

NOTHING ABOUT US: THREE MODELS OF DISABILITY IN THREE WORKS OF
LITERARY FICTION

By

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ABSTRACT

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This project explores how the three umbrella models of disability (medical, functional, and social) are shown in several disabled characters from three novels published after the passage of the Americans With Disabilities Act: *Parable of the Sower* by Octavia Butler, *The Fault in Our Stars* by John Green, and *Good Kings, Bad Kings* by Susan Nussbaum. Through the utilization of literary analysis from a cultural studies perspective, this project shows that the models of disability, despite the various flaws in their respective designs, prove to be useful lenses to see disability through, both in these novels and in real life, to help further its mainstream understanding, at least on a basic level. My goal is to make these ways of seeing more accessible to those not well-versed in the field of disability studies.

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TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iii
INTRODUCTION	1
Key Terms and their Implications.....	6
Defining Disabilities Specific to the Three Novels	14
Genres of Disability Literature	15
LITERATURE REVIEW	17
METHODS	30
THE FAULT IN OUR STARS AND OTHER TROPES.....	34
Young Adult Literature and Sick Lit	34
Plot Summary of the Fault in our Stars.....	34
YA Sick-Lit Genre Analysis.....	36
Analysis of Medical Model.....	41
Tonguebreaker	43
PARABLE OF THE SOWER AND WHAT IT MEANS TO BE VISIBLE	50
Parable of the Sower Summary and Hyperempathy	50

Hypermpathy and the Models of Disability	56
“God Is Change”	64
GOOD KINGS, BAD KINGS, AND WHO HAS THE POWER	73
The Nursing Home Industrial Complex.....	73
“Emphasis on ‘Ill’”	77
An Embodied Notion of Disability and Power/Knowledge	83
CONCLUSION.....	93
REFERENCES	103

INTRODUCTION

There are estimated to be at least seven billion total people in the entire world, with the number only going up, and it is further estimated by the World Health Organization that at least 1.3 billion of those people are disabled, or about sixteen percent of the global population and possibly more. Disability is, according to researchers Shaun Grech and Karen Soldatic, “one of the most significant and ever-present human conditions in human history, transcending space, time and geopolitics, while cross-cutting the confines of the discursive and the material” (2). Despite the wide prevalence of disability and disabled people throughout the world, representation of disabled people in all forms of media is and has been sorely lacking on both a local and a global scale. In the last few years leading up to the publication of this research project, there have been pushes for diversity in storytelling, and there have since been fluctuating increases and decreases in the number of stories across mediums featuring women (both white and nonwhite), nonwhite people, queer people of all genders and sexualities, non-Americans, and disabled people, not to mention plenty of intersecting identities across the board. Content, stories and other works of art created by people of marginalized identities and backgrounds that are about the communities and groups they come from and represent, sometimes called “own voices,” have also seen varying increases in output along with increased critical and commercial recognition. The Cooperative Children’s Book Center at the University of Wisconsin-Madison, which began tracking statistics for children’s and teen’s books they received that are by and about Black, Indigenous, and People of

Color (BIPOC) in 1994 (they only tracked books written by and about Black People from 1985 to 1993), has been reporting dramatic increases in the number of these books that they received, mainly in books by and for Black/African people (they received 3,682 books in 2018 and 4,075 books in 2019), but also in books by and for Indigenous people, Asian people, Pacific Islanders, Latine people, and Arabs. The Center received less books from 2020 to 2022 because of disruptions caused by the COVID-19 global pandemic, which led to smaller numbers of books reported, but the actual number of books from those years could possibly be higher than they were able to report.

Although there has been an increase in the visibility and consumption of these stories, actual understandings of the real people and issues they represent have been comparatively slower on the uptick. Even worse, deliberate and fundamental *mis*understandings of these stories have led to books being challenged and even banned in schools and libraries across the country in what has become the biggest effort at book banning and censorship in the history of the United States. 2022 was a record year for book challenges and bans at the K-12 grade level. The vast majority of these efforts have been directed towards books that feature nonwhite characters and LGBTQIA characters, and while some of these books may also happen to feature disabled characters, the same vitriol has not been directed towards books that are known to specifically feature disability as a core focus. This does not necessarily mean that no one wants to ban those kinds of books; rather, it could mean that they have just not gotten around to it yet, or have not thought of wanting to ban them yet. Whether this phenomenon happens to books about disabled people or not, it remains true that in any case, “struggles for recognition

never end and practices of recognition are dynamic relations—even when social relations of recognition are achieved and institutionalized, they are always subject to new contestation” (Maia 165).

The general idea of disability—and sometimes the reality of disability, depending on where you look—is somewhat well known throughout the world, at least in parts of it; however, effective ways of seeing, knowing, and understanding disability have proven to be lacking outside of the global disabled population. Media dramatizations of disabled people can sometimes be popular, such as the made-for-TV Temple Grandin biopic that landed neurotypical actress Claire Danes an Emmy Award for playing the title role of an autistic scientist best known for her contributions to Animal Science and helping to eliminate social stigma around autism, but aside from stories like this one, they often do not adopt the viewpoint of the disabled person and instead tend to invoke feelings of shame and pity towards them (189-190). This is where the models of disability come into play. Broadly speaking, there are quite a few named models with various similarities and differences; generally speaking, there are three main models that will be examined in this project: the medical model, the functional model, and the social model, which will be defined along with the rest of the key terms. Generally, it is known that not everyone in the world is able bodied and that some people need a certain kind of help to be able to participate in society, like how people who cannot walk for any reason use wheelchairs and blind people use canes and/or seeing eye dogs to help them walk around. Most people, however, do not understand that many people have disabilities that are not always so straightforward in the effects they cause. Some people with physical disabilities may

be able to walk without help sometimes, but not all of the time; others have disabilities that are not obvious to the naked eye, but despite what popular opinion would have you believe, this does not make them any less disabled than those who are “obviously” disabled. The nuances that come with being disabled often confuse able bodied people who have been indoctrinated into binary ways of thinking that decide that all people are either perfectly healthy or deathly ill and sometimes act violently when the presence of a disability complicates that binary or even outright rejects it (for an example, see Ellen Jean Samuels’s anecdote about an able-bodied person following another person with a placard for handicap parking spaces from a parking lot to a building to look for perceived signs of disability such as a limp and difficulty breathing just because they were young and ‘well-groomed’ in “My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse”). The models of disability exist to help contextualize any and all disabilities without causing the damage that such binary thinking often causes.

This project is framed by the following research questions: how do the research subjects use the three umbrella models of disability in their stories?, how do the uses of those models affect how the stories function?, and what do these works say about how others see disability? In this project, I take those three main models of disability and study how they are applied to three novels: *Parable of the Sower* by Octavia E. Butler, *The Fault In Our Stars* by John Green, and *Good Kings, Bad Kings* by Susan Nussbaum. I made sure to choose novels that were published after the passage of the Americans With Disabilities Act (ADA), as these three were, because the Disability Rights Movement that led to the passage of the ADA brought unprecedented visibility not just to the mere

existence of disabled people, but their plights as well, and with increased visibility usually comes increased representation as well as increased research opportunities. Disability studies as a field had its inception in the early nineteen-eighties, but the first disability studies program at a four year university was created at Syracuse University in 1994, just four years after the ADA was passed. The Americans with Disabilities Act, which will be referred to as the ADA throughout this project, was passed in 1989 and made effective in 1990. The function of the ADA is to prohibit discrimination against disabled people in employment, transportation, accommodations, communications, and access to government services and programs. Separate laws exist to protect disabled people in regards to their education, such as the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act, which has since been modified to become the Individuals with Disabilities Education Act, abbreviated as IDEA. These laws are not a main area of focus, but will be included in some areas as part of the discussion. The ADA was one of the most significant results to come out of the Disability Rights Movement of that era, and certainly one of the most visible accomplishments of American disability activists. Because of the visibility of the law and the widespread recognition and impact that came after, I felt that I would find more stories to pull from if I narrowed down my search to publications from after that time, although I was still sure that I would not find much no matter which time period I focused on.

Key Terms and their Implications

Key terminology for this project include the following: disability, invisible disability, visible disability, physical disability, developmental disability, model of disability, medical model, social model, functional model, young adult, sick-lit, speculative fiction, science fiction, pediatric cancer, thyroid cancer, osteosarcoma, chemotherapy, palliative chemotherapy, psychological illness, psychological disorder, hyperempathy, institution, institutionalization, hospitalization, Americans With Disabilities Act, and disability rights movement. Some of these terms have already been defined in this introduction.

For the context of this project, we recognize disability as a physical and/or neurological difference in a person that can either impact one's ability to function biologically and/or their society's willingness to accommodate them so that they may function. This may seem like a gross oversimplification, as "disability" is quite a loaded term with many implications that still somehow does not scratch the surface of possibilities of what it could mean. For instance, one may be diagnosed with a disability by a physician or a psychologist if they meet the criteria agreed on by medical professionals and/or leading psychological associations, but a professional diagnosis alone is often not enough to be eligible for services that are meant to help disabled people, such as speech therapy at school or disability payments from the state and/or federal government; service providers and government agencies have their own criteria for service availability that often includes proving that having a disability causes a deficit

that needs to be made up with the help of the services you are applying for (i.e. proving that your disability makes it harder to find and keep gainful employment in order to get monthly Social Security checks and having to be reevaluated for eligibility every few months, or getting a diagnosis from a school psychologist for a student to receive accommodations in public education even if they might already have gotten a diagnosis from someone outside of the school), so one must be considered “disabled enough” or disabled in a certain way to receive anything, even services at a reduced capacity, from them. I have experienced this reality firsthand. When I was first diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) as a young child, I was not considered eligible for services from the regional center where I received my diagnosis, but I was eligible for an Individualized Education Plan (IEP) from my schools. It was not until PDD-NOS was moved under the blanket diagnosis of Autism Spectrum Disorder (ASD) that I was reevaluated by the regional center and deemed eligible for their services. My case with them was not open for long, as I was sixteen when I was reevaluated and then chose not to renew my case when I was nineteen, but when it was, my mother and I asked a caseworker about applying for Social Security disability benefits, and the caseworker told me that I would likely be turned down if I applied because I could essentially function within society as well as any neurotypical person. I had spent a lifetime feeling forced to learn how to mask my autism (not that I put in much effort) and function as well as I could, and now that I had done what was expected of me, I was no longer considered disabled enough to get a certain kind of help.

Disability can also be fluid both in presentation and clinical definition. Special education scholar David J. Connor includes an anecdote in an article called “Kiss My Asperger’s: turning the table of knowledge” about a meeting in which several of their colleagues disagreed over which category of disability that Asperger’s Syndrome belonged to, including autism spectrum disorder, learning disabilities, and behavior disorders, and Connor notes that Asperger’s (which ceased to be its own diagnosis sometime after this paper was published) could fit into many different categories, but could not easily fit into just one. All of this marks a big difference between disability *as a diagnosis* and disability *as a construct*. As a social construct, disability can mean anything, biologically and/or mentally, or even just behaviorally speaking, deviating from what social structures are defaulted to accommodate. Social construct is where the models of disability will come in, as they are both products *and* results of the many social constructions of disability.

These models and the others not yet listed here can and do act as a framework for how one sees disability. Seeing disability through the medical model might mean seeing disability as being biologically wrong and needing to be corrected as much as medical science can allow at that moment, while seeing disability through the functional model might mean seeing disability strictly as a deficit, and seeing disability through the social model might mean emphasizing that disability itself is not a problem, but refusing to accommodate disabled people so that they may fully function and even fully participate in wider society is very much *the* problem.

In part because of the diagnostic criteria issues that I mentioned earlier and also in part because of many other factors that range from the progress of scientific and psychological research to the simple nature of change, definitions of disability have historically been weaponized against other marginalized groups. After all, it was only a few decades ago that homosexuality was classified as a mental illness (it was first listed as a “sociopathic personality disorder”) in the Diagnostic and Statistical Manual (DSM), which psychologists in the United States still use today as their criteria for their diagnoses. It took years of researchers privately and publicly disputing the idea of homosexuality as illness and the activism of a gay psychologist named Charles Silverstein alongside other gay advocacy groups to eventually change the mind of the American Psychiatric Association (who dismissed protestors of the inclusion as insane for years) and have it declassified as a mental illness (homosexuality was included from 1952 to 1973; to satiate those who wanted to keep it in the DSM, the wording was changed to “Sexual Orientation Disturbance,” and it took additional changes in 1980 and 1994 to finally have it entirely removed). Even though it is no longer *officially* considered a mental illness, the fact that it was ever considered one in the first place created an illusion that gay people are mentally ill has never completely gone away; in turn, the ostracization that has come from both instances can and does result in gay people experiencing *actual* mental illnesses such as depression, anxiety, and self-harming behaviors (Price).

