. The medical paradigm may be more practical and useful to disabled individuals, but it has limits; Couser states that when science confronts something anomalous, it tends to fall back on the symbolic model and “reinscribe prejudicial tropes” (23). He brings up several historical examples of the harm done to disabled individuals by medicine in the past. Finally, Couser explains the social meta-paradigm which distinguishes impairment from disability and exposes the previous paradigms as “constructions of particular cultures or mindsets” (24).

However, the author does not subscribe to the idea that one must choose between models, or that one is empowering and the other oppressive. He suggests that the medical and social

models work complementarily, with a common goal and a mutual understanding between medical professionals that some individuals may favor one or the other. The article ends with an explanation of the “minority model”, a variant of the social model which suggests that atypical ways of being are both valid and valuable. This model can and should inform medical professionals who face issues where the medical and social models appear to collide, such as selective abortion and assisted suicide. Suffering should never be presumed in the absence of testimony, and many resources are suggested for the reader to listen to the words of disabled individuals themselves. When infused with empathy and understanding, the medical and social models have much to gain from working in harmony.

*“(Re)Writing the Genetic Body-Text: Disability, Textuality, and the Human Genome Project”*

One area of medicine that is typically viewed as contrasting with the social model is genome mapping. The general understanding tends to be that genome mapping aims to correct genetic errors; this would support a “construction of disability as textual error” (67). The ‘textual’ analogy, which appears frequently in the media, implies the existence of a ‘standardized’ body-text which is the goal or ideal when in fact the ‘consensus’ sequence is only a statistical generalization (69). Thinking back to Lennard J. Davis’s ideas about our conception of ‘normal’, here we find a modern example of how the ideal comes to be perceived as the norm. The idea that a ‘correct script’ exists is overly simplistic; however, the true nature of genes as integrated within a many-layered network of body-environment interactions is not popular with the general public or with organizations that fund research. Scientists may therefore be tempted to create a ‘spectre’ of disability to generate funding, once again reinforcing disability as a personal tragedy and a public burden (72). The main problem is therefore not the research, but the rhetoric that surrounds it.

Although it may not be as straightforward as the ‘genetic script’ explanation, the public promotion of a more accurate view of gene - environment interactions and genetic variability would be a powerful tool for progress in the realm of disability studies. Genetics should pave the way towards a new understanding of and appreciation for variation, which is in fact essential for the survival of a species. The idea that a single ‘correct script’ exists is not only factually inaccurate, it is also dangerously similar to the point of view that first led scientists to adopt eugenic practices. It is time to stop pretending that genetics research is a straightforward, black-and-white cure to disease and disability, and instead value the information for its ability to reveal that human beings are far more complex and varied than anyone could have imagined.

*“Universal Design and the Problem of ‘Post-Disability’ Ideology”*

The era of eugenics and the institutionalization of the disabled left in its wake a society unable to imagine public spaces hospitable to different bodies. This ongoing theme of disqualification was finally brought to light by the emergence of Disability Studies in the 1980s, and in particular by the development of the social model of disability (287). As previously stated, this theory critiques the medical model of disability by describing disability as experienced discrimination due to inaccessible environments. Eventually, theorists proposed that this model did not adequately “challenge the cultural logics of ableism” (288), and critical disability theory was developed out of Max Horkheimer’s critical social theory to emphasize the importance of treating disability as a valid and valuable way of being (Horkheimer, Davis, Shakespeare, and others). Author Aimi Hamraie uses the concept of universal design, also called accessible design, to illustrate the strengths and challenges of these two theories through a real-world application. Universal design describes a built environment that is usable and freely accessible to all, regardless of age, ability, or status (Mace, Goldsmith).



