Reframing (Dis)Ability: Representations of Impairment as Concept and Composition

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B efore my sabbatical, I had only encountered the basics of disability studies and disability theory. One of my very good friends had included disability theory in his dissertation, and we had discussed some of the concepts over the years. He said I'd be interested in it, based on my previous work with Michel Foucault and thinking about how bodies are classified and disciplined. The more that I heard about disability studies and looked into it, the more that I realized how important a topic it was and is becoming. I was not aware that there were already twenty years of scholarship in this field, which I was attempting to wrap my head around in sixteen weeks of research. And in some ways, my sabbatical would only begin to scratch the surface. Nonetheless, I put together my reading list and delved deeper into the two decades of existing scholarship. What follows are the highlights of some of the things that I discovered and that you might find most interesting. Here, I cover some of the concepts and theoretical frameworks that I came in contact with as well as brief examples of fiction and film that illustrate a few of the ways that disability can be represented.

Some of you may have already heard of disability studies. In a nutshell, it is an interdisciplinary approach to disability, and it considers disability a cultural identity and a political construct, not simply a medical condition. That is very important. My list in Figure 1 is by no means an exhaustive one, but, as seen here, this approach pulls from seemingly disparate groupings of disciplines at times.

Disability Studies

- History
- Sociology
- Medical field
- Ethics
- Politics and policy
- Philosophy
- Social Justice
- Literature, Film, and other arts

Figure 1. Many of the disciplines that make up Disability Studies.

At the beginning of my research, I became most interested in the larger cultural and institutional frameworks of disability. I came across the text *Disability Theory* by Tobin Siebers, published in 2008. I think one of the reasons why this is such a seminal work is because he braids together and helps unify many of those disparate perspectives and disciplines into one cohesive field. His work and others' also help to create a trajectory for the development of disability studies and, in particular, disability theory, which my discipline is most interested in regarding the analysis of fiction and film within those theoretical frameworks. I would recommend picking up this text in particular if you are interested in learning more about disability studies.

Another facet that I became interested in was the theoretical framework of the "medical model" of disability. Essentially, the medical model contradicts a "social model" of disability. I would like to share with you these competing models, which are two very different perspectives on disability in general. The medical model is a more traditional model of framing disability. The first tenant of this model claims that a person is rendered disabled by their "deficiencies" and/or "abnormalities" of *their* body or *their* mind. Moreover, the medical model of disability sees the disabled person as part of "the problem," the deficiency, and the locus of impairment. In keeping with that perspective, the medical model posits that these abnormalities need to be "fixed" or "cured" by the medical institution.

Second, this model assumes that a person with a disability needs caregivers, treatments, and decisions to be made for them about their care. This perspective paints those with impairments as passive patients, lacking agency or ability to make decisions for themselves and their health. Instead, they must follow the lead of the medical institution. In this way, perhaps, those with disabilities are portrayed as victims needing to be saved. The medical model's stance in this case is this: "We know what's best for you."

Third, those with disabilities are not considered "normal" or completely "able" by this model, yet they are still expected to adjust to and fit into mainstream society. If someone with impairments is, indeed, able to fit in and function in society, they might be seen as heroic or inspirational. If they cannot and if they are struggling, they might be ostracized or exiled. They maybe even be "institutionalized" and further removed from mainstream society.

Ultimately, according to the medical model, rising above and overcoming one's disability is required in order to be part of mainstream society and achieve full capacity as a human being. If not, then those with disabilities are only viewed as partial bodies or minds – incomplete. Again, it's the individual with the impairment that is imperfect, and that is the problem. The individual has the impairment, they are disabled, and, therefore, they need to be fixed or cured, and they need to find a way to fit into society.

On the other hand, according to the social model of disability, a person may happen to have an impairment, but it is their environment that disables them and is the problem, not their body or mind. This is a very different theoretical perspective from the medical model. To reiterate, according to the social model, it is not the person with an impairment that is the problem; instead, it is the environment, which disables the individual.