There are two key takeaways from this point in history that apply here: one, that the definitions of and the criteria for the diagnosis of disabilities change over time; and

two, that so-called “expert opinions” cannot always be trusted to be accurate or truthful to what and/or who they claim to represent. Of course, this is not exclusive to homosexuality; for centuries, it was assumed that women were genetically predisposed to mental and physical illnesses, and when they were considered to be difficult, upset, or actually sick, they were diagnosed with hysteria, which no longer exists as a medical diagnosis in the modern West. In this case, disability was wielded as a misogynist weapon for conformity against women. In the case of homosexuality, it is now agreed that bias against homosexuality was the basis for its label as a sign of insanity. In the case of the Tuskegee experiments, in which around four hundred Black men in the town of Tuskegee, Alabama were deliberately infected with syphilis, a sexually transmitted disease, without their knowledge or consent and with no intent on the doctors’ part of having it treated, illness and the study and progression of its treatment became a weapon; or, at least, the human subjects of study were made to be an afterthought when their bodies were no longer considered to be of use, which is not any better. With autism spectrum disorder, which is diagnosed as and widely seen as a disability despite growing sentiment that it is not one, particularly among those with a diagnosis (a 2015 article from *The Guardian* reports that much of what was then current autism research was funded by the pharmaceutical industry, raising questions about the financial profitability of framing autism as a disease); the psychologist Ole Ivar Lovaas worked for years, starting in the 1960’s in the United States, to develop Applied Behavioral Analysis (ABA), a method that aims to change a person’s behavior to become more socially acceptable, to “treat” middle class white male children with ASD (whom Lovaas called “surprising deviants”)

with subversives such as slapping and electrical shocks in order to curb their behaviors; in his work with these male autistic children, Lovaas emphasized the expertise of the psychologist over the patient and even the patient's parents within treatments. Lovaas would later go on to work with the psychologist George Rekers, who had been his doctoral student at the time, to develop what would become gay conversion therapy, which uses techniques that are strikingly similar to and have much in common with ABA, including the use of violent subversives to curb undesirable thoughts and behaviors. While Lovaas would later acknowledge that subversives were ineffective methods and quit using them in his own practices, their use in ABA and other psychological methods continues on today; additionally, his expert-as-God emphasis remains a cornerstone of autism-specific psychological treatments as well as other psychological treatments not related to autism. To learn more about the history of autism, I recommend *Neurotribes: The Legacy of Autism and the Future of Neurodiversity* by Steve Silberman. Since its publication in 2015, it has been considered to be the definitive text on autism and neurodiversity, and for good reason. Silberman dates autism history long before the mid-twentieth century (which was when the vast majority of people started paying attention), goes into painstaking detail of all the ways in which autism has been approached from ABA to anti-vaccine conspiracies, and includes disability justice as a part of his theoretical framework. I cannot recommend this book enough.

In the early twenty-first century, realities like this still exist, like the conservatorship of pop singer Britney Spears, her oppressive treatment under its legal ruling, and the attention it brought to disabled people placed under similarly oppressive

conservatorships. Before and during any of this, it was considered normal, even expected, to institutionalize disabled and mentally ill people—or anyone who refused to work or broke a law or did anything even remotely considered out of the ordinary whether it was harmful or not—for the rest of their lives because they were seen as a menace to societies all over the world, particularly in Europe and the United States (Price). Disability history is full of these kinds of horrors, and there is not nearly enough time and space here to list them all. Situations like these could easily happen and certainly have happened with just about any other condition listed as an illness or disability inside and outside of the DSM.

The medical model of disability is a way of seeing disability through a strictly medical lens. Through this model, disability is an individual problem seen as a disease that needs to be cured and/or managed with medical science. The functional model sees disability as an inherent deficit that limits one's functionality; like the medical model, it considers disability to be an individual problem to be solved with individual solutions, if it can be solved at all. The social model of disability sees disability through a sociopolitical and societal lens; namely it states that people are not disabled by their own bodies or by any so-called moral failings, but that society disabled those who do not fit their definition of able bodiedness and disability would not be a problem otherwise. For example, Deaf people are not disabled by school systems that are specifically for Deaf people and run by them as well, but they can be and often are disabled in mainstream educational settings that consider them to be less intelligent and overall less human than the non-Deaf people they cater to and therefore refuse to provide resources for them, effectively setting them up for failure. Early iterations of the social model mainly drew

on history and experience; newer iterations place the person front and center and contextualizes how the world perceives them in their identities.

Disability advocates primarily use the social model as their theoretical framework and have done so for decades, possibly since its inception in the mid-to-late twentieth century. It is common for them to take issue with the medical model for many reasons, including how it pathologizes and dehumanizes disabled people, and the fact that its rigidity makes it unable to adapt to changing understandings of disability (Pieter Verstraete refers to this as “medical motionlessness” [Towards a Disabled Past 57])--as well as the fact that not all people who are socialized as disabled agree that they actually are disabled. Even those with the same diagnosis and/or symptoms can and do disagree with each other on this point. Scholars generally agree that the medical model can be applicable for some disabilities, but definitely not for all disabilities.

Physical disabilities are disabilities that affect the body directly, such as a limb amputation or paralysis. Developmental disabilities begin to show their presence during a person’s developmental stage and can affect physical, language, learning and/or behavioral functioning; examples of this include Down Syndrome and intellectual disabilities. Visible disabilities refer to disabilities that are apparent upon sight; for example, one sees a person who uses a wheelchair and can immediately guess that they are disabled. Invisible disabilities refer to disabilities that are not obvious upon first glance, like traumatic brain injuries, developmental disabilities and psychological disorders. A psychological disorder is defined as a disturbance of one’s cognitive function that often leads to extreme behavioral changes.

Defining Disabilities Specific to the Three Novels

The chapter on *The Fault In Our Stars* includes some mentions of the forms of cancer shown in the book as well as their treatments. Pediatric cancer refers to children under the age of eighteen who are diagnosed with cancer. Thyroid cancer, which the main character has, is a type of cancer that starts to show up in the thyroid glands in the neck. Another character has osteosarcoma, a common occurrence among pediatric cancer patients, which is a type of bone cancer that most commonly begins in either arms or legs. The chapter on *Parable of the Sower* frequently mentions hyperempathy, which only exists in the novel and is characterized by physically feeling and reacting to what they perceive as what another person is feeling, usually pain or pleasure. The chapter for *Good Kings, Bad Kings* discusses the institutionalization of disabled people throughout history. The word “institution” is usually attributed to both state-run and privately-run facilities or asylums for disabled people to be placed in whether their condition actually warrants it or not; similarly, the word “institutionalization” is attributed to the act of admitting disabled people to such institutions and/or asylums. One of the goals of the Disability Rights Movement has been to eliminate institutionalization as the first or only option for disabled people, if not eliminate their existence entirely (as many have understandably called for). The Disability Rights Movement is an ongoing effort to ensure equal rights and responsibilities for disabled people around the world.

Genres of Disability Literature

Although it is not a main research focus, this project contains some discussion of literary genres. One of those genres is the young adult genre, also called YA. It refers to books targeted at children aged twelve to eighteen years old. A subgenre of YA that will be discussed is young adult sick-lit, which consists of young adult novels featuring characters dealing with an illness such as cancer. Another genre discussed is speculative fiction. To be considered a work of speculative fiction, a story must diverge from reality, not necessarily in a fantastical or delusional way, but in a merely speculative way, hence the name. These kinds of speculative stories are common within its popular sub genre of science fiction, although they are not exclusively science fiction stories. The science fiction genre is categorized by speculations of the future based on scientific and technological advancements and, more often than not, being set in outer space; other elements of science fiction include space travel, time travel, the multiverse, artificial intelligence, and life on/the colonization of other planets.

Disability studies is an academic overview of disability. It came about as a result of the disability activism of the late twentieth century. The field includes a range of disabilities from physical to chronic to mental. Broadly speaking, disability studies encourages the idea of disability as something that is cultural. Key concepts and debates of this field include, but are not limited to, quality of life, intersectionality, fears around disability, disability as a perceived moral and social threat to others (here I am particularly thinking about religious codes around morality and how being disabled was

seen as an extension of someone's lack of morality, something Devon Price writes about in *Creating a Neurodiverse World*, normalization of disability (and how it can be done without accidentally causing erasure”)", disability as a metaphor, interdisciplinarity (such as with critical race studies and feminism) and disability approaches to other fields (e.g. anthropology), global perspectives of disability, history of disability, problems with medical discourse, accessibility, and disability theory. Disability theory is a part of disability studies, which, as described above, uses an academic lens to examine what it means to be disabled.

LITERATURE REVIEW

For the literature review, I will be exploring how we as an audience can understand disability as a social construct by 1) reading the three models of disability (medical, functional, and social) through the lens of Foucauldian power/knowledge, in conjunction with the theoretical frameworks offered by Stuart Hall, 2) exploring how other disability and cultural theorists can inform the possible answers to my research questions, and 3) synthesizing how other researchers have used Foucauldian ideas, including power/knowledge, to understand how disability is seen in the books and the world at large.

I am coming into this research from the perspective of a disabled person, and specifically as someone diagnosed with autism spectrum disorder, or ASD, who can often pass as nondisabled in most social circles. I also have the perspective of someone who grew up in a rural area in California with limited access to medical services and disability services outside of the public school system. Additionally, I have a college-educated white woman's perspective and a roughly middle class perspective.

Before we get into the literature, I want to take note of two common types of language practices used for discussing disabled people: person-first language, which emphasizes the person before their disability with the intent of emphasizing one's humanity (i.e. person with a disability), and identity-first language, which puts a person's disability at the forefront of their identity in the same way one might refer to gender and/or ethnicity (i.e. disabled person). In many disability circles (here I am thinking

particularly of the autism community, where the language debate has especially been prominent), disabled people are the primary users of identity-first language while parents and professionals who work with disabled people are the primary users of person-first language. Why this disconnect exists is something I can only speculate about, and I will not do that in depth here, if at all. For the time being, I recommend reading *Demystifying Disability: What To Know, What To Say, And How To Be An Ally* by Emily Ladau for more insight. In any case, the disability community has long debated over these language uses. Some disabled people may prefer to use person-first language, and some may prefer to use identity-first language, each for their own individual reasons. Some disabled people may not want their disability to be so pointedly emphasized, and besides, not all disabilities can be readily applied well to identity-first language (for example, imagine referring to a cancer patient as a “cancerous person,” and then imagine their reaction); likewise, some disabled people may feel that their disability needs to be emphasized—and if not emphasized, then at least acknowledged as an inherent part of their identity—or else it will never be addressed and contribute negatively to their quality of life. After all, disabilities cannot be accommodated if everyone keeps forgetting about them. In both my personal life and my professional life, I prefer to use identity-first language, as I feel that it accounts for the fact that disability is intrinsically tied to one’s personhood in a way that renders the both of them inseparable from each other, which I believe they are, and I find person-first language to be inadequate at best and almost victim-blaming in its nature (for lack of a better phrase) at worst in a lot of contexts. While I will mostly use identity-first language throughout this project, I may use person-first language in some contexts if

it feels necessary to me, mainly in the discussions on *The Fault In Our Stars* and *Parable of the Sower*.

I have chosen to use the philosophy of Michel Foucault, and the Foucauldian idea of power/knowledge in particular, as a theoretical lens for my research because of how I think it can apply to current concepts of disability. Power/knowledge is a philosophy that states that power is based on knowledge and its use and reproduction in dominant discourses by those in power, making power and knowledge entangled with each other rather than being separate from each other. As cultural theorist Stuart Hall explains in his extension of Foucault's theory "knowledge linked to power not only assumes the authority of 'the truth', but has the power to *make itself true*. All knowledge, once applied in the real world, has real effects and, in that sense at least, 'becomes true'. Knowledge, once used to regulate the conduct of others, entails constraint, regulation and the disciplining of practices" (Representation 33). Furthermore, "knowledge does not operate in a void. It is put to work, through certain technologies and strategies of application, in specific situations, historical contexts, and institutional regimes" (Representation 33). Nondisabled people hold the power over disabled people in the government, in corporations, and in social circles, and therefore get to manage and reproduce the constructed truth around what all they consider to be disability or not in order to maintain their own power structure. As an example, one of the most well known organizations related to autism is Autism Speaks, but while they experience high visibility and command mainstream respect, the organization is almost entirely made up of neurotypical people who view autism as a terrible disease that needs to be cured; within

their ranks, there is nary an actual autistic person in sight. While Autism Speaks has lately begun to be scrutinized by non autistic people as they have been scrutinized by autistic people, and groups run by actual autistic people like the Autistic Self Advocacy Network are seeing a rise in recognition, the neurotypical mainstream still has a lot of work to do with their treatment of autism and neurodiversity. To provide another example of this power structure, it will be noted once again that a diagnosis alone may not be enough to receive disability benefits from the government or services from a public school; rather, one must be disabled on *their* terms to qualify for them. Differences in diagnostic criteria between care providers is its own discourse, so I can only say so much here without having to create an entirely new statement. What I can say is that one of my focuses is on how discourses on disability are formed, and understanding power/knowledge can help put those ideas into perspective.

