This is a story about disability narratives. This is a story about stories. Stories cannot be separated from those who tell them and from those about whom they tell. This is a story about people with disabilities fighting to control their narratives. This is a story about people with disabilities being controlled by their narratives. ‘The personal is the political’ is the narrative. This story is not a narrative. There is no narrator.

People with disabilities are rarely strangers to pity. This pity takes many forms. It manifests itself as expressions of condolences for impairment, platitudes about future cures, or patronizing gestures of assistance. However protean the creature of pity may be, its propensity to be conjured in response to disability is a reaction to one fundamental idea: Disability is tragic and inconsistent with a meaningful quality of life. Disability scholar Rosemarie Garland-Thomson states this well in her New York Times editorial “Becoming Disabled.” For most people, she observes, those with disabilities “merely seem to be people to whom something unfortunate has happened, for whom something has gone terribly wrong. The one thing that most people do know about being disabled is that they don’t want to be that” (Garland-Thomson).

With such a bleak public image, it is no wonder that people with disabilities have endeavored to assert their collective and individual identities as people who are, contrary to popular belief, capable of living fulfilling and successful lives. Often, and especially historically, individuals been able to do this by distancing themselves from their impairments and adopting an overcoming narrative. They flout the ways in which their disability is less significant than it appears to be, and emphasize the ways in which they have achieved despite their disability. These narratives value qualities such as independence, intellect despite physical disability, and
athletic ability *despite* intellectual disability. This genre also includes narratives of miraculous cures and tenacious recoveries. The message of the overcoming narrative is that those with disabilities can succeed by distancing themselves from their disability.

*Disability is equivalent to dependance. Disability is a burden to society.*

*Overcoming disability means being independent. Succeeding means overcoming disability. Asking for help means not succeeding. I am not the narrator, there is no narrator. You wonder why I don’t ask for help when it seems to inconvenience me not to.*

*It is because smartness and disability are inconsistent. Smartness means overcoming. I have been patronized before. I have been doubted. I need to prove my smartness first.*

*Even being steeped in the social model of disability, I cannot fully let go of the overcoming narrative.*

The overcoming narrative gives people with disabilities a framework through which to display competence despite their disability. Asserting competence, however, is a much more tiresome task outside the carefully manicured sentences of a novel or speech. The person with a disability who is conditioned to enact the overcoming narrative must weigh the advantage of soliciting accommodation over the disadvantage of admitting the effect of their disability. Trial lawyer Carol Steinberg summarizes this conundrum in her New York Times opinion piece “Standing Up for What I Need.” She describes the discomfort she felt when first receiving accommodation in the courtroom. “The judge agreed before the jury came in that I could violate protocol and remain seated while I addressed her and them during the trial. But when she later told the jury that I had difficulty standing because of a health condition, I was embarrassed. After that, I tried not to draw attention to my needs in the courtroom” (Steinberg). Steinberg felt that publically receiving accommodation was harmful to her image as a competent lawyer (nevermind that content of one’s argument is not diminished when sitting rather than standing).
‘I don’t like being helped, but obviously I don’t like bumping into things either.’

‘Which do you dislike more?’ ‘Being helped.’ ‘Okay.’ That is not completely true, help is fine as long as you are not seen as helpless.

The overcoming narrative goes hand in hand with the idea of the ‘good disabled person,’ a person with a disability who is not dependant on others despite their disability. Georgina Kleege describes, in her memoir “Sight Unseen,” why she was for a long time reluctant to use the word ‘blind’ to describe her visual impairment. “The blind beggar stand alones. As long as we can manage, we keep our distance, both because he makes such a displeasing spectacle, and because we know the consequences of claiming identity with him” (Kleege). It is not so much that Steinberg elects to adopt an overcoming narrative, but rather that it is the tool that is available to her to squelch the notion that her physical impairment is tantamount to weakness, especially in the context of a profession that places much stake in presentations of confidence.

Perhaps the most notable instance of the overcoming narrative being necessary for success is that of Franklin Delano Roosevelt. Roosevelt went to great lengths to downplay the extent of his physical impairments during his presidency. The public was alright with a physically disabled president, as long as they didn’t have to see it. It takes little speculation to imagine that people felt that Roosevelt had achieved despite his disability, and that it was this overcoming of his disability that qualified him to act as a world leader. The utility of the overcoming narrative relies on the fact that it is ubiquitously recognizable. It exists naturally, maybe innately, outside of the realm of disability and those who think about disability. Disability is a problem, and problems can be overcome. Those with disabilities can move towards success by moving away from disability.