According to the social model, disability can be caused by existing physical barriers in one's environment. For example, there may be a lack of access to transportation, a lack of access into buildings, or issues for individuals negotiating spaces inside buildings. There may be an absence of Braille signage or closed captioning available for those who utilize it. There are also attitudes and social barriers such as stereotypes or stigmas that can also "disable" individuals. The social model asks that society adjust its own biases and physical barriers to provide needed accessibility and to accommodate those with impairments. This, too, is in contrast to the medical model that expects those with impairments to adjust to mainstream society.

Second, the social model, as well as other elements of disability theory, posits that disabled individuals are valid human beings and that we must ensure their equal rights and access to society *just as they are*. This message contrasts with the medical model, which conveys that impairments need to be fixed, removed, or cured. In addition, via the social model, individuals with impairments have a right to autonomy, choice, and informed consent in their own lives. Again, this opposes the idea of passive patients and disempowered victims produced by the medical model. I have read accounts of individuals with a range of impairments who state that they are happy just how they are. They do not see themselves as "abnormal"; they do not want or need to be "fixed."

Last, the social model conveys that the disabled person should be supported by society because they are an equal member of that society. They have a right to inclusion, which is also a social justice issue.

After reading the Siebers text and considering the two conflicting theoretical perspectives framing disability, I considered literary, cinematic, and other media representations of disability. I kept coming back to the idea of the medical model of disability and thinking about individuals who are seen as having physical or cognitive "abnormalities," how they might be depicted as the "Other," and also how those abnormalities could be viewed as needing to be cured or prevented. As a result, I immediately thought of Quasimodo from Victor Hugo's 1831 novel *Hunchback of Notre Dame*. In the novel and in some of the earlier film adaptations, Quasimodo has a disfigured face and a growth over one eye, making him partially blind. He has a limp and is infamously known for his kyphosis, often called a "hunchback." He is also mute, and he goes deaf because he rings the huge Cathedral bells that are so loud that they actually cause him to lose his hearing. Therefore, we have depictions of a character with a number of impairments

who is represented as something to be feared. In fact, he is considered to be so "abnormal" and even "evil" that he must be hidden away from mainstream society, forced to live in the Cathedral bell tower. Interestingly enough, in some of the earlier film adaptations, Quasimodo is also depicted as a sexual deviant, which plays out in his unhealthy lust for Esmerelda. When she doesn't return his advances, he torments the populace until, ultimately, a mob forms and kills him. In that representation, we have an individual with impairments depicted in numerous and extremely negative ways.

There is not a more sanitized version of this story than the Disney adaptation.[1] In that animated film, we still have an individual with a number of impairments, but he is not as feared as in the other adaptations. He is not seen as a physical threat, at least sexually. He is still viewed as physically abnormal, but there are some redeeming features of this character in this adaptation: he has a positive attitude, he is upbeat, he wants friends, he is gentle—all despite his disabilities. What I found to be interesting, and I'll touch on some more examples later on, is that two extremes of representation are set up here: extremely negative and almost extremely positive.

Compare Quasimodo, though, with our next representation of disability: Captain Hook, the archenemy of Peter Pan from the James Barrie play *Peter Pan; or, the Boy Who Wouldn't Grow Up* and subsequent book and film adaptations with that name.[2] Hook enjoys tormenting the children of Neverland and wants to kill Peter. What I find to be most significant about Captain Hook is the fact that his disability and his hook prosthesis precede his identity and physically mark him as evil and menacing. Applying the medical model, Hook's body is incomplete and abnormal as a result of his missing hand and his prosthetic hook. He is an evil man in his deeds, but he can be viewed as even more so due to his disability and prosthesis in these ways. Furthermore, in the film, he uses the prosthesis to appear all the more threatening by wielding it as a sharp weapon. Hook's name even reflects what the children in Neverland (and those reading or viewing at home) fear most about him.