Of course, I am not the only person to study disability through a Foucauldian lens, or even through a cultural studies lens. Several researchers and theorists have done so over the years and will continue to do so for a long time. Even theorists and writers who do not explicitly cite Foucault as a direct source and/or influence on their research seem to invoke several of his ideas in some way.

In “The Disabled Body, Genealogy and Undecidability,” Margrit Shildrick uses Foucauldian ideas of postmodernism, disability, genealogy, and power/knowledge to argue that “binary differences are constantly undone by the irreducible difference of the disabled body” (755), meaning that the mere presence of disability complicates binary notions of “sick” bodies and “well” bodies; further, she writes that while the medical

model of disability tends to pathologize the human body, the social model of disability does still run into its own resistance, and she uses these complications and others to further complicate “alternative” Foucauldian approaches to disability theory. In “Towards a Disabled Past: Some preliminary thoughts about the history of disability, governmentality and experience,” Pieter Vertstraete draws on some Foucauldian texts on power and subjection (and also on some similar texts by philosopher Walter Benjamin) to help bridge the gap between educational history and educational philosophy as they relate to disability studies in order to help readers reconsider the history of disability in a way that allows disabled people to face today’s problems. Regarding the idea of power/knowledge, he says that “Power produces knowledge, it produces classifications, it produces measuring instruments and, more importantly, it might also have produced ways of looking at the world and the self” (p. 59). As this all relates to disability studies and disability theory, Verstraete writes that disabled people have come to obtain their own history just as history has come to rediscover them. In “Discourse and the containment of disability in higher education: an institutional analysis,” Susan Gabel and Maja Miskovic look at disability discourse using Foucauldian concepts of discourse and power through a social model lens to demonstrate how one U.S. university’s containment model (meaning disability-as-difference in this case) for excluding disabled students can function at an institutional level. One of the strongest points of this paper is the juxtaposition of the perception that less than one percent of the student population is disabled because of official self-reporting demographics with the reality that the real statistic is closer to about ten to twelve percent according to university surveys that are

less intrusive and time consuming. In “Nothing without us or nothing about us?” Neil Crowther writes about how the British government cannot be relied on to continue the trajectory of disability rights on their own and require more pushing from disabled citizens to make any kind of progress (while Crowther does not explicitly cite Foucault in the article, the article is at least somewhat Foucauldian in its discussion of governmental power structures). Similar to the Susan Gabel article, in “The Model Of Becoming Aware: disabled subjectives, policy enactment, and new exclusions in higher education,” Francesca Peruzzo uses Foucault’s work on governmentality to frame “the subjectivities of disabled students and new forms of exclusions during the enactment of disability policies in the Italian higher education context” (482). Here, the model of becoming aware is more of an analytical tool than a social construct; it takes a situational approach to determining the scope of the subjectivity of disabled college students in Italy with autonomy and sensitivity as its frameworks of power. In “The Constitution of Impairment: modernity and the aesthetic of oppression,” Bill Hughes utilizes ideas from Foucault and from philosopher Jean-Paul Satre to expand the definition of the social model of disability, saying that “the invalidation and disfigurement of impaired bodies is, therefore, not simply an economic and cultural response to them, but also arises in the mode of perception which visualizes and articulates them as strangers” (155); additionally, he states that the social model as it currently stands does not critique modernity enough and should “adopt a strategy of epistemological pragmatism (Turner, 1992) which includes the priority of setting aside its own conceptual imperatives, if and

when, alternative perspectives can help to illuminate the forms of oppression and discrimination that characterize the lives of disabled people” (156).

In a somewhat similar train of thought, Hughes also wrote “The Social Model of Disability and the Disappearing Body: towards a sociology of impairment,” in which it is argued that “the realignment of the disability/impairment distinction is vital for the identity politics of the disability movement” (25). Again, he discusses modernity with disability, referring to disabled people as “imprisoned by what Foucault (1967) called ‘the great confinement’ and excluded from and denied access to many of the key sites of power and privilege” (325) and calls for the expansion of the social model. In “Kiss my Asperger’s: turning the table of knowledge,” David J. Connor implicitly invokes power/knowledge and the expert-as-God mentality by juxtaposing perspectives of autistic people with so-called official definitions of Aspergers’ syndrome (this was published prior to the DSM putting Aspergers’ under the wider umbrella of ASD instead of keeping it as its own diagnosis) created by nondisabled medical professionals. Connor includes a satirical reference to the fourth edition of the DSM and criticisms of advertisements of autism to make his point.

In “A Threatening Space? Stigmatization and the Framing of Autism in the News,” Avery E. Holton, Laura C. Farrell, and Julie L. Fudge analyze how the news media has constructed a hostile space for the portrayal of disability, and autism in particular. They note that newspaper journalism has mainly taken a “cure” approach to covering autism as though it is a cancerous disease rather than a neurological difference, and often do not provide viewpoints of actual autistic people, a clear cut implication of

power/knowledge. In “‘Not to Discover Weakness Is The Artifice of Strength’: Emily Dickinson, Constraint, and a Disability Poetics,” Clare Mullaney studies Emily Dickinson (who had been sick in her later lifetime and would die from illness) and her poetry through a disability studies lens as a way of showing how disability theory can play out in creative writing. For instance, writer Ralph Waldo Emerson had once written that the poet was destined to overcome all sickness, yet it appears to the author that Dickinson’s ailments actually enabled some of her work rather than disrupted it. In “Guy de Maupassant, Louisa May Alcott and Youth at risk: lessons from the new paradigm of disability,” Catherine J. Kudlick reads two short stories with disabled main characters from the late nineteenth century with a Critical Disability Studies lens. Specifically, Kudlick chooses two stories, one from Guy de Maupassant and one from Louisa May Alcott, with blind main characters that directly contradict the functional model of disability.

In “My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse,” Ellen Jean Samuels discusses the complications and the discourse that comes from coming out as disabled. At one point, Samuels invokes Foucault’s Panopticon reading (in which he states that society is set up in a way that heavily suggests but does not outright confirm constant surveillance, which compels everyone to follow the rules anyways, much like the prison architectural style it was named after) when discussing various analogies for disability and coming out. In “Making Do With What You Don’t Have: Disabled Black Motherhood in Octavia E. Butler’s *Parable of the Sower* and *Parable of the Talents*,” Anna Hinton argues that Butler uses her *Parables* book duology

to examine the relationship between black studies theory and disability theory by positioning the main character, who is disabled, in a maternal role as the founder of a religion called Earthseed and later as an actual mother in order to show how ableism is used to devalue motherhood both in the texts and in real life. In “The autism predicament: models of autism and their impact on autistic identity,” Melissa Anderson-Chavarria draws on the history of disability and the medical and social models of disability to create a new model for autistic identity called the “predicament model,” which aims to encompass all of the individualized and varied nuances that come with being autistic in everyday life, which they feel the medical and social models fail to do sufficiently. The biggest problem with the medical model is that it makes so-called disability out to be wholly undesirable with its hyperfocus on deficits, while the biggest criticism of the social model is that it can be too reliant on social and institutional critique. The predicament model put forth here, like the model of becoming aware put forth earlier in a different article, calls for a situational approach to seeing disability to account for all of the nuances and varied experiences that come from being disabled.

In the introduction to “Disability and Colonialism: (dis)encounters and anxious personalities,” Shaun Grech and Karen Soldatic place disability and disability studies in the contexts of colonialism and postcolonial theory, which has historically not considered disability much, if at all, especially not to the degree as it has considered gender, race, and ethnicity. Furthermore, disability studies from the global North has done little to bridge the gap between itself and postcolonial theory, in part because of its ignoring of the global South. In “Recognition and Moral Progress: A Case Study about Discourses on

Disability in the Media,” Rousiley C.M. Maia and Anna Carolina Vimiero utilize disability representation in Brazilian media from 1960 to 2008 as a case study of German philosopher Axel Honneth’s ideas on recognition, normativity, progress and morality, which state that increases in autonomy and individuality should be thought of as normative progress.

In addition to articles, I found several books to aid me in my research. In *Chronic Youth: Disability Studies and U.S. Media Cultures of Rehabilitation*, Julie Passante Ellman examines pop culture and media depictions of disability, particularly those featuring and aimed at young audiences; my particular focus is on chapter three, which analyzes popular books from the young adult “sick-lit” genre and how they became popular during a time period in which there was a push to get young people to read outside of school more often. In *Bodyminds Reimagined: (Dis)ability, Race, And Gender In Black Women’s Speculative Fiction*, Sami Schalk details her extensive research into works of speculative fiction written by Black women and the many ways they disrupt and redefine the various conventions of their respective genres. In *Authoring Autism/on rhetoric and neurological queerness*, M. Remi Yergeau deconstructs mainstream ableist rhetoric on autism and creates an entirely new one informed by disability studies, rhetorical studies, their own lived experiences as an autistic person, and the lived experiences of other autistic people. Each chapter of the second edition of *Social Justice Pedagogy Across The Curriculum: The Practice of Freedom*, which is edited by Thandeka K. Chapman Nikola Hobbel, takes on a different form of social justice and how to apply its tenets to K-12 educational settings; chapter three, researched and written by

David J. Connor and Susan Gabel, summarizes the history of special education and the many other forms of oppression it perpetuates in its current form, such as racial segregation and isolation, while offering ways to change the field entirely. In *Unmasking Autism: Discovering the New Faces of Neurodiversity*, social psychologist Devon Price blends his academic expertise with his own experiences as an autistic person to create a theoretical lens through which he studies the social burden of masking autistic traits and lays a foundation for unmasking. In *Feminist, Queer, Crip*, Alison Kafer begins by writing about how after she became disabled, the able-bodied people around her expressed that she had no future as a disabled person, at least not one that she could look forward to with anything other than dread, and then counters that narrative by imagining what a disabled future could and should look like, which also includes the future being queer and feminist. The futures she imagines are nothing like the futures she had been told to expect upon her disablement: no long-term psychological therapy just to deal with being disabled, no inevitable descents into drug or alcohol addiction, no abandonment, no suicide to avoid a disabled life, no able-bodied people assuming to know a disabled person's needs better, and no "cure," "healing," or "overcoming" disability suggested or required. This is not to suggest that Kafer imagines perfect futures; rather, she deconstructs the dismal futures that have been imagined for disabled people—when they are imagined at all—and imagines better ones based on the work of disability theorists and activists in their place.

To a lesser extent, this project is also informed by the books *Far from the Tree: Parents, Children, and the Search for Identity* by Andrew Solomon and *Neurotribes: The*

Legacy of Autism and the Future of Neurodiversity by Steve Silberman. *Farm from the Tree* is a heavily researched book about parents who end up raising children different from themselves, including able-bodied and/or neurotypical parents who raise disabled and/or autistic children; other chapters focus on parents whose children were conceived through rape or committed crimes. It was expanded from some of the author's previous works of journalism, most notably from his work on Deaf culture and communities.

Neurotribes chronicles the history of autism, the beginnings of autism research, how psychologists have been approaching autism, the public emergence of autistic people over the past few decades, and the rising sentiment among autistic people that autism is not a disease or disability. It provides a standard for what a comprehensive disability history should look like.

As limited research and information as there is regarding disability in literature, and viewing disability in real life through a Foucauldian lens, and/or a cultural studies lens informed by Stuart Hall, there is clearly much to be said and much that already has been said on the subject. However, there is always more to be added. There are also several ideas and talking points that I hope to add to these conversations with my own research, such as, but not limited to, the three models of disability being both a tool and product of social construction as an addition to disability studies and further explorations of other models of disability, like the predicament model and the model of becoming aware that I came across, as well as other alternatives and subsets of the medical, functional, and social models (such alternatives and subsets include the minority model, the moral model, the empowering model, the economic model, the relational model, and

the spectrum model, just to name a few). Even though I do not explore the other models here, I would like to explore them at some point in some way, both in this project and beyond. Ultimately, what I *have* done here in this literature review is make some connections between disability studies, disability theory, the Foucauldian concept of power/knowledge, ideas from Stuart Hall, and a focus on cultural studies while utilizing a mixture of research that takes individual focus on each subject and also has some overlaps with each other in terms of focus, ideas, and conclusions. I attempted this because the subject matter is of great importance in academic research and the real world, and it will take multiple perspectives from multiple research backgrounds to paint a full picture.