Early on, the movement for universal design (which began in the 1960s) focused exclusively on issues of exclusion without questioning why normalcy was of such value in the first place. Rehabilitation experts began to suggest the removal of architectural barriers, and although this removed some aspects of the presumed inherent defects of disabled bodies, it still situated disability as a problem to be eliminated (291). Thus, universal design appeared to be flawed similarly to the social model of disability. In 1990, the Americans with Disabilities Act (ADA) was passed to legally guarantee equal rights for the disabled. Unfortunately, at this point universal design began to depart from disability rights discourses because passage of the ADA was believed to mean that ableism had been adequately addressed. “Post-disability” ideologies emerged once more; however, just as race-neutral ideologies function to “hide racial inequality within new institutions”, post-disability theories only treat oppression as inconsequential and reinforce rehabilitation logics (296). Because of this, universal design did not develop to become more consistent with critical disability theory. Hamraie therefore challenges the reader to consider how universal design might be used to “...embrace, preserve, and celebrate disability, rather than promot[e] its elimination” (303). Universal design clearly illustrates the important difference between theories and solutions that attempt to normalize and those that manage to celebrate the value of difference.

*“Postmodernism: A Very Short Introduction”*

During the mid- to late-20<sup>th</sup> century, a large-scale departure from modernism began to take shape. Philosophers such as Michel Foucault, Jacques Derrida, Jean-François Lyotard and others greatly influenced the rising movement of postmodernism, which spanned fields such as the arts, philosophy, architecture, and criticism (6). This new “framework of ideas”, largely guided by reinterpretations of Marxism, first hit the U.S. in the form of post-war poststructuralist

theory; this philosophy replaced “ethical and individualist existentialism” with “far more skeptical and anti-humanist attitudes” (6-7). Postmodernism is by nature a challenging concept to grasp; in fact, theorists might even use intentionally obscure language to reinforce some of the main tenants of the theory, such as a defiance towards clarity and the desire to exist outside of any “consensual and cooperative framework” (9-10). However, the ideas that have emerged from postmodernist thinking have greatly influenced disability theory and are therefore important to analyze further.

The first important facet of postmodernism is philosopher Jean-Francois Lyotard’s emphasis upon the decline of “master narratives” and the maintenance of a skeptical attitude (13). In *La Condition Postmoderne* (Lyotard 1979, as cited in Butler 2002), Lyotard argues against metanarratives such as progressive emancipation through religion and theory or the triumph of science and knowledge (13). In general, metanarratives work by giving cultural practices legitimation and authority; Lyotard emphasizes skepticism towards such totalizing explanations, thereby placing postmodernists in alliance with the subordinated and marginalized who do not “fit’ into the larger stories” (13-15). Next, philosopher Jacques Derrida adds to postmodernism a “deconstructive attitude” through his writing about relativism in language. Deconstruction argues that “the relationship of language to reality is not given, or even reliable, since all language systems are inherently unreliable cultural constructs” (17). By this avenue of thought, social systems and human identities are constructed by language, and it simply does not make sense to claim that our constructions are the way that things “really are” (21). Finally, Michel Foucault’s analysis of the relationships between knowledge and power greatly impacted postmodernism. Foucault studied the history of law, prisons, and medicine to show how discourses can be designed to exclude and control; this occurs when a particular group pushes a

“normalizing” discourse and thereby brings into being a deviant “other” (46). Discourses formed by controlling individuals also permeate society, appearing more “natural” as they become more prevalent (47). Foucault uses this type of thinking to explain how sexism, racism, and imperialism create the subordinate identities of women, non-whites, homosexuals, and prisoners (46).

Postmodernism has historically run into difficulties in its attacks upon the objectivist claims of science. While scientists commonly view themselves as contributing to some common, unifying theory, postmodernists might argue that scientists do not *discover* reality so much as *construct* it and that their work cannot be considered objective or universally applicable (37-38). It is clear that the motivations for and consequences of scientific discovery can and should be criticized; what is less clear is whether the standards and tests themselves can be “independent of any political context” (39). Scientists have pointed out that postmodernist critics tend to misunderstand empirical claims and that their use of obscure language and metaphor leads to further misinterpretation (40). Thus, the author claims that postmodern criticism is much more successfully applied to ethical and social problems than to laws of evidence (43). I see the intersections between science and postmodernism as very important to disability theory and to the field of occupational therapy in particular; this idea will be discussed further in the section titled “Reconstructing the Field: Applications for Occupational Therapy”.