The relatively recent emergence of Disability Studies as an academic discipline and the corresponding social ideas of disability identity and disability pride have endeavored to permute
disability from a physical problem to be overcome to an entity that is primarily socially constructed. The field of disability studies rests on distinctions between the social and medical models of disability. The former views disability as a function of the way our society is constructed, and tends to focus more on accessibility, discrimination, and exclusion. The latter views disability as a question of physical and/or mental differences and tends to focus more on ideas of cure, treatment, and overcoming limitations. In relation to this dichotomy, the word *impairment* refers to a physical or mental difference, while the word *disability* refers to the ways in which one's impairments affect the way in which they function in society. For example, an impairment might be a neuromuscular difference that requires someone to use a wheelchair for mobility, while disability would be the fact that there is not a ramp by which they can easily enter their local store.

The social model says that disability is identity. The social model says that disability is pride. Society doesn’t understand disability. Disability is not defect. The disabled person is not defective. Society needs to be cured. Disability is good. Society got it wrong. Disability is not bad. Everybody got it wrong. Spread the word. Impairment is not bad.

Georgina Kleege discusses how the writing of ‘Sight Unseen’ allowed her to claim a disability identity, saying that writing the book “made [her] blind.” In an illustration of this newfound comfort in her impairment, she describes how she would have liked to respond to a man who reacts with pity upon finding out that she is a legally blind writer. “This is not a tragedy. This is merely a fact of my life. Get over it. I have” (Kleege). Kleege is able to neutralize the concept of disability in her memoir by revealing to the reader the ways in which disability is socially constructed. She tells the reader that visual impairment is not as troublesome as popular conception imagines. “This really isn’t as terrible as you were always led to believe. You
can make a list of things that are impossible to do with your eyes closed, but the list is not very long. And with a little more thought and perhaps some organizational tricks, you can take care of yourself and even others.” Narratives such as Kleege’s promote the idea that it is not impairment which is the problem, but rather the way in which society reacts to it.

**Disability is good and I am not the narrator. There is no narrator. I cannot be limited by impairment. I can only be limited by society. This defends me against presumptions of incompetence. I can ask for help. If I ask for help I am imagining a more ideal society. I am imagining a better society. Impairment is not alienation. Disability is alienation. Impairment is neutral. Impairment is good. Impairment is not bad. I can’t talk about impairment with anything other than pride. Then you won’t believe me. Then you will pity me. Then you will say that disability is incompetence. Then you will pity people with disabilities. Then you are superior, then I am inferior, then… Impairment is neutral. Impairment is biological difference. Society disables us.**

The disability identity narrative has political, in addition to personal utility. When people with disabilities are seen as a legitimate minority that experiences discrimination, then charity campaigns can be replaced by rights movements. In lawyer and activist Harriet McBryde Johnson’s memoir “Too Late to Die Young," she ardently promotes the idea that people with disabilities have just as fulfilling lives as their non-disabled counterparts. Throughout the book, she reacts with righteous indignation whenever she encounters inaccessible situations. She, in part because her disability is very visible, does not try to downplay her impairments. Her disability is not inconsistent with, but rather integrated with her identity as a professional woman.

Johnson rejects the overcoming narrative in favor of a disability identity narrative. She has to work to assert this social model narrative because it requires convincing the reader that disability is not terrible. This is perhaps most apparent in the chapter in which she describes her
public conversation with philosopher Peter Singer, the consequences of whose theories on personhood are that infanticide is morally justified for infants with severe disabilities. She addresses, in this chapter, the belief that people with disabilities are ‘worse off.’ “Are we “worse off”? I don’t think so. Not in any meaningful sense. There are too many variables...We take constraints that no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own. We have something the world needs” (Johnson).

The organization, Not Dead Yet, that Johnson was arguing on behalf of is an organization that, as stated in their mission statement, “opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill, and disabled people” and “demands equal protection of the law for the targets of so called ‘mercy killing’ whose lives are seen as worth-less.” Johnson and activists at Not Dead Yet are arguing for their lives, so there is not a lot of room for nuance. In the pursuit of exposing the reader to the social model of disability, Kleege and Johnson have to craft their narrative as unwavering defenses of the idea that it is disabled and not impairment, societal rather than medical factors, that cause disability. Any obstruction could be eliminated if society would only embrace the idea that people with disabilities are oppressed by the existing structures.