METHODS

Once I settled on my research topic of disability theory and disabled main characters, it was relatively easy to choose my research subject texts from there. I chose these novels because I had already read them at different points in my life and felt that, at least on a surface level, they each represented at least one model of disability: *The Fault In Our Stars* most strongly represented the medical model, *Parable of the Sower* most strongly represented the social model, and *Good Kings, Bad Kings* most strongly represented all three. As I reread the books and conducted research, I came to the conclusion that each book fits all three models in some way or another, as each chapter discusses in more detail. I chose the medical, functional, and social models because as I began to study them, it became clear that these were the most well-known and commonly used models. The more I researched them, the more models I found, and I came to realize that these three particular models were more like umbrella models that the more specific models fell under.

I did consider analyzing other sources besides literature. Initially, I had hoped to cover a wider variety of sources for analysis, including the representation of disabled cartoon characters like Toph Beifong, a blind character in *Avatar: The Last Airbender* and Princess Entrapta, an autistic-coded character in *She-Ra and the Princesses of Power*, representation of disabled comic book and graphic novel characters like the blind Marvel Comics superhero Daredevil, and the rhetorical presentation of disability from real life disabled people like convicted murderer and former Paralympic sprinter Oscar Pistorius.

In the end, I realized that I would likely not be able to have as wide of a scope for my project as I wanted, so I narrowed it down to just the three novels so that I could maintain a more specific literary focus, and I would only bring up other pieces of literature and other media if they became relevant to my discussion points. I do, however, still believe that disability representation within these other forms of media is a worthy research topic and that it deserves to be the focus of its own project.

This project takes a cultural studies approach to literary analysis, and it also moves towards rhetorical analysis at some times. While these methods allow for plenty of study and observations that are detailed throughout the project, some things are beyond the scope of my research. As I said earlier, I was unable to focus on as many sources as I wanted to because of the research constraints. If I had been able to study more forms of media, I might have been able to come up with insights into the application of disability theory within other forms of media and not just in books. Besides, literary analysis has its own limitations. While I did my best to contextualize these books within real life settings, they are still works of fiction and somewhat set in isolation as a result. They are not meant to mirror the experiences of all disabled people in the United States, let alone the whole world.

One of the biggest limitations of my analysis is that while I mentioned other factors in a disabled person's life such as race, gender, sexuality, and socioeconomic status, my analysis did not go deep enough into those intersections. Since my subjects were mainly focused on disability, it made sense to me to mainly focus on disability as

well, and while I took notes of intersectionality, deeper analyses of intersectionality within disabled identities will be required for further research.

Additionally, the fact that all three novels are set in the United States of America severely limits this project's viewpoint and conclusions. Disability studies as a whole is largely skewed towards the global North, so much so that it is a noticeable problem among certain scholars, and unfortunately, this project is no exception. An expanded scope that included stories from the global South could have provided an opportunity to critique this issue and maybe even help expand the scope of disability studies. This is undoubtedly one of the other biggest limitations that this project faces, and I have had to face the ethical complexity of keeping my research focused on books published in the United States. I made this decision out of familiarity with the source material, and also because I have personal experience with being a person who is socialized as disabled in the United States. I felt that this was a subject that I could do justice to. While I came across research articles that addressed disability in other countries and plan to continue learning about disability realities across the world, I ultimately did not feel that I could do justice to those focuses, too.

I did, however, come across a peer reviewed journal called *Disability and the Global South* that published its first issue in 2014 and specifically takes disability studies to countries in the global South and is the first peer reviewed international journal created just for that focus. Articles published by the journal include “Can the implementation of the Sustainable Development Goals (SDGs) be achieved without addressing disability rights?,” “Invisible to the Law: COVID-19 and the legal consciousness of persons with

disabilities in Bangladesh,” and “State of the art of the Latin American discussion on ableism.” Anyone interested in taking their knowledge of disability studies across the world should start with this journal, which is an open journal that can be accessed on J-Gate, Directory of Open Access Journals (DOAJ), Index Copernicus, IJIFACTOR, and the European Reference Index for Humanities and the Social Sciences (ERIH PLUS). The website is linked in the References section.

I have several recommendations for future research. First, I hope that a future researcher will be able to apply other methods and stories to disability theory besides literary analysis, although I also hope that others will continue to apply a cultural studies approach to their research. Additionally, I would like to see future researchers study other storytelling mediums through a disability studies lens, such as film, television, and comics. I believe that such a project would provide some interesting findings. As I stated before, I especially hope for future researchers to focus on identities that intersect with disability. Finally, I most strongly hope and recommend that future research will continue emphasizing the global South in their studies rather than just keep prioritizing the global north. A truly inclusive and/or interdisciplinary field of study is one that covers every population that the research affects, and that means more than just the people the researchers see every day.

THE FAULT IN OUR STARS AND OTHER TROPES

Young Adult Literature and Sick Lit

The inception of the young adult literature genre, or YA, which it has become better known as, has proved to be a highly profitable one for the book publishing industry in the United States and abroad; in that vein, the inception of both young adult romance novels and young adult novels that feature main characters who are diagnosed with cancer and/or other illnesses, also known as YA sick-lit, are especially popular subgenres of YA literature. While YA sick-lit has enjoyed steady success among its faithful audience in the United States since the early nineteen eighties, it arguably hit its peak in 2012 with the publication of *The Fault In Our Stars* by novelist John Green and its subsequent film adaptation in 2014. Its mainstream critical and commercial success has extended so far beyond the young adult market that it is now one of the best selling books of all time. Similarly-plotted novels had been published before and after *The Fault In Our Stars*, but its popularity has been almost entirely unmatched.

Plot Summary of the Fault in our Stars

The Fault In Our Stars mostly takes place in contemporary Indianapolis, Indiana (with a brief detour to Amsterdam later on) and follows a sixteen year old girl named Hazel Grace Lancaster, who has been living with an incurable form of stage four thyroid cancer along with multiple lung tumors since she was thirteen, and Augustus Waters, a

seventeen year old boy whose right leg was amputated after a diagnosis of osteosarcoma, a type of bone cancer, as they meet and develop a romantic relationship. When the novel begins, Hazel is forced by her parents to attend a support group for kids with cancer after her mother and doctor come to believe that she has depression, “presumably because I rarely left the house, spent quite a lot of time in bed, read the same book over and over, ate infrequently, and devoted quite a bit of my abundant free time to thinking about death” (Green 3). Depression can be a side effect of cancer treatments such as chemotherapy and other medications, and while Hazel’s mom and doctor feel more inclined to believe that this is the case for her, Hazel herself is not so inclined to believe this and says that depression is, in fact, a side effect of dying. Hazel finds the support group itself to be quite depressing, but goes at her mother’s behest, and at one such meeting, she meets Augustus for the first time. Afterwards, they start spending time together outside of the support group and bond over their shared love for a book about a girl with leukemia, a type of blood cancer (this plot point opens the door for literary metacriticism, but sadly, this potential is never fulfilled, which is why this chapter will only discuss it sparingly), and while Hazel develops feelings for him that match the intensity of Augustus’ feelings for her, she is deeply afraid that her impending death will hurt him more if they start a relationship. Despite her fears, she does not ignore her feelings or push him away.

As far as Hazel’s thyroid cancer is concerned, it is made clear from the very first page that she will not be free of it and that she is, in fact, dying. She has been able to stay alive for this long following what she calls her “Miracle,” an event in which she came

very close to dying before the medicine she had been given at the hospital finally started to take effect, and subsequent medical treatments to manage her cancer, but her and her family understand that there is no cure in sight for her and her remaining time is limited, though they have no way of knowing exactly *when* she will die. Hazel frequently refers to herself as a grenade waiting to explode because of this. Augustus, on the other hand, is in remission when he is introduced (meaning he has not had cancer since his leg was removed) and has been in remission since his leg was removed, and as the book points out, eighty percent of osteosarcoma patients, many of which are in his age group in real life, tend to remain so after an amputation, which makes for great odds of survival. On top of that, most children who get pediatric cancer end up living to adulthood, so Hazel's experience is not a very common one. Upon first read, even those unfamiliar with the tropes of sick-lit might assume that the novel would end with Hazel's death while Augustus lives on. Instead, Augustus gets a recurrence of cancer that spreads all throughout his body, and he is the one who dies while Hazel is still alive at the end of the story; furthermore, although Hazel is still alive at the end, she is very much not cured of cancer, nor will she ever be, and her condition is overall unchanged.

YA Sick-Lit Genre Analysis

Early teen sick-lit novel writers were heavily reliant on the medical model of disability as the framing device for their stories. This is made clear throughout chapter three of *Chronic Youth: Disability, Sexuality, and U.S. Media Cultures of Rehabilitation*. The book, written by Julia Passante Elman, examines pop culture and media

representations of so-called troubled teenagers and how they became vessels for ideas and anxieties surrounding heteronormativity, able-bodiedness, and late twentieth-century neoliberal policies. Chapter three in particular, titled “Cryin’ and Dyin’ in the Age of Aliteracy,” focuses on popular young adult sick-lit novels from the nineteen-eighties and early nineteen-nineties (prior and leading up to the disability rights movement and passage of the Americans with Disabilities Act), when the genre began its rise in popularity during a simultaneous push for encouraging young people to read more. During the decade prior, young adult novels that were considered realistic, or “problem novels,” became the preferred genre among young adult readers, which would be capitalized on in the form of after-school specials, and this decade would see the problem novel expand into sick-lit and develop its own literary formula. That formula is as follows: “The illness plot begins with a white teen girl’s manifesting unexplained bruises or fatigue, which end up being symptoms of a chronic illness, such as cancer. During her treatment, the obligatory romance plotline begins, in which the ill girl’s pursuit of a boy parallels and positively affects her process of ‘getting well.’ Generally, the sanctioned object of the ill girl’s affections is a ‘normal boy,’ which is to say, nondisabled and not ill. This second narrative strand subtly differentiates teen sick-lit from problem novels, which do not always involve a love story” (Elman 94).

Like all story formulas that create genres, this one has both created new literary tropes and refashioned old ones. Also like other literary genres, tropes are often shaped by time and place. Many tropes of the teen sick-lit novels of the eighties in particular are shaped by the time’s conservative social politics (unlike its problem novel predecessors

in the seventies, which were shaped by ideas and anxieties from progressive social movements). “Among its other strategies,” Elman writes, “teen sick-lit often endorsed rigorously gender-differentiated roles for its characters while it also maintained the co-constitutive relationship between compulsory able-bodiedness and heterosexuality. Ill boys demonstrate their athleticism and virility ‘in spite of’ their illness or during their remission, while ill girls endlessly cultivate their normality by rehabilitating physical beauty in a largely ‘female world of love and ritual.’ A ‘normal’ boy, who has never been ill, however, is usually depicted as the ill girl’s most treasured prize. Thus, the novels’ linkage of illness and romance plotlines manifests how the logics of heteronormativity and able-bodiedness materialize as disciplinary frameworks within teen sick-lit” (95).

While the chapter takes many notes on teen sick-lit from the eighties and early nineties, it also has a note on *The Fault In Our Stars*. Elman does not say much about the novel, as it falls outside of the time period of this chapter’s study, but she does acknowledge in the Notes section that unlike its predecessors, *The Fault In Our Stars* does not fall into the particular tropes listed above; in fact, those tropes are constantly mocked by the characters who have cancer, even the more minor ones. Additionally, the object of the main character’s affections is a disabled cancer survivor like herself, and their romance does not serve as a form of cure or rehabilitation for either of them. There is never any hyperfocus from either them or their families on finding a cure for their cancer, even when Augustus gets his recurrence, and neither of them are very occupied with their looks (at least until they first meet) or how their medical treatments affect them, although they do acknowledge them from time to time. Compared to many of their

eighties and nineties counterparts, Hazel and Augustus live “ordinary lives, neither heroic nor tragic” (Clare 13), the kinds of lives that disabled people are almost never shown or thought to live despite their commonality in the real world.