#### *“Mapping the Terrain”*

Authors Mairian Corker and Tom Shakespeare provide another perspective on the importance of the twenty-first century’s shift toward postmodernism for disability theory. The authors state that the individual and medical models of disability, characterized by deviance, personal tragedy, and deficit, are characteristic outcomes of modernity, which always reinforces

normalcy as its goal (2). While the social model of disability represents an initial challenge to modernity, the authors assert that, like the medical model, its goal of explaining disability universally “exclude[s] important dimensions of disabled people’s lives and of their knowledge” (15). Postmodernism is declared to be a second challenge to the logic of modernity. By targeting the very culture of the Enlightenment, postmodernity encourages a “shift from meta-narratives to local narratives and from general theories to pragmatic strategies” while emphasizing the limits, uncertainties, and incompleteness of knowledge (5).

In relation to the medical field, I believe a more widespread adoption of postmodernist thought would be extremely valuable. In practical terms, I believe this would mean less overarching diagnostics with universally applied treatments and more individualized assessment including input from the patient at every step. Current medical research is already beginning to adopt an individualized approach to disease treatment; the medical and therapeutic approach to disability should be no different. Additionally, a postmodernist appreciation for the uncertainties and incompleteness of knowledge is extremely valuable for those encountering disabled individuals. Every realm of the medical field has its limits and should not attempt to address problems outside the boundaries of its actual usefulness. These ideas will be explored further in later sections.

*“A Postmodern Disorder: Moral Encounters with Molecular Models of Disability”*

By examining the currently accepted ‘molecular model of disease’ in relation to postmodern thought, this essay synthesizes several important ideas regarding the interactions between healthcare and disability theory. Author Jackie Leach Scully explains that the molecular model, which aims to describe the entire disease process from genetics to pathology, represents the current version of the medical model meta-narrative (50). She also states that this

meta-narrative, grounded in modernist faith in reason and rationality to produce advancement, “runs directly counter to the post-modern trend in other areas of thought” (51). While postmodernism emphasizes a diversity of knowledges and subject standpoints and the construction and negotiation of meaning, biomedicine depends upon the promotion of a distinctive way of being, and no space is left to explore variation in terms other than deficit (53). The author suggests that, alternatively, the medical field should consciously restrict itself by acknowledging “that the area of medical relevance is limited, that only a subset of possible approaches is being used, and that many others, equally useful to the comprehension of disability, lie outside its boundaries” (55).

In practical terms, the restriction of medical relevance might mean that people being trained in a healthcare field should be made more aware of the variety of methods, approaches, and practices that exist and should learn to look for value in each one rather than asserting that their chosen field holds all the correct answers. If the medical field must rely so heavily on a very narrow construction of being, then it must be recognized that this construction cannot and should not be applied universally. But an important question still remains: Is it possible for medical practice to merge with postmodern thought, to allow for the existence of many kinds of bodies and many ways of being?

The various models presented throughout this section represent a snapshot of the modern lenses through which we view disability. After investigating the literature, it is clear that these models and the factors that shape them are in many ways intertwined; they influence, critique, add to, and challenge one another. Figure 3 represents my understanding of these complex interactions, which picks up where Figure 2 left off with the rise of the scientific / medical meta-narrative. While this map is only one of many possible representations and clearly does not

account for every possible factor and interaction addressed in the literature, it does aid in simplifying some of the major effects of the different models and in visualizing where postmodernism might fit into the larger picture.