One of my all-time favorite fictional characters remains Darth Vader from *Star Wars*.[3] I remember waiting in line with my father when I was four years old to see the first film. Darth Vader tries to coerce—spoiler alert—his son, Luke, to come over to the Dark Side. In this situation, we have another evil depiction of someone with a disability. Anakin Skywalker, who becomes Darth Vader after being severely disfigured and nearly killed by a lava flow during a lightsaber battle, is saved by being equipped with a number of mechanical processes, prosthetic legs and arms, as well as the iconic mask and the computerized system that regulates his biological functions.

In many ways, Darth Vader becomes more machine than man. Thus, he, too, is preceded by his disabilities and the prostheses he must rely on as a result. In fact, what he is most remembered by and what literally represents the character is his iconic mask. Even the breath that he takes is dependent upon the prosthetic mechanics that are now a part of his "body," producing the distinctive sound of his

mechanized breathing. Therefore, Vader, in somewhat similar ways, echoes Captain Hook in how their disabilities are at the forefront of their identities and make them appear even more menacing.

Conversely, Forrest Gump is a kind and even noble character. He sincerely loves Jenny, wants to take care of her, and always tries to do the right thing. Forrest overcomes a disability from childhood that required him to wear leg braces and prohibited him from running. With a near mythical recovery one day, which only Hollywood could deliver, he sheds his braces and, almost literally, never stops running for the remainder of his life. Despite overcoming that disability, he cannot outrun his mental impairment. The film never clearly articulates exactly what his impairment is, but it does not go unnoticed by some characters in the film, who refer to him as "slow" and "stupid." Despite how he is treated by some, Forrest is still kindhearted and does some impressive and even inspiring things in his lifetime. In some ways, he is depicted as quite heroic. In fact, Forrest saves Lieutenant Dan's life in the Vietnam War. On the battlefield, Lt. Dan's legs are injured, and Forrest rescues him. Despite Lt. Dan demanding to be left on the battlefield to die, Forrest carries him to safety. Lt. Dan survives but ends up losing his legs, and he is quite bitter and angry about it. He lives begrudgingly with his disability. In this way, the film juxtaposes how disability is experienced emotionally by the two characters as well as how it is experienced physically: one is born with a disability and overcomes it, the other is born able-bodied but later loses his legs and must depend greatly on a wheelchair.

Another representation of disability in a fictional work is from the film *Million Dollar Baby,* which is often described as a tragic story.[4] The film depicts a young woman who survives abject poverty as well as a difficult and abusive home life to have a promising career as a boxer. Another spoiler alert: Because of an accident in the ring, she becomes paralyzed and only has movement above her neck. Ultimately, she cannot accept having such an extreme impairment and tries to commit suicide. She bites her tongue over and over, trying to bleed to death. Her trainer decides to "help" her and "put her out of her misery." This is a tragic and very negative representation of disability. It's important to pause and ask a key question here: What is the message that is sent in this moment? It is better to be dead than to live with that disability.

The same message is conveyed in the film *Me Before You,* the story of a successful banker who, because of an accident, must utilize a wheelchair, having lost the use of his legs.[5] Ultimately, he seeks assisted suicide, echoing the earlier message that it may be better to be dead than to live with this impairment. These are very loaded representations, but we can see some of these themes repeating throughout a number of works.

These few examples provide some extremely negative and positive depictions of disability. We see instances of individuals with impairments who are depicted as scary or angry, like Captain Hook or Lieutenant Dan; individuals who are depicted as needy or who might be seen as victims, possibly, and

invoke our pity, like the Disney version of Quasimodo; and a depiction of a tragic, helpless victim in need of an end to her suffering, like in *Million Dollar Baby*. Conversely, we have also seen extremely positive examples of disability represented by those portrayed as heroic or inspirational, like Forrest Gump. This polarity is quite remarkable, and disability scholars have examined both.

One of the things that I have found noteworthy in that research, especially when considering the extreme positivity of some of those depictions, is the concept of the "Super Crip." The Super Crip trope or stereotype denotes an almost superhuman likeness or ability when depicting those with disabilities. J. S. Clogston, one of the early eminent disability scholars, stated, "The person with a disability is portrayed as 'superhuman' or as 'special' because they live *regular* lives 'in spite of their disability.'"[6] For instance, Clogston gives the example of a deaf high school student who plays softball. She is not just a good softball player; she is also always identified as and celebrated for being a *deaf* student who plays softball. Here, the idea of "triumphing over tragedy" comes into play, depicting the student with an impairment still being successful in playing a sport in spite of her disability. As a result, the Super Crip can be seen as inspiring, "special," or heroic by able-bodied and able-minded people.