Hazel and Augustus also directly call into question the real life inspiration porn attributed to cancer patients, or, as Augustus says, “the trope of the stoic and determined cancer victim who heroically fights her cancer with inhuman strength and never complains or stops smiling even at the very end, etcetera,” to which Hazel responds, “they are kindhearted and generous souls whose very breath is an Inspiration to Us All. They’re so strong! We admire them so!” (Green 173). When Hazel goes to see their mutual friend Isaac after his eye is surgically removed, one of the first things he says is “come over here so I can examine your face with my hands and see deeper into your soul than a sighted person ever could” (Green 74), echoing a real trope/stereotype attributed to blind people in fiction and real life, much like the blind character played by sighted actor Al Pacino in the 1992 film *Scent Of A Woman*. At Augustus’ funeral, the minister who is officiating the church service gives a speech about his so-called courageous battle with cancer and his heroism in the face of sickness being inspiring, which would have been dehumanizing enough by itself, but then he says that Augustus will be healed and whole once he reaches Heaven, and Hazel is furious at the minister’s implication that he had not been a whole person back when he was alive with a body full of cancer and short of one leg. These examples call to mind Catherine J. Kudlick’s description of the medical model in the article “Guy de Maupassant, Louisa May Alcott and youth at risk: lessons from the new paradigm of disability. Kudlick notes that the medical model is “now increasingly

called the 'pathology' or 'deficit' model," and defines it as a framework that "regards disability as a problem or lack located in the individual. It sees disability only as an isolated person's physiological defect or social deficiency. Dating from the nineteenth century, it prescribes medical intervention and rehabilitation as the only effective remedies. It celebrates individuals who engage in heroic striving to overcome personal tragedy. For those who are not heroes, it offers pity and charity" (37). As far as being cancer patients goes, the characters in *The Fault In Our Stars* express that they do not wish to be either other people's heroes or their objects of pity; rather, they wish to act on their own terms.

Ultimately, genre-wise, *The Fault In Our Stars* tries to be more of a young adult romance novel with sick characters than a YA sick-lit novel. However, the attempt is more of a surface-level one with surface-level results that fall flat. Concerningly, the characters do not seem to practice what they preach in terms of how they present themselves versus how we actually see them live. They say that their lives and personalities do not revolve around their cancer, but from what the story shows, this is not true at all. The vast majority, if not every single one, of the character's interactions with each other involve talking about cancer, nurses, doctors, fellow patients, or something related to one or all of those subjects. Many of Hazel's inner thoughts also revolve around how she feels about having cancer and her impending death, especially in regards to what will happen to her parents afterwards. Admittedly, this last hyperfocus is understandable given the circumstances, despite the fact that we see very little about the

family's relationship outside of them taking care of her. When she learns that Augustus is dying, this becomes her biggest hyperfocus.

Analysis of Medical Model

The medical model of disability, while greatly problematic most of the time, has its applicability to cancer. While the medical model sees all disabilities as a disease, cancer is *actually* a disease, and it can also be a disability. Hazel, for instance, cannot breathe on her own and requires an oxygen tank because of the tumors in her lungs. She also develops problems with fluid accumulating in her lungs, which at one point leads to a brief hospitalization and the development of a medical plan to have more frequent drainings of the lung fluid. Again, when she is diagnosed with depression, she notes that it is considered a side effect of a lot of medication, although she counters (albeit to herself) that depression is a side effect of dying. Augustus can function perfectly fine without his right leg, but driving is difficult for him because he cannot feel weight in his prosthetic leg. Prior to his diagnosis, he had been a talented basketball player, but he quit playing after his leg amputation, which he attributes to growing to dislike the sport rather than to losing his leg. When his cancer returns, he starts to undergo palliative chemotherapy to manage his symptoms, but stops it when he goes on his trip to Amsterdam. After he discloses his cancer recurrence to Hazel (which had been diagnosed off-page earlier in the novel, while Hazel was experiencing her own hospitalization), he becomes a wheelchair user fairly quickly afterwards in order to keep his heart from overworking itself and remains so for the rest of his life. Between the cancer and the

treatments, he is tired more often than not. Their mutual friend, Isaac, who is in their support group, has one eye removed because of eye cancer (the type of eye cancer is never specified, although Hazel refers to it as “fantastically improbable,” which implies that it is not a common form [6]) before the start of the novel, and then has the other removed after a recurrence, leaving him completely blind and forcing him to adjust his life accordingly, even going to rehab for further treatment once he recovers from surgery. He plays video games, an activity he also took part in when he still had his eyes, but he learns to play them on a voice-activated console; he also gets a voice machine to read his emails out loud to him.

These characters are somewhat disabled by cancer, which, as Hazel and Augustus regularly note, is made of themselves and their bodies, but also by the medical treatments used to cure and/or manage them. Isaac gets cancer, but ultimately, it is the surgery to remove his eyes that actually blinds him, not the cancer itself, although it is possible that he could have gone blind from the cancer if it did not kill him first. The same thing can also be said of Augustus; his leg is surgically removed, but if that had not happened, osteosarcoma might have deteriorated the leg bone to the point of losing all functionality anyways, and he certainly would have died then. Hazel is still alive because of treatments and medications, but her doctors theorize that the experimental medication that prevents her tumor growth may also be causing her excess lung fluid to build up, which adds to her breathing problems and requires more medical care to manage. Taking her off of that medication, however, would undoubtedly lead to much worse problems down the line and maybe even to her already premature death. As dangerous as the lung fluid is,

dealing with the buildup by draining the fluid every so often (by the time she comes to clear consciousness in the hospital, a liter and a half of fluid has been drained from her lungs) is still safer than the alternative. These medical realities call into mind some of the contradictions of cure that Eli Clare comes across in *Brilliant Imperfection: Grappling With Cure*; namely, that “cure saves lives; cure manipulates lives” (xvi). Medicine can manage cancer and sometimes cure it in certain cases, usually when the cancer has been caught early enough for it to not have spread very much, but the side effects of chemotherapy and radiation can cause their own damage, some of which is irreparable and long-lasting.

Tonguebreaker

One can reasonably believe that a book about disability and disabled people is different when written by a non-disabled person versus a disabled person, and this has certainly been claimed. In what follows, I explore this idea by comparing *The Fault in our Stars* with the literary collection *Tonguebreaker* by Leah Laksmi Piepzna-Samarasinha, a disabled Sri Lankan activist, performer, and writer, to examine their many differences and look for any similarities.

The most obvious differences between these texts are in genre and presentation. While *The Fault In Our Stars* is a young adult romance novel about teenagers with cancer, *Toungebreaker* is a set of poems and performance texts primarily about the author’s lived experiences of being physically disabled as well as being Sri-Lankan in the United States and in Canada. Several of the fictional characters in Green’s book either do

die or will die offscreen from their respective forms of cancer, but manage their conditions with the help of doctors and medication while they are alive. Piepzna-Samarasinha writes about their life, but also more about their friends with chronic conditions that may or may not end up killing them in the end, but their community at large seem to focus more on staying alive in ways that have nothing to do with medicine; rather, they want to eat and pay their bills and make the kind of art that fulfills themselves. Piepzna-Samarashinha also pays tribute to some of their friends and fellow activists who have died by suicide, and to a disabled community at large that uplifts each other in various ways no matter what when they know that no one else will if they do not. It is also worth noting that Hazel, Augustus, and Isaac are white and presumed middle class, which affords them many social privileges and does not force them to think much of the world outside of themselves; Piepzna-Samrashinha, on the other hand, is visibly not white and writes a lot about living in poverty, giving them much to worry about besides being disabled.

Something else that I find interesting is that *The Fault In Our Stars* does not so much as touch on how much it can cost to treat cancer. Health insurance is not mentioned even once throughout the novel. Nobody talks about money or paying for hospital visits. Economic class is left out entirely, so much so that there is no way of knowing what class these characters are a part of (this may not matter very much, but in any case, it points to a missed opportunity to even briefly comment on the healthcare system in the United States and the cost of keeping a child alive). The only mention of income is when Hazel mentions once that her father works for a real estate company, but it is not made clear

what exactly he does there. We also know that Mrs. Lancaster takes care of Hazel full time, and we learn that she plans to become a social worker upon finishing her Master's in Social Work degree, but we do not know if she worked prior to her daughter's diagnosis and therefore have less ways of guessing how drastically their financial situation would have changed as a result of suddenly having to leave a job. One could argue that because the protagonist and love interest are teenagers, they would likely pay less attention and/or have less awareness of such issues, but I have a hard time believing that Hazel would not even overhear a conversation between her parents regarding hospital bills and/or something related, such as an insurance payout or a collections notice. This is especially concerning given that Hazel has been undergoing an experimental treatment for her lung tumors for at least a couple of years, and health insurance companies in the United States are notorious for not covering the often extraordinarily high costs of experimental treatments and procedures for *any* kind of medical condition, not just cancer. One could also argue that Hazel would have no interest in learning about such things since she will not live long enough to see the kind of adulthood her parents embody, but there is no textual evidence of that, either. The financial reality of a situation like Hazel's is undeniable when one actually considers it, yet *The Fault In Our Stars* gives it so little consideration that there are not even enough breadcrumbs to explain away the lack of conversation.

Toungebreaker, on the other hand, does not have the luxury of shying away from talking about money and does not pretend that it does. In the introduction, Piepzn-Samarasinha writes that the literary organizations that funded them with grant money

when they were an up and coming writer in their twenties and thirties, but now that they are slightly older, not only do those organizations turn them down for grants, they sometimes ask for them to sit on their grant juries to give other writers money. They also write about community members lending each other a few dollars here and there during especially hard times, even when the person in need has been painful to deal with lately. Housing is a consistent topic as well. One poem called “Femme Houses” has a stanza about living in a house for \$175:

“fig tree and black mold and chill to the bone
and oven for heat
and it was ok to cry in front of the washerdryer
it was ok to borrow someone else’s fucked up car.
You could always live off the eggs and kimchi in your pantry if you needed to.
We were always ready for the end of the world” (lines 26-33, 34).

The stanza before that one touches on gentrification:

“We’ve all lost our beloved places
to five dollar lattes and shiny white couples pushing children.
I want there to be neighborhoods they’re afraid to go to.
I want them to know there are places they don’t belong.
I want them to hate us, to fear us,
to not see anything pretty in our houses that makes them want to buy them
up for cheap.” (lines 19-25, 33).

Also unlike *The Fault In Our Stars*, the speaker of the poems and performance texts that make up *Tonguebreaker* does not think about disability in a philosophical way; although there are some quasi-elements of philosophy, they are more grounded in a sense that recalls writer Cherri Moraga’s notion of theory in the flesh. This notion, which Moraga coined in her seminal essay collection *This Bridge Called My Back: Writings by*

Radical Women of Color, declares that a theory in the flesh “means one where the physical realities of our lives—our skin color, the land or concrete we grew up on, our sexual longings—all fuse to create a politic born out of necessity” (23). Since theories often tend to work better on paper than they do off of it, theory in the flesh asks us to build theories out of lived experiences so that they might make more sense and be more applicable. *Toungebreaker* understands this idea in a way that *The Fault In Our Stars* does not.

In *The Fault In Our Stars*, when the characters talk about cancer, they do not talk much about their lived experiences, and while they certainly do come up in conversation, they do not come up as often as one would expect. Hazel and Augustus do discuss the possibility of an afterlife on one occasion, but they speak about it in more general terms regarding its potential existence and not within the context of their respective illnesses, how one gets into a potential Heaven or potential Hell, or if an afterlife even consists of a Heaven or a Hell as opposed to other imagined versions of an afterlife. In any case, when the characters do discuss the realities of cancer, it is only in specific circumstances, such as when Augustus is driving with his prosthetic leg on the gas and brake pedals, when Augustus is further deteriorating from his recurrence, when Hazel summarizes the near death experience she had early in her diagnosis, and when Isaac has his second eye removed, although that particular conversation is more about what qualities they prefer in nurses than cancer itself.

Other than that, Hazel and Augustus also spend many of their conversations discussing the meaning of life, what it means to have lived well, and what it would mean

to die well. S.L. Huang, a fiction writer and survivor of pediatric cancer and adult cancer, writes in her 2015 review of the book that their discussions present a misleading representation of cancer patients: “I’ve known a lot of kids with cancer. We all had depth to our personalities outside of it, interests and motivations that didn’t have to do with ‘pain demanding to be felt ... Cancer treatment is a part of our lives. But it does not define us. Nor does it magically make us deep. Not a single one of us cancer kids were half as pretentious or *profound* as any of the kids in Green’s book. I quickly became exhausted by both Hazel and Gus’s existential ridiculousness.” Furthermore, Huang finds herself frustrated not just with the unrealistic pretentiousness of the characters, but with the novel’s representation of pediatric cancer patients as a whole. Mostly, she finds it hypocritical that a book would claim not to be a “cancer book,” whatever that means, go on to claim that these characters are more than their cancer, and then write those characters into a story with lives that entirely revolve around their cancer, noting that “Even Hazel’s reading choices and Gus’s videogame-playing are reflections of their reactions to cancer.”