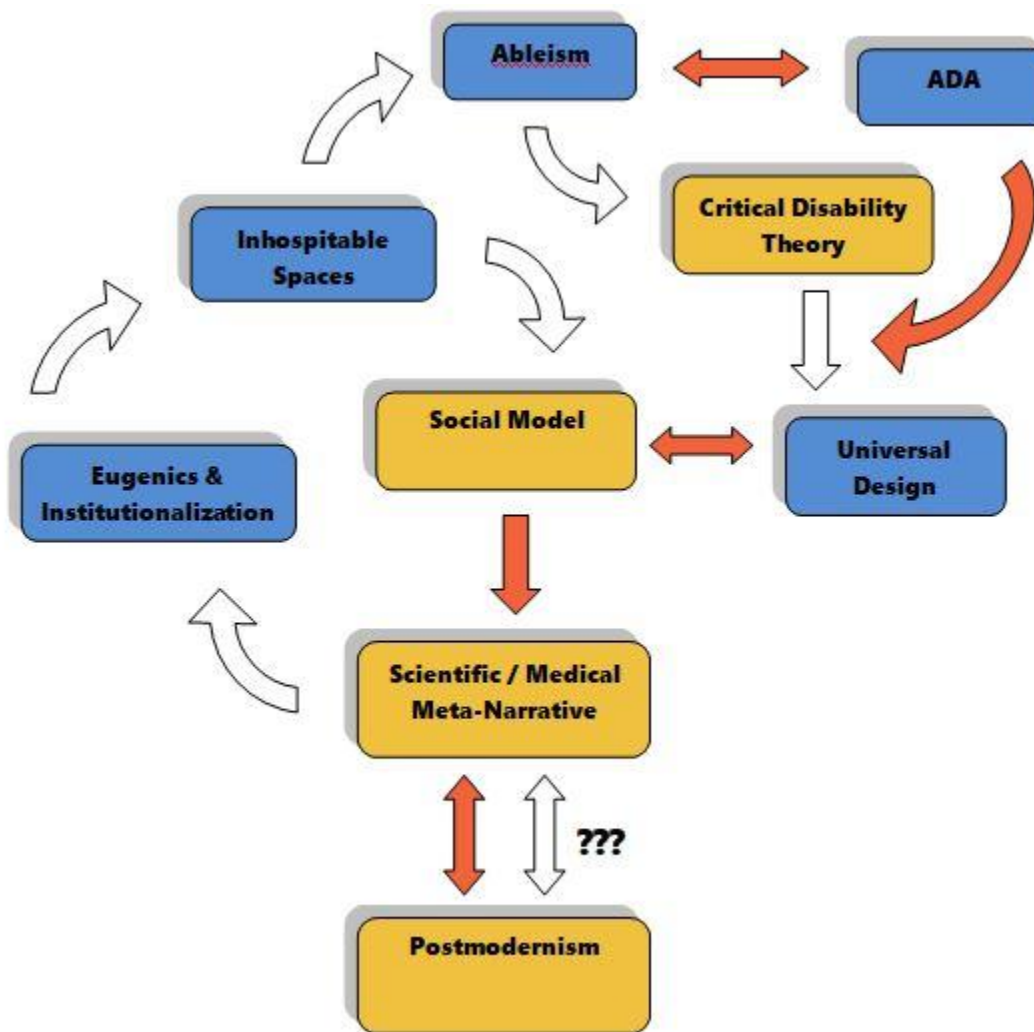


Figure 3. Interactions between and outcomes of some important modern models in Disability Theory.

## **Moving Forward: Finding Value in the Atypical**

*“Invisibilia: The Problem with the Solution”*

In the United States, we as a nation take great pride in our ability to tackle problems and put forward solutions. In just about every realm of life - including product design, politics, education, and technology - solutions are continuously presented as having the ability to transform agony into relief. In this fascinating podcast hosted by Hanna Rosin and Alix Spiegel for National Public Radio, the question is turned on its head as the hosts ask, “Can the American desire to find solutions ever become a problem?” In regards to solutions for mental illness, they propose that the answer is yes. As evidence, they juxtapose the current situation surrounding the treatment of and stigma towards mental illness in the U.S. with the very unique environment found in the Belgian city of Geel. For hundreds of years, the citizens of Geel have been welcoming mentally ill individuals into their homes, over time forming an unofficial foster care network that eventually came to be regulated by the local hospital. At its peak in the 1930s, one-fourth of the citizens of Geel were reported to have a mental illness. The foster families are not trained professionals, and the hosts suggest that Geel’s system is successful because its goal is not to change or fix the mentally ill “boarders”, but simply to welcome and accept them. Over time, all traces of stigma have vanished merely by means of exposure. As further evidence, the hosts discuss a U.S. study of males with schizophrenia. Upon returning home from rehabilitative institutions, individuals whose families expressed criticism, hostility, or ‘emotional over-involvement’ had a two to three times higher chance of relapsing. In other words, the family’s desire to fix the problem was doing just the opposite and was actually becoming a destructive force.