Another concept from disability studies also applies here: "cripspiration." This term takes its prefix "crip" from the word "cripple," appropriating that term like in "Super Crip." And it also borrows from the term "inspiration," blending the two together. Phillipa Willitts states, "Cripspiration does nothing at all to advance the cause of disabled people. We do not exist to be living, breathing models of inspiration, and presenting us in this way is objectifying and reductive."[7]

Clogston further claimed that, by underscoring their "abnormalities," the role of the Super Crip reinforces the idea that people with disabilities are deviant, different, or special, also seen earlier in some of the film and literary examples. Moreover, the impaired person's accomplishments are considered amazing for someone who was less than "complete." Therefore, the student from the previous example is not just a good softball player, but, again, a student with an impairment, which makes her achievement playing softball seem even greater because she must overcome the disability to do so. The language used with images of para-athletes often includes words like "inspiring," "heroic," "resilient," "special," and "in spite of…." In Figures 2, 3, and 4 below, we see, in turn, athletes running with blades, a swimmer who is an amputee, and para-athletes playing wheelchair basketball, who might also be categorized in the same way – that "in spite of" missing appendages or being relegated to a wheelchair these athletes are "resilient" and can overcome their disabilities to complete at a high level and, therefore, can be seen as "heroic" and "inspiring."

Figure 2. Team Navy/Coast Guard member Lt. Daniel B. Cnossen runs the 800-meter during the second annual Warrior Games. 17 May 2011. Source: U.S. Navy photo by Mass Communication Specialist 1st Class Andre N. McIntyre as part of his official duties and, thus, is in the public domain.

Figure 3. Australian Paralympic team member Jay Dohnt at the 2012 Summer Paralympic Games in London. Source: Australian Paralympic Committee, is licensed under CC BY-ND, https://commons.wikimedia.org/wiki/File:060912_-_Jay_Dohnt_-_3b_-_2012_Summer_Paralympics_(02).JPG.

Figure 4. Sharon Slann, with the ball, in action for the Australian women's basketball team at the Barcelona 1992 Paralympic Games. Source: Australian Paralympic Committee, is licensed under CC BY-SA, https://commons.wikimedia.org/wiki/File:AUS-USA_women's_basketball_match,_1992_Paralympics.jpg.

Considering the Super Crip concept, especially in media where a person with disabilities is depicted as a "superhuman" overcoming challenges in spite of their disability, made me think of Christy Brown from the biopic *My Left Foot*.[8] An Irish writer and painter with cerebral palsy, Brown only had articulation of his left foot with the remainder of his body below his neck immovable. Yet he became quite well-known and lauded for his artwork and writing. Christy Brown, when viewed through the lens of the Super Crip, can be seen as superhuman because, in spite of his severe disability, he achieved greatness as a painter and writer. I think it's apparent from these examples just how the idea of the Super Crip can influence those who are able-bodied to potentially see individuals with impairments doing everyday activities as amazing and superhuman. In Brown's case, he may be considered even more superhuman and incredible in his achievements due to the adeptness of his work.

Similarly, we can see the Super Crip ideal applying to the character Arty from the television show "GLEE." He's not just someone with a beautiful voice; he has a beautiful voice despite his impairments that relegate him to a wheelchair.