Tonguebreaker’s theory in the flesh approach to discussing disability makes for more realistic and more effective disability representation. Piepzna-Samarasinha’s life does not revolve entirely around any one of their disabilities (they have disclosed being diagnosed with autism and fibromyalgia). They are autistic, disabled, nonbinary, American, Canadian, and Sri Lankan. Each of these aspects of their identity impact their life in different ways, and they all combine to create, as Moraga detailed, a politic born out of necessity. Piepzna-Samarasinha also deftly integrates the medical model (they

frequently mention inexpensive home remedies for chronic pain), the functional model (there are times when a poem's speaker has periods of time where the pain is so bad they have to spend days at a time in bed), and the social model of disability (social barriers and attitudes towards disability are also topics), while *The Fault In Our Stars* tries to concern itself with all three models and ends up falling into the medical model-enabled tropes it tries to criticize. There are far worse representations of disabled people and cancer patients in literature, but I cannot, in good conscience, call John Green's attempt at disability representation of the good ones.

PARABLE OF THE SOWER AND WHAT IT MEANS TO BE VISIBLE

Parable of the Sower Summary and Hyperempathy

When most people think about imagined futures, they usually first think in terms of technological advancements. They might typically imagine a cartoonish *Jetsons*-like future with flying cars and robots everywhere doing almost everything in service of humans. The more apocalyptic-minded people usually might imagine something more akin to the science fiction movie *Blade Runner* or a Cormac McCarthy novel. They also typically imagine, or rather, don't imagine, the people that might live in these futures. No matter what the example is, it is usually considered that the people who would live in these futures are mostly, if not entirely, straight white able bodied cisgender males who are usually adults but sometimes children (this is definitely not exclusive to any one medium or to works of speculative fiction and/or science fiction, but the point still stands).

In writing the 1993 novel *Parable of the Sower*, Octavia E. Butler imagines the exact opposite of the norm in futuristic science fiction and speculative fiction. Her main protagonist, Lauren Oya Olamina, is fifteen years old at the beginning of the novel, which gives the start date as the summer of the year 2024, Black, female, and was born with a fictional (or, as Sami Schalk calls it, nonrealist) disability called hyperempathy, which is not explicitly called a disability in the story but is implicitly socialized as one whether scholars recognize it or not, and as we will discuss later, many of them do not.

This alone makes *Parable of the Sower* radically different from many other works of speculative fiction, and the specificity and clarity with which Butler writes makes it even more so. As scholar Sami Schalk points out in *Bodyminds Reimagined: (Dis)ability, Race, And Gender In Black Women's Speculative Fiction*, “Butler’s construction of hyperempathy in a future dystopian California challenges the notion that a technologically created, disability-free future is an inherently good future” (102). The pursuit of technological progression is shown to be the cause of many of the problems this world faces; in fact, as we discuss later, it is the innovation and misuse of new drugs that lead to the emergence of hyperempathy and the destruction enacted by those addicted to them. The notion of a disability-free future being inherently good is also something that Alison Kafer challenges throughout *Queer, Feminist, Crip*. Nondisabled people may believe in the inherent goodness of a future without disability and the grimness of a future for disabled people, but disabled people themselves often imagine their own futures as fruitful, “as lives lived fully” (2). Lauren spends the whole first half of the book not just planning for any and all possible disasters, but imagining a better future for herself in which she can freely express her belief in her own God, work a well-paying job, get married, maybe have children, become as self reliant as possible, build a functioning community, and not have to spend every waking moment worrying about her safety.

While genre is not a main focus of this chapter, the ways in which the genre is subverted are noted because of their importance to the contexts in which this book is written about and discussed. Arguably, the biggest subversion of the science fiction genre

is the lack of out-of-this-world technological advancement. There are some advancements, to be sure, such as new drugs being developed and methods of space travel being tested out, all to varying results. However, this is an apocalyptic world, and during an apocalypse, societies do not move forward in any capacity; rather, they fall back, and this society very much falls back.

One of the most important elements of Lauren's story is her hyperempathy, or, as she calls it, her sharing. When Butler initially began writing *Parable of the Sower*, hyperempathy took a different shape than she ended up with in the published version. At first, it was something that would spread via skin to skin contact, somewhat like the most common illnesses. Hyperempathy would take several different variations of this idea throughout chapter fragments and some of the novel's early drafts before it became something one was born with, usually following a pregnancy during which the mother abused drugs, as happened with Lauren. As a result, Lauren experiences both the pain and the pleasure of everyone she sees experiencing them; or, as she describes it, "I feel what I see others feeling or what I believe they feel," hence why she calls herself a "sharer" (Butler 12). In instances when she encounters someone getting shot, she goes right down with them, sometimes even falling unconscious from the pain, and has to take time to recover. During sexual intercourse, she experiences her partner's pleasure as well as her own (this is assuming the sex is consensual; but even if she did not consent, she still would experience the other person's pleasure). As a very young child, she even used to bleed upon seeing someone else bleed (or pretend to bleed, as her younger brother Keith used to do by drawing on himself with a red pen in her line of sight as a cruel

prank), but that had stopped upon getting her first period, something that came as a relief, but she expresses her wish that “all the rest of it had gone away, too” (11).

In the chapter of *Bodyminds Reimagined* that focuses on *Parable of the Sower*, Sami Schalk writes about how so many scholars do not recognize hyperempathy as a disability; in fact, she writes, some of them even see it as a superpower for Lauren, unconsciously characterizing her as a supercrip. Very few scholars appear to see the writing on the wall; those who do often tend to see it as a negative. Of those who do not recognize hyperempathy as a disability, Schalk writes that “they tend to refer to hyperempathy as an affliction, condition, or disease—language that resides in the medical model of disability and is counter to the work of the disability rights movement to understand disability as simultaneously social, relational, and material” (*Bodyminds Reimagined* 88). Others tend to discuss it as a metaphor, which is an easy trap to fall into given its fictional nature. The understanding that comes from reading hyperempathy as a metaphor is that making Lauren disabled is, according to Schalk, “a pragmatic move not intended to demonstrate anything about (dis)ability or ableism, but to make readers think about other issues such as social barriers, cultural indifference, the need for connection, and the sociopolitical value of empathy. While these readings all hold important truths about the implications of Lauren’s disability and Butler’s authorial choices in constructing hyperempathy as she did, reducing disability to simply metaphor erases the material importance of hyperempathy to the series” (94-95). Besides that, Schalk argues, “metaphorical readings of hyperempathy obscure what this speculative fictional disability might indicate to us about disability in the real world, especially in relationship to race

and gender and visions of the future. As a result, this totalizing metaphorical approach to Lauren's disability tends to be reductive and to deflect from the centrality of disability to the *Parable* series" (95).

Unfortunately, the failure to properly contextualize disability within literature is not limited to Octavia E. Butler and *Parable of the Sower*. In "'Not to Discover Weakness is the Artifice of Strength': Emily Dickinson, Constraint, and a Disability Poetics," Clare Mullaney writes in the introduction about a literary critic from 1890 who criticized the poet Emily Dickinson's work by insisting that her ailments caused her to fail as a poet and writer. Others tried to give a name or even diagnose her with various disabilities, none of which she got when she was alive, as she refused medical intervention and the naming of her sickness (she was known to have had a persistent and severe cough as a child and experienced problems with her eyes in her thirties); and some others even deny that Dickinson ever had a relation to any disability. Her actual relationship to disability, Mullaney argues, was far more complicated than any critic will admit. She shunned medical diagnosis, but she wrote about disability frequently in her poems, making references to "loss of vision, pain, sensory deprivation, the brain's 'cleavings,' and death" (51).

Despite the limited number of scholars known to properly understand and contextualize Lauren's hyperempathy as a disability, Schalk is not the only scholar known to have taken notice of this issue. While writing in a similar vein, Anna Hinton notes in "Making Do with What You Don't Have: Disabled Black Motherhood in Octavia E. Butler's *Parable of the Sower* and *Parable of the Talents*" that the

conversation about disability in the *Parable* series and Butler's body of work as a whole is a more recent one. Hinton also writes that:

“Because hyperempathy syndrome is psychosomatic and invisible, people often disbelieve or doubt the legitimacy of Lauren’s disability. For instance, though Lauren admires her father, a preacher and professor, as ‘the best person she knows,’ ableism strains their relationship. He insists that she can overcome her disability if she tries hard enough. For him, hyperempathy’s delusional nature renders Lauren’s experiences of pain and disablement unreal. Though Lauren’s hyperempathy is triggered by her visual perception and interpretation of other bodies, that does little to mediate the phenomenological experience of pain. Lauren affirms, “I’m crazy. I get a lot of grief that doesn’t belong to me, and that isn’t real. But it hurts” (Sower 8). Though Lauren never overcomes her disability, her father teaches her to hide it, so she often, for her own safety, passes as able-bodied. The invisible nature of her disability and her ability to pass as able-bodied underscore the doubt and disbelief evoked by hyperempathy’s delusional quality” (445-446).

As noted in the above quote from Hinton, hyperempathy is considered to be an invisible disability as opposed to a visible one, meaning that the untrained eye cannot tell that Lauren has hyperempathy just by looking at her, at least not under nonviolent circumstances. While that makes it easy for her to assimilate into a primarily able-bodied community (she was raised and spends the first half of the book in a fictional suburb of Los Angeles called Robledo, which is predominantly nonwhite but racially diverse with little other mention of disability), it also means that she has to “come out” to others as disabled, so to speak, every time she discloses the information to someone; this also puts her at risk of being “outed” as a sharer if she trusts the wrong person with her secret at the wrong time.

Despite frequent comparisons, coming out as disabled is not quite like coming out as gay, something that Ellen Jean Samuels notes about disabled coming-out narratives in

“My Body, My Closet: Invisible Disability and The Limits of Coming-Out Discourse”:
“coming out is primarily portrayed as the process of revealing or explaining one’s disability *to* others, rather than as an act of self-acceptance facilitated by a disability community” (239). Lauren, similar to other people with invisible disabilities, comes out several times in this exact manner, with the first time being the most notable. When she is forced to leave Robledo behind after a group of outsiders violently burn it to the ground, she comes out to her two fellow survivors because she has no other choice if she wants them to survive with or without her. The act of coming out to them entails disclosing her family history, what exactly it means to have hyperempathy, and what she needs from them if they are going to stay together as a group, all of which she does for the very first time. Both survivors react in different ways: Zahra, whom Lauren had not known well before, reflects on growing up around children born from drug-addicted parents and tells Lauren there is nothing wrong with her, and Harry, whom Lauren had known better growing up, is shocked and upset that he did not know her as well as he thought, but ultimately does not leave. From then on, she only tells the people whom she feels needs to know about it, never to complete strangers and only if she gets to know the person well enough.

Hyperempathy and the Models of Disability

When it comes to the three main models of disability—medical, functional, and social—hyperempathy can fit in all three, all for different reasons. The medical model frames disability as something to be managed with medical science and technology

whether it can be scientifically classified as a disability or not; the functional model frames disability as an inherent deficit that limits one's functionality; and the social model frames disability as something enacted onto Others by unaccepting systems of power with the purpose of exclusion.

I wrote earlier that historically, the medical model of disability has been the dominant narrative; lately, it is becoming more widely understood as a problematic narrative framework that causes more harm than good to the people it seeks to define. Despite this problematic history, hyperempathy can somewhat fit into this model, at least a little bit. There is never any mention of medical treatment or cure for hyperempathy ("my neurotransmitters are scrambled," Lauren says, "and they're going to stay scrambled" [Butler 12]), even potential ones, but like many real life illnesses and disabilities, its primarily known cause is by drug abuse during pregnancy, though it can also be a hereditary condition. Lauren's biological mother abused a fictional drug named Paracetco that had been created for Alzheimer's patients, but became popular among people in academic circles (although its frequent use was not exclusive to academics and students; Lauren's friend and neighbor Zahra, who grew up homeless and surrounded by addicts, says it was "baby milk" [193]) and gained the nickname "the Einstein drug." She would die giving birth to Lauren (it is unclear how much her drug abuse had to do with this), and the stigma of having a drug-addicted mother who died in childbirth would follow her throughout her entire childhood: "To my father, the whole business is shameful. He's a preacher and a professor and a dean. A first wife who was a drug addict and a daughter who is drug damaged is not something he wants to boast about. Lucky for

me. Being the most vulnerable person I know is damned sure not something I want to boast about” (12).