Narratives based in the social model of disability often make a stark distinction between disability and impairment. By virtue of having to overhaul society’s conceptions of disability, the pity and the overcoming narrative, they do not leave room for the narrator to express vulnerability. It is as if even a momentary admission that impairment could be troublesome or that the author might consider mitigating their disability if given the opportunity would invalidate the narrative and the entire social model of disability. The enforcement of the binary between
disability and impairment, while essential in changing widespread perceptions of people with disabilities, is incomplete when it comes to individual disability identity.

Educational psychologists Anastasiou and Kauffman comment on the consequences of enforcing the dichotomy between disability and impairment and assert that “people will benefit most by recognizing both the biological and social dimensions of disability.” (Anastasiou and Kauffman) They argue that a theoretical perspective that ignores the biological aspects of disability removes the theory from its relevance to real human beings. Such a theory “allows proponents of a social model to give to their theoretical constructs complete autonomy, to argue as if people were empty of biological features.” The authors mention the idea of disability as predicament. Still consistent with the social model of disability, predicament seems to be the acknowledgment that disability comes with objective functional limitations and, depending on the disability, pain and discomfort. The authors reference a paper by Shakespeare and Watson who, in illustrating the shortcomings of a fully social model of disability point out, “Most activists concede that behind closed doors they talk about aches and pains and urinary tract infections, even while they deny any relevance of the body while they are out campaigning. Yet this inconsistency is surely wrong: if the rhetoric says one thing, while everyone behaves privately in a more complex way, then perhaps it is time to re-examine the rhetoric and speak more honestly (Shakespeare and Watson).

One could go further than these authors do and argue that not only does a sharp separation between disability and impairment removes the social model of disability from reality, but also that it is actively harmful to people with disabilities. The social model of disability has many benefits for individuals. Adopting the social model narrative give people a defense against pity and discrimination by enabling them to locate disability in society rather than in the individual. This is in many ways better for the individual than the overcoming narrative, in that
they now have a narrative through which to embrace, or at least to not have to reject, their disability. Disability is no longer antithetical to success, and it is no longer necessary to downplay the signs of impairment. If society changed, disability would no longer exist and impairment would simply be another form of diversity. Adopting this narrative, however, forces people with disabilities to be selective in what features of disability they are allowed to discuss. Expressing pain, insecurity, or feelings of limitation in relation to impairment contradicts the narrative that society, not bodies, are the locus of disability.

Eli Clare’s narrative ‘Exile and Pride’ shows that a more nuanced version of the social model can be integrated into personal narrative. Clare’s narrative is notable in the ways in which it allows for nuance. His narrative is grounded in the social model of disability and in (intersectional) disability identity, but is able to resist the tendency of the social model narrative to squelch vulnerability surrounding impairment. In his chapter entitled “The Mountain,” Clare explicitly acknowledges the artificiality of the separation between disability and impairment. “On good days, I can separate the anger I turn inward at my body from the anger that needs to be turned outward, directed at the daily ableist shit. But there is nothing simple or neat about kindling the latter while transforming the former. I decided that [separating impairment and disability] makes theoretical and political sense but misses important emotional realities” (Clare).

Clare’s discussion of disability and impairment does something that is unusual for a social model narrative when it recounts a scenario in which he prevented from doing something by his impairment - he recounts a hiking trip during which he was forced to turn back before reaching the summit of the mountain. Even while admitting that he has felt disappointment and embarrassment as a result of impairment, he is still able to take pride in his disability, and this admission of vulnerability surrounding impairment does not diminish his pride or force him to ‘overcome’ his disability. He envisions a world not in which the effects of impairment as
eliminated by the restructuring of society, but rather one in which impairments are understood differently. ‘Post-revolution I expect there will still be literal mountains I want to climb and can’t, but I will be able to say without doubt, without hesitation, “Let’s turn around here. This one is too steep, too slippery for my feet.”’ Perhaps, following in the example of Clare, the social model narrative can evolve to give people with disabilities a more nuanced tool for counteracting the notion that disability is inferior to ability.

Narratives are not reality. Reality gives a template for narratives. Narratives give a template for reality. We recognize reality through narratives. Reality cannot be purged of nuance. Narratives mimic nuance. A nuanced narrative is to reality as an intricate painting is to a landscape. Narrative is not reality. Narrative has an agenda. Reality has no agenda. This is not a narrative. If this is a narrative, then I am the narrator. I am the narrator.

Works Cited:


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