Next, consider superhero characters in the Super Crip context (this is something that I want to dive into more in later research). Some superheroes have impairments or become impaired as a result of

their disability. For example, Daredevil is blind, but he has other hyper-sensitive senses that allow him to fight crime. So, quite literally, he is a Super Crip: despite his disability, he fights crime; he is seen as "superhuman" or, in other words, a superhero. The same applies to Cyborg, who my eight-year-old daughter, Rowan, introduced me to via the "Teen Titans Go" show. As I researched Cyborg more, I found that his backstory is quite interesting and applies to some of these theories. From what I understand, he was a very successful college athlete, which could set up that Super Crip dynamic even more. His father was a scientist; some of his home experiments had gone awry, leaving the young athlete maimed. Ultimately, his father fashioned mechanical prostheses for him to keep him alive. Similar to Darth Vader, Cyborg is made up more of machine and prosthetic parts than of his former biological and normative body. Cyborg becomes "superhuman," as a result not only overcoming his disabilities but doing so with enhanced abilities due to his prostheses, again symbolizing or personifying the Super Crip.

In all, these were some of the highlights, concepts, and applications of disability theory that I thought you would find most interesting from my sabbatical research. As a result of my work, I presented a paper at the American Comparative Literature Association's annual meeting last spring titled "Morbid Specimens: Creating Cathartic Bodies in Alasdair Gray's *Poor Things*." The novel *Poor Things,* on which I also taught a course this year, is a fascinating reworking of Mary Shelley's *Frankenstein* and a nice platform for introducing students to disability theories in the future.[9] I also began working on bringing disability concepts into other existing courses. In my course Boys Will be Boys: Masculinities in Fiction, we watched *Murderball,* a documentary about the U.S. para-rugby team that was competing for the World Cup in 2005.[10] We had some great discussions about the intersections of masculinity and disability as a result.

For future teaching, one of the things that I want to concentrate on is researching and incorporating more cognitive and "hidden disability" topics since my focus has been primarily on physical impairments and thinking about "normality." Other ideas that I would like to continue looking at are intersectional identities and thinking about disability with regard to race, gender, class, and sexuality, along with disability as "Other," and juxtaposing disability to the standard white, straight, able-bodied, male archetype.

To end, one of the most remarkable concepts that I came across regarding disability is that able-bodiedness is a *temporary* identity at best; it's not fixed. In fact, it's much less stable than other identities. If we live long enough, we will all most likely experience some form of impairment.

NOTES

1.   *The Hunchback of Notre Dame*, directed by Gary Trousdale and Kirk Wise, performances by Demi Moore, Jason Alexander, Mary Kay Bergman, and Tom Hulce (Walt Disney Pictures, 1996).

2.   *Peter Pan*, directed by Clyde Geronimi, Wilfred Jackson, Hamilton Luske, and Jack Kinney, performances by Bobby Driscoll, Kathryn Beaumont, and Hans Conried (Walt Disney Productions, 1953); R. H. Disney, *Walt Disney's Peter Pan.* Little Golden Book (1952; New York: Penguin Random House, 2007.

3.   *Star Wars: Episode IV—A New Hope*, directed by George Lucas, performances by Mark Hamill, Harrison Ford, and Carrie Fisher (Lucasfilm and Twentieth Century Fox, 1977).

4.   *Million Dollar Baby*, directed by Clint Eastwood, performances by Hilary Swank, Clint Eastwood, and Morgan Freeman (Warner Brothers, 2004).

5.   *Me Before You,* directed by Thea Sharrock, performances by Emilia Clarke and Sam Claflin (Warner Brothers, 2016).

6.   J. S. Clogston, "Changes in Coverage Patterns of Disability Issues in Three Major American Newspapers, 1976-1991" (paper, Annual conference of the Association of Education in Journalism and Mass Communication, Kansas City, MO, August 1993).

7.   Phillipa Willitts, "Bad Attitudes Do Not Cause Disability Any More Than Good Attitudes Guarantee Health," *The Independent* (London), August 1, 2012.

8.   *My Left Foot*, directed by Jim Sheridan, performances by Daniel Day-Lewis, Brenda Fricker, and Alison Whelan (Ferndale Films, 1989).

9.   Alasdair Gray, *Poor Things* (Champaign, IL: Dalkey Archive Press, 2002).

10. *Murderball*, directed by Henry Alex Rubin and Dana Adam Shapiro, performances by Joe Soares, Keith Cavill, and Mark Zupan, Paramount Pictures, 2005.