Lauren’s father told her never to tell anybody outside of their immediate family about her hyperempathy, and though he never said it outright, she knows he seemed to think the pain was all in her head, echoing a dominant attitude toward those with chronic pain and similar chronic conditions. Lauren herself says “Maybe this sharing thing is in my head? Of course it is! And I can’t get it out. Believe me, I’d love to” (Butler 194). Even the doctors in Lauren’s world refer to hyperempathy as “organic delusion syndrome.” The choice of words here tells us two things: one, that hyperempathy is above the understanding of medical science at this point in time; and two, that because doctors cannot understand it, then it must be all in a patient’s head, otherwise the word “delusion” would not be included in the name. This attitude exposes one of the biggest problems with the medical model, which is that it does not believe in anything that medical science does not yet understand—nevermind the fact that scientific progress can take years, sometimes even centuries, for something to truly be developed and understood, and even then, our understanding of any given disease or disability can always change for some reason or another. Unfortunately, this attitude is not limited to doctors. People with invisible disabilities are often accused by nondisabled people in public and private (and on the Internet, if the public spectacle of actress Jameela Jamil coming out as having multiple chronic disabilities, including Ehlers-Danlos Syndrome, and being subjected to harassment from Internet sleuths determined to prove she was “faking” is any indication of the issue) of faking their disabilities and even harassed for

“lying.” Similarly, women, and Black women in particular, disabled and non disabled alike, have historically been marginalized by the American medical profession in a myriad of ways that often boil down to their concerns and pain being outright dismissed by doctors, such as when tennis great Serena Williams, a Black woman, felt the beginnings of a pulmonary embolism after childbirth, but was dismissed by the nurses until she insisted on getting the tests enough for them that they relented, and sure enough, she was right. The consequences of this kind of behavior by physicians in all fields have led to irreparable harm suffered by their female and nonwhite patients, and sometimes even to their deaths, many of which could have been avoided had these patients been taken seriously. This topic is not explored in *Parable of the Sower*, but given that the protagonist is a Black girl and racism is shown to be alive and well in this world, it very much warrants recognition.

For her part, Lauren believes and understands that her father was just trying to protect her by instructing her to hide her hyperempathy from non-family members, stating that “In this world, there isn’t any room for housebound, frightened, squeamish people, and that’s what I might have become if everyone had known about me—all the other kids, for instance. Little kids are vicious” (Butler 194). She also says that even though her father was wrong about her being “normal,” she was glad he tried to convince her that she was anyway; though she does not elaborate on why she feels that way at that moment, it is reasonable to assume her gratitude has to do with the survival skills she learned from it, as she would use them even after her father and her community were gone. This attitude calls to mind an observation from sociologist and journalist Andrew

Solomon about child prodigies reflecting on how their parents raised them in his book *Far from the Tree: Parents, Children, and the Search for Identity*: “if the gamble pays off, the sacrifices are easier to live with ... what looks like abuse in the present abuse in the present does not necessarily seem so once it’s been completed successfully” (455). This is not to insinuate whether Mr. Olamina was or was not abusive in how he treated Lauren’s disability; this is merely to suggest that Lauren chose to learn from her life experiences instead of dwelling on them.

She also seems to feel mostly ambivalent about her hyperempathy, which might also factor into her feelings about this situation. If she feels ambivalent about having hyperempathy, she would likely not have strong feelings about being told to act like she did not. Additionally, she does not romanticize the condition or say that it made her a stronger person or a better person, and she does not treat it like a tragedy that unfairly befell her. She also never appears especially angry about the perceived notion from others that it must be in her head; she just faces the reality of her situation and takes it as it is. She does what she can while she can do it, and she does whatever she has to do to survive. It may not be self-acceptance in the traditional sense, but it is a form of self-acceptance nonetheless.

Hyperempathy fits into the functional model in more practical ways. When Lauren experiences someone’s pain, it can indeed limit her functionality, especially if the pain is caused by particularly violent means. Late in the novel, when her travel group is attacked, she witnesses one of the attackers get shot. When they go down, she goes right down with them and falls unconscious. While she does get back up and back to normal

eventually, her early moves are slow and painful, and the whole group has to take it easy for a while to accommodate her. On another occasion, she sees a friend vomit from the effects of a concussion and feels sick herself at the sight, and not in the way that one might generally feel nauseous from watching someone else throw up. That kind of feeling is amplified for Lauren and others like her.

While, again, hyperempathy fits into all three main models of disability, it fits the most strongly into the social model. Lauren is almost never preoccupied with feeling other people's pleasure, as "there isn't much pleasure around these days" (Butler 12), but she is extremely anxious about feeling other people's (and also animal's) pain. She knows from an early age that she will have to kill people to save herself in deadly situations, and when she ends up in those situations, she kills people in self-defense without a second thought, and while she does not enjoy it at all, she feels no particular remorse over it. If the world around her had no violence, or even if the world just had less violence than there is, she would have less of a problem or even no problem with her hyperempathy, something that Lauren starts to think about when Keith's dead, violently mutilated body is found and buried:

"It's beyond me how one human being could do that to another. If hyperempathy syndrome were a more common complaint, people wouldn't do such things. They could kill if they had to, and bear the pain of it or be destroyed by it. But if everyone could feel everyone else's pain, who would torture? Who would cause anyone unnecessary pain? I've never thought of my problem as something that might do some good before, but the way things are, I think it would help. I wish I could give it to people. Failing that, I wish I could find other people who have it, and live among them. A biological conscience is better than no conscience at all" (p 115).

Instead, she has to move through the world ready to defend herself and others at a moment's notice and avoid any situation in which she can be made emotionally and/or vulnerable. When she witnesses someone's extreme pain, she can quite literally become physically disabled. In the end, it is the prevalence of violence that makes hyperempathy a "social disability," in the words of Devon Price (*Creating a Neurodiverse World*), which "goes hand in hand with the obligation to mask."

Furthermore, much of the violence around her is only made possible by the deterioration of this world's society as well as the corruption and ineffectiveness of the United States government at large. Local police never seem to even attempt to solve crimes; whenever called, they usually just take a service fee from the caller and go on their way. When they come to Robledo to investigate Keith's death, they look for a reason to arrest Mr. Olamina for the murder after a spiteful neighbor makes allusions to their frequent arguments, but when the rest of the community does not provide them with a reason to arrest him, they leave in a huff. When an astronaut dies in space while on a mission, most people just see the news and express the feeling that funding space expeditions is a giant waste of the government's money. Company towns make a comeback, and they more or less enslave the people who apply and get accepted to live there without consequences from law enforcement. When one of the families in Robledo gets accepted to live in a new company town nearby, armed guards from the company come to escort them, which tells Lauren all she needs to know about the place. We come to learn that those who run those towns especially target those with hyperempathy to come work for them because they are thought to be easier for them to control than those

who do not have it. Lauren, admittedly, is more privileged than most in her world—she lives in a house in a gated community, her father and stepmother are PhD-level educated with stable jobs and are highly respected, her family and neighbors can grow food in their gardens at a time when store bought food and ingredients are very expensive, which, all in all, renders her less likely to become disabled by the sight of someone in extreme pain than those without such privileges—but she is under no illusion that she is even remotely safe, let alone completely safe, even as a fifteen year old who can hardly go outside of her gated community.

Lauren is shown to not be the only one around who notices how badly the world is falling apart, but she is shown to be one of the only ones to make any kind of preparations for the possibility that the ongoing destruction will come to them. Of those few, she is one of the only ones to recognize that in the end, the only real option will have next to nothing to do with a new president (the novel opens during an election year, which results in a Ronald Reagan-esque politician with a similar following taking office in a landslide win), company towns, or their community. In the end, she knows she will have to leave her home one day, and she knows she will have to brave dangerous parts of the outside world to get anywhere worth going to. In the meantime, she prepares herself as best she can. She makes an emergency go-bag and fills it with as much money, seeds for planting, spare clothes, matches, forks, spoons, writing materials, and nonperishable foods as she can carry. She teaches herself about edible plants and goes outside of the walls for target practice with some of her neighbors so that she can get better at using a gun. On one of Keith's visits, she asks him questions about what goes on where he has

been staying outside of Robledo. She also takes the time to learn more niche things like how to skin and clean a rabbit.

When Zahra, her neighbor who taught her how to handle dead rabbits and later survived the massacre of Robledo with her, asks why she wanted to learn, Lauren says “I wanted to know that I could do that—handle a dead animal, skin it, butcher it, treat its hide to make leather. I wanted to know how to do it, and that I could do it without getting sick...Because I thought someday I might have to. And we might out here. Same reason I put together an emergency pack and kept it where I could grab it” (186). In short, she made sure to think of everything she possibly could.

“God Is Change”

On that note, adaptability is easily the most consistent theme throughout *Parable of the Sower*, and that is no coincidence in a story with a disabled protagonist. Only a disabled person or a person of another marginalized identity—or multiple identities intersecting—could or would think about adaptability in the terms that Lauren thinks of them in. A person who has never experienced minoritization might never have thought of “God is Change” or thought to build a religion around adapting to change. It is partly because of how Lauren lives her life as a minoritized person that she is able to consider so many factors to an evacuation plan, to think so far in advance about leaving her home and traveling to somewhat safer places, to prepare herself for the more unsavory tasks that will be required of her if she wants to survive. A non minoritized person might never have thought to do anything that she did; at least, they might have been less likely to

make the same decisions. Inherently, to be minoritized is to always be ready for change, and for the possibility of it.

All that being said, Lauren's perspective as a disabled person (not that she would necessarily call herself disabled) is definitely not the only reason she thinks the way she does about change and adaptability. It also has to do with living during a time of massive change. There are big, seemingly surface level changes that happen early on in the story, such as the presidential election and the reemergence of company towns. Other big changes include the emergence and fast spread of a new highly addictive drug named Pyro, which causes users to feel an unusually strong gratification by watching fire burn that is comparable to sexual gratification. Robledo undergoes changes within its walls in just about every chapter: a neighbor dies and some of her family members move into her house; almost all of those family members are later killed in a house fire; a toddler dies by accident and her mother later goes missing in a fit of grief; people get married and/or have children; Lauren's younger half-brother Keith moves out and later gets killed; her father goes missing and is presumed dead; her best friend Joanne's family gets accepted to live in a company town called Olivar and moves away; and break-ins and robberies become more and more frequent until the neighborhood is finally burned to the ground altogether and looted in the aftermath. At least some of the residents of Robledo recognize that their world and their community is changing for the worse as these things happen. Joanne's family applies to Olivar for the promise of safety and better economic opportunities than they can find in or near Robledo. Lauren's boyfriend Curtis asks her to marry him and leave Robledo with him so that they can escape the place he sees as dying;

once he realizes that she was already thinking of leaving, and probably without him at that, he feels affronted but agrees to wait for her to be fully ready. He knows she has to wait for her family to stabilize, but has never known about her hyperempathy, and Lauren wonders if he would leave her once he knew. In any case, she knows that she has to tell him before they can get married, but she never gets to do either after Curtis dies in the massacre of their neighborhood.

The Olamina family dynamics change greatly as well. In the months before his murder, Keith had been getting more and more bold in his defiance of his father, not just in his questioning of his father's rules, but also in his blatant flouting of them. He takes to leaving Robledo without permission for hours, sometimes days at a time until he eventually moves out for good and only comes to visit when he knows that his father will be out of the house. When her father and Cori, her stepmother, argue over his inability to find Keith after spending a whole day looking for him, Cori exclaims to him that "If it were your precious Lauren out there alone, you would have found her by now! You don't care about Keith" (96). Up until this point, Lauren had thought that Cori loved her, even though they only came to be so close and never really thought of themselves as mother and daughter, but this moment made it very clear that she did not, and even though her dad tries to convince her otherwise, she knows better than to believe it, and it does hurt her. The relationship between Cori and Lauren is irreparably damaged after that night, and we hardly ever see them so much as acknowledge each other ever again, let alone interact with each other, until the night Robledo falls, and even that interaction is

momentary and a more general family effort to get everyone else to hurry up and run as fast as they can to safety.