This podcast was included for review in order to juxtapose the complex theories and propositions of Disability Studies. With so many contributing voices, opinions, and concerns within the field, one may start to feel that reaching an alternative state is an all but impossible goal. The realization that in Belgium, a viable alternative has already existed for hundreds of years, comes as breath of fresh air. While the podcast hosts admit that replicating Geel in the U.S. might not be realistic, it is my opinion that Americans and healthcare professionals in particular need to become more familiar with the healing powers of acceptance. It sounds quite simple, but the concept of “healing without a cure” is in fact radically counter-cultural. Of course, I am not suggesting the complete abandonment of medical care for the disabled. The tension arises when the constant goal of care is to fix and change every atypical aspect of a person’s being, thereby implying that the person is not good the way they are. What we all need to develop is an understanding that there is value in difference and that not every “problem” demands a solution.

*“All in the Mind: The Art of Neurodiversity”*

Presented by BBC, this podcast episode aims to celebrate the diversity of human perception through the arts. Professor Jill Bennett, director of Australia’s National Institute for Experimental Arts, speaks about the concept of neurodiversity, stating that variations in the human genome can and should be understood as positive identities and that neurodiversity should be celebrated and accommodated similarly to cultural diversity. She also discusses her work studying empathy, stating that the associated mechanisms are naturally directed away from those we don’t identify with; therefore, in order to increase our capacity to encounter and enable difference, we need to enable the sharing of experience. Technology and the arts are two proposed methods of doing just that. One example is provided by Tom Middleditch, an autistic



writer and actor who now directs A\_tistic Theater Company. The company employs neurodiverse individuals and has created an actor training model for non-autistic actors to play autistic individuals; the goal of such training is to challenge assumed expectations and values and to create awareness and acceptance of 'atypical' behaviors. Several other artists are also interviewed, each one illustrating the ways that their art can reveal their individual neurodiverse experiences.

If the U.S. as a nation is to continue to move toward a less deficit - centric understanding of disability, platforms such as this podcast will be of vital importance. One unfortunate truth about our current state is that many large and powerful organizations claiming to help disabled communities still spread messages of fear and rejection in their conquests to find cures. For example, in the 'I Am Autism' campaign video presented by the advocacy organization Autism Speaks, autism is represented as a terrifying disorder that takes people captive and ruins lives. Autism Speaks is still one of the nation's largest non-profit organizations, despite the fact that many in the autistic community have expressed frustration at their methods and lack of inclusion of autistic individuals. The fact that such an organization still holds such enormous name recognition and fundraising power highlights the huge need for opportunities to reach people with a different message - one of positivity, inclusion, and celebration of neurodiverse talent. As explained by Professor Jill Bennett, empathy requires shared experience. And while every person can benefit from gaining empathy, training healthcare professionals without cultivating empathy for their patients is a definite recipe for disaster. It is easy to imagine how an actor training model or a virtual reality simulation might be used in the classroom to help students better understand the perspective of the disabled patient. This simple yet powerful idea might help

those in the healthcare field better distinguish what demands to be fixed from what ought to be celebrated.

### **Reconstructing the Field: Applications for Occupational Therapy**

When I first became interested in Disability Studies, my thinking was greatly influenced by the words of Angela Davis, who spoke at Western Washington University in May of 2017. During her speech, she asked the audience to consider the value of social justice movements that attempt to create spaces for marginalized groups within structures that were originally built upon foundations of exclusion ([www.ustream.tv](http://www.ustream.tv)). Why would marginalized and oppressed people groups even want to be a part of the very structures that marginalize and oppress them? Upon hearing these words, I was struck with the realization that this very principle underlies my chosen career in occupational therapy. One day soon, it will be my job to help disabled individuals better function within a society that was built in ignorance to their needs and without consideration of their opinions. I will be responsible for fitting those people branded ‘abnormal’ and ‘deviant’ into a society built by and for the able-bodied and able-minded. This realization truly challenged my belief in the field of occupational therapy as a type of medical practice that helps and respects the disabled person in every possible way. I therefore aimed to learn about various models of disability so that I would be better equipped to recognize and challenge any harmful logics that exist within the field of occupational therapy.

Throughout my research, I have come to recognize that the thought process that led me to this project was in many ways distinctly postmodernist. I had already confronted scientific thinking and the medical model as a problematic meta-narrative, questioning its assumed universal authority and asking, “What other perspectives exist? How might these various

perspectives interact? Can multiple approaches work together?”. I then embarked on a journey through literature and history where I encountered various models, the many factors that have influenced their development, and their implications for the medical field in general or for specific topics in medicine. My research eventually led me to develop a more thorough appreciation for postmodernism, but I was still left wondering how this new knowledge could apply specifically to occupational therapy. Attempting to reconcile my scientific background with postmodernism has been a challenging and fascinating exercise. Therefore, in this section I will further develop my ideas concerning problems in the field of occupational therapy and how these might be addressed with an awareness of postmodern thought. The question of whether medical practice can adapt to allow for many equally valuable ways of being truly highlights the difficult intersections of science, postmodernity, and disability theory.

To tackle this question, it is first important to understand what occupational therapy is and what it aims to accomplish. According to the American Occupational Therapy Association’s website, “Occupational therapy is the only profession that helps people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities (occupations). Occupational therapy practitioners enable people of all ages to live life to its fullest by helping them promote health, and prevent—or live better with—injury, illness, or disability” (aota.org). Additionally, the occupational therapy website for Eastern Washington University, where I hope to pursue my graduate studies, lists some specific tasks that occupational therapists might perform. These include “Adapt[ing] home, work, school and play environments; teach[ing] adapted techniques for greater independence in self care, home care and work performance; help[ing] people gain greater self-esteem and confidence through activities; and provid[ing] neuro-rehabilitation for return to productive lives” (ewu.edu). To the general reader, these

statements would likely appear to be constructive and positive. However, a closer inspection reveals the influence of some of the harmful logics that have contributed over time to our cultural construction of disability. Adopting a postmodernist mindset to analyze and rethink these problem areas turns out to be very informative.

Postmodernism first demands an acknowledgement of the power dynamics created through knowledge and discourse. My position as an occupational therapist, one of relatively few professionals with in-depth knowledge on what are considered by the medical community to be the best rehabilitation and treatment techniques, will grant me a certain power over the patients I interact with. The danger is in allowing this power granted by knowledge to translate into normalizing discourse. I see evidence of this problem already appearing when I read the statement, “Occupational therapy practitioners enable people of all ages to live life to its fullest” (aota.org). Even this simple sentence constructs the disabled as the ‘other’ in need of some form of normalization in order to experience fulfilling lives. The underlying discourse being promoted is still that old concept that disabled existence is inherently less valuable. Recognizing this power dynamic and the power of the discourse that I choose to engage in as an occupational therapist will help to steer me away from an insistence upon normalization. When I interact with patients, I hope to be able to remove myself from the prevailing discourse that there is a single “better” way to look, act, and be. I want to approach each patient with the mindset that their current way of being is just as valuable as any other, and that not every individual will desire an identical outcome. This also ties into EWU’s description of tasks that occupational therapists might perform. When it comes to adapting environments and teaching adapted techniques, I hope to open plenty of opportunity for dialogue with each patient regarding their unique goals. Two patients with very similar physical impairments could have very different values regarding what

constitutes achievement and the importance of independence. This should play a major role in my determination of the appropriate treatment route to take.

Another important aspect of postmodernism is its shift away from totalizing master narratives and emphasis upon maintaining a self-critical or skeptical attitude. Clearly, the discipline of occupational therapy is still largely informed by the grand narrative that promotes the triumph of science and reason; and although this narrative may not necessarily be in decline, I do believe that maintaining my own skepticism will be important. I will never be able to erase the scientifically-oriented and trained parts of my mind, nor do I wish to attempt to help people without validated research informing my technique. However, there are ways that I can escape from the deficit-informed, normalizing mindset that the scientific metanarrative promotes. Asking thoughtful questions such as, “Will this technique be more useful for certain patients than others? Why is this particular approach necessary and who will it benefit? What values am I promoting by accepting this practice as valid?” can help me to use scientific research to inform my best practices without falling into the dangerous assumption that research is always objective and universally applicable. Accepting and acknowledging the limits of knowledge will prevent me from imposing solutions that could actually do more harm than good. A second distinctly Western narrative is that of capitalism and the emphasis placed upon individual productivity. This narrative so dominates American culture that a life lacking physical productivity is hardly considered a life at all. This type of thinking is evident in EWU’s claim that neuro-rehabilitation will allow “for return to productive lives” (ewu.edu). This statement clearly implies that the productive life is the desirable and fulfilling life. In this regard, maintaining skepticism might mean allowing individuals to place value in non-material forms of productivity or even to build meaningful lives in the absence of productivity.

Finally, yet another key aspect of postmodern thought is the questionable relationship between language and reality and the ability of language to construct social systems and identities (Butler 21). If those wielding power truly do “talk people into being” (Butler 47), then my goal should be to maintain a hyperawareness of my own language and of the mistaken belief that language always corresponds to reality (especially to another person’s reality). In my interactions with patients, their family members, and coworkers, I should strive to eradicate language that implies deficit or assumes suffering. This might often mean listening far more than I speak, and it will certainly mean doing whatever I can to step in to the patient’s shoes and develop empathy towards their unique situation. As I pondered the statement that the occupational therapist’s goal is to “help people gain greater self-esteem and confidence through activities” (ewu.edu), I realized that all the great activities in the world would do nothing to address the root cause of those self-esteem struggles. It is the language of society that ostracizes, separates, and tears down “the other”. The disabled individual experiences disability only as we speak and construct it into being, making so many spaces inhospitable. Therefore, as a person aware of these truths, it will be my job to listen carefully to those who live out the disabled existence each day and to transfer their wisdom over to other environments where people are less conscious of these issues. Some might say that nothing will truly change until unjust systems are overturned and rebuilt. While this might be somewhat true, the postmodernist would argue in return that we cannot wait forever, and that the small changes made through everyday interactions are far better than no change at all.

## **Concluding Thoughts**

My journey to more fully understand the construction of disability has taken me through history and around the globe and has challenged many of the fundamental assumptions about the power of science and medicine that I used to cling to. Now that I have completed this project and have thought extensively about the various challenges facing disabled communities, I can see that the long-term value of my work will be in the way that my mind has been stretched so that I can no longer ignore injustice or sit by while harmful logics persist. I imagine myself passing on the skills I have gained to empower others and to develop and employ new strategies to break down barriers and confront ableism.

It has not escaped my notice that there is a rather ironic flaw in the design of this project. While I have tried to include literature and to learn from a wide variety of sources and voices, time and other constraints did not allow me to conduct interviews in order to include the opinions of local medical professionals or of people in my life who have experienced disability firsthand. It would be entirely counter to one of the main conclusions drawn from my study of postmodernism to say that I could possibly represent or speak for disabled communities or individuals; I understand that many of the conclusions I have drawn are not universally applicable. My future work will be to build from these initial conclusions, adapting and altering them to become more useful in various situations. Additionally, my hope is to eventually continue this research as I pursue my Master's degree by conducting interviews and seeking out intentional conversations with disabled individuals about these issues in order to continue to understand and respect the plurality of perspectives that exist in our world. This work has been incredibly challenging and meaningful, and I look forward to continuing this journey in the years to come.

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