The biggest, most impactful, and arguably worst change that comes to the Olamina family is when Lauren's father goes missing one day after leaving for work and not coming back. As a college professor and Baptist preacher, he had been both the moral authority of their family and community and the family breadwinner, and then he was suddenly gone without a trace. After eventually giving up the search for him and having a funeral without a body to bury, Cory becomes the breadwinner by taking over her husband's job at the college, and then Lauren takes over Cory's job as a teacher to the kids in the community (she had been teaching the younger kids to some degree already, but took on more duties during this time). Cori also applies to move the family to Olivar, but Lauren does not believe that they will be accepted, and even if they are, she shares her father's recognition that such a town is little more than a trap meant to ensnare its victims in lifelong indentured servitude. She resolves that once her family becomes more financially stable, she will leave Robledo to go north to the Oregon border for safer places and better job opportunities, possibly further on to Canada if she is able to, and she believes that she will likely be all on her own as she does this. Eventually, when Robledo is raided and destroyed with only Lauren, Zahra, and their other neighbor Harry surviving the attack (or so it seems, but the possibility of other survivors is never considered until the sequel novel, *Parable of the Talents*, which was published in 1995 takes place years after the first novel ends), there is no choice for them but to band together and go north on foot as soon as they get their bearings. The biggest, most catastrophic of all possible

changes requires the most drastic of actions, and after experiencing their own personal apocalypse, anything that had seemed unthinkable before is no longer quite so unthinkable, especially when the only other option is death.

Lauren also thinks about change in ways that are not strictly material. When discussing Earthseed with Travis, a man who becomes her first convert, she tells him “Change is ongoing. Everything changes in some way—size, position, composition, frequency, velocity, thinking, whatever. Every living thing, every bit of matter, all the energy in the universe changes in some way. I don’t claim that everything changes in every way, but everything changes in some way” (218). Even at the beginning of the novel, Lauren has already started to change. The first chapter opens with what has become the most well known Earthseed verse:

“All that you touch
You Change.

All that you Change
Changes you.

The only lasting truth
is Change.

God
Is Change.” (3).

The second chapter’s narration begins with the confession that Lauren has not shared her father’s God and church for the past three years, since she was twelve. She only gets baptized into his church out of a sense of duty, and also because she does not want to disappoint him, something that she calls herself a coward for. She also notes that

the only reason she and the other neighborhood are getting baptized in an actual church outside of the neighborhood walls (Mr. Olamina holds his services in the family home and has done so since his own church was burned down after years of being affected by vandalization and vagrancy) is because the adults want to return to a sense of normalcy from the time before their neighborhood needed walls and one did not need to carry a gun anytime they went outside of those walls. Lauren herself has never known any other way of life and remarks that it seems crazy to her that a neighborhood would not have walls to protect itself. A neighbor's family even gets killed in their unwalled neighborhood when someone lights their house on fire. In any case, Lauren, unlike some of the adults in Robledo, has no faith that their society will return to the way it was before, and anything that does return will not be the kind of return that does any good.

Another Earthseed verse touches on learning and intelligence:

“Intelligence is ongoing, individual
 adaptability. Adaptations that an intelligent species
 may make in
 a single generation, other species
 make over
 many generations of selective breeding
 and selective dying. Yet intelligence is
 demanding.
 If it is misdirected by accident or by
 intent, it can
 foster its own orgies of breeding and
 dying” (Butler 29).

Another reads:

“Earthseed
 Cast on new ground
 Must first perceive

That it knows nothing.” (Butler 179).

Lauren knows that learning is a lifelong process, and that learning fundamentally changes a person, even if they learn something that they do not wish to know, hence this other Earthseed verse:

“Drowning people
Sometimes die
Fighting their rescuers” (Butler 61).

For example, when Lauren tells her best friend Joanne about her expectation that Robledo will fall and her plan to escape it, Joanne becomes so scared of the prospect that she tells her mother and accidentally gets Lauren in trouble with her father, an act that damages their relationship. It is only when Joanne’s family gets accepted by Olivar and she has a way out that she feels comfortable discussing the dismal state of Robledo, and but then, she remains in denial when Lauren says that Olivar will likely not be better and that other company towns are bound to follow; ““Oh, God, there you go again. You’ve always got a disaster up your sleeve,” to which Lauren responds, ““I see what’s out there. You see it too. You just deny it”” (Butler 129).

When the Olamina family discusses the prospect of applying to Olivar, with Cory arguing that they would be better off there and Mr. Olamina remarks that the well-off people who lived there before the corporate takeover may not understand that they are essentially opening the door to becoming enslaved, Lauren says “I don’t think they’d dare let themselves know,” and later thinks to herself that “I’m still learning how dogged people can be in denial, even when their freedom or their lives are at stake. He’s [Mr.

Olamina] lived with it longer. I wonder how” (121). Harry spends his first few days out on the open road in denial of the idea that he, Lauren and Zahra might have to hurt and/or kill people to protect themselves, but after some close calls involving robbers and several speeches from Lauren and Zahra about getting his head out of Robledo and into thinking about protecting each other, he stops objecting to the idea but does not outright repeat their rhetoric. However, Earthseed also believes that “Kindness eases Change,” (Butler 167), and it is through radical acts of kindness that enable Lauren, Harry, and Zahra to band together and walk north, and as the second half of the novel progresses, similar radical acts of kindness enable Lauren to create an entire community and settle down somewhere new.

Besides the necessity of learning and adapting, Earthseed revolves around the declaration that God is Change, with the word “change” always being capitalized in Earthseed verses just as the word “God” is capitalized in Earthseed verses and just about every monotheistic religion’s chosen text. In this religion, God is not a king or a master or a parent. God is Change in the same way that God is nature, in that it cannot be shaped in the eye of the beholder. God just *is*, God just happens, just as change just happens whether you want it to or not. As Lauren writes in Earthseed: The Book of the Living,

“We do not worship God.
 We perceive and attend God.
 We learn from God.
 With forethought and work,
 We shape God.
 In the end, we wield to God.
 We adapt and endure,
 For we are Earthseed
 And God is Change.” (Butler 17).

In other words, God is often seen as an inevitable, unstoppable force, but in the flesh, Change is the inevitable and unstoppable force that all of life revolves around. Disabled people know this all too well, hence why so much of real life disability advocacy rhetoric revolves around adaptation, and why many disability advocacy groups and movements have variations of the word “adapt” in their names. Lauren, as a disabled person living both in the aftermath of great change and at a time of even greater change (for even regression is a kind of change) that too many people around her try to ignore as best as they can to varying degrees of success or failure, comes to an understanding of the importance of the life-saving ability to adapt to all situations. Misuse of medicine gave her hyperempathy that could affect her functionality at times, and she had to learn to adapt to the world around her for her own survival because the world would not change for her. The lived realities of the models of disability in this world all came together for Lauren to create Earthseed, and beyond survival, she made it her life’s work to teach the principles of adaptability to others—but that’s another story.

GOOD KINGS, BAD KINGS, AND WHO HAS THE POWER

The Nursing Home Industrial Complex

In the preface to the 2009 edition of their book *Exile and Pride*, disability scholar and activist Eli Clare notes that progressive activists, both disabled and nondisabled, historically have not and usually do not engage in multi-issue organizing and thinking. To encapsulate this claim, Clare writes about a flier they saw at an ADAPT event that read “You think prison is bad, try a nursing home” (xxii). “In one simple slogan,” Clare opines of the sign, “disability activists advanced a hierarchy of institutions and oppressions, defined disability as their sole focus, and revealed profound ignorance about the ways being locked up in prisons cause bone-crushing damage, particularly in communities of color. This slogan and the disability politics behind it leave little chance for making connections and addressing the daily complexities of folks who know the grief and outrage of both prisons and nursing homes” (xxii).

A bit later on in the preface, Clare also recalls seeing a different sign at an antiwar rally declaring the age-old saying that an eye for an eye makes the whole world blind, as though blindness is an inherent deficit and a blind world can only result in absolute destruction. They write that “this slogan is one of many that turns disability into a metaphor, reinforces that disability means broken and is fundamentally undesirable, and ignores the multitude of actual lived disability experiences connected to war. For folks who know blindness/disability as a consequence of crushing military force, the “eye for

an eye” slogan offers a superficial rationale for nonviolence but no lasting justice. In response, I’d like to stand next to those anti-war activists and hold a placard that reads “Another cripple for peace,” or maybe, “Blindness is sexy; military force is not” (xxiv).

As a way of bridging the gap between these issues, Clare writes of wishing to “introduce disability activists to prison activists, to stories of solitary confinement, rape, and death row, to the rampant injustice of the so-called criminal justice system and the staggering incarceration rates for Black and Latino/a men, women, and trans people. In turn, I’d like prison activists to hear disability stories about nursing homes, group homes, psych wards, and state-run hospitals, about neglect, punishment, rape, abuse of power, about the many pressures that force disabled people into institutions and trap them there. The ensuing conversations across communities and issues—hours of talk about violence, isolation, forced sterilization, medical experimentation, institutional cruelty and indifference—would be painful and vitally important, exposing the interlocking power structures that both cause disability and lock up disabled people” (xxii).

This may or may not have been the point that Clare was trying to make here, but something that I took from these quotes is that prisons and institutions for disabled people have a lot in common, especially their intended purpose and functionality. Of course, one should not ever be used to minimize the problems of the other, but a lot can be said about direct comparisons between the two. Both are extreme forms of confinement and isolation. Both are considered to be unique horrors to those who have experienced them. Both are primarily populated by poor people and people of color as well as people who are both, not to mention queer people and disabled people across all spectrums.

Investigations into both types of facilities find high levels of physical and sexual violence committed against those who are forced to be there. Both have documented histories of forced medical experimentations and sterilization, although this history is lesser known in the mainstream. Both also have the same problems whether they are state-run or privately-run entities. The officials who work at and run these institutions are also not above corruption and bribery to benefit their own self-interests. When one is admitted to a prison or a facility for disabled people, getting out is hard, sometimes even impossible, sometimes depending on a person's circumstances.

Sami Schalk also directly addresses the criminalization of disabled people in the introduction to *Bodyminds Reimagined*, although she addresses it in the context of another novel and its movie adaptation, called *The Girl With All The Gifts*. That story takes place in a post-apocalyptic world in which zombies can be created by transmitting a parasitic fungus through bodily fluids. The protagonist is a child with a zombie's appetite for brains and flesh and a human's functionality who has spent her whole life imprisoned on a military base until she is forced to escape, and even on the run, the soldiers treat her as a criminal with a dangerous disability, while the doctor character just sees her as a body she can dissect at will to satisfy her scientific curiosity, and the girl's consent, let alone her humanity, is never a question. It takes the extreme act of creating an atmosphere that would turn everyone in the world that is not already a zombie into one for there to be any possibility of personhood for her. Sadly, the mentalities that lead up to this are not limited to this science fiction story, or any fiction story.

Author Susan Nussbaum (who, sadly, died of complications from pneumonia at age 68 as I was researching for this project) got the idea to write *Good Kings, Bad Kings* from a *New York Times* article that reported the death of an autistic boy named Jonathan Carey at the hands of an employee at the New York institution where he had been placed and the extensive abuse and corruption that took place there. The employee who committed the murder laid the boy face down and sat on him while they were in the backseat of a moving vehicle until he suffocated to death; while doing so, his coworker, who was driving the van, claims that he said “I can be a good king or I can be a bad king.” Nussbaum would use this as inspiration for the title and also write this quote into the book as a line of dialogue.

Jonathan’s murder prompted an investigation into the institution, and the results were beyond horrifying. The institution was underfunded and understaffed, which meant resources were spread thin. On the day of Jonathan’s murder, the employee who killed him had been working for fifteen days straight without a day off, and he was also found to have been present during another abusive incident involving Jonathan (he also had a ninth grade education, a marijuana conviction, and a conviction for firing a shotgun in his attic, all of which should have made him unqualified for the job in the first place). The driver of the van that day had been fired from four other similar institutions prior, all for different kinds of offenses, before getting hired there, even though a state official admitted to knowing that the employee lied about not having a suspended driver license when he applied there in the first place. A different employee regularly came to work drunk. Aides were not paid living wages. Inspections by the Health Department found

that management routinely ignored obvious injuries and signs of physical abuse against the residents. Two months after Jonathan was admitted to the institution, they were barred from admitting more, which his family never knew about, nor did they know about the high number of uninvestigated injuries that lead to the ban. Whistleblowers and affected family members of residents were often retaliated against for reporting abuse, either from the institutions directly or from the Office for People With Developmental Disabilities, who never acted on any reports of abuse. In rare cases of complaints being taken seriously, abusive employees were usually just reassigned to different duties. Sometimes, employees were even fired and rehired, including those with recommendations not to be. The *New York Times* investigation also cited similar cases in other state institutions; they also reported that these institutions managed to secure billions of dollars in state and federal funding and averaged spending less than half a million dollars per resident for their care. In the years since the story broke, it has become abundantly clear that the same problems lie everywhere you care to look, and everywhere you don't.

“Emphasis on ‘Ill’”

Like too many institutions in real life, the Illinois Learning and Life Skills Center, a.k.a. ILCC, “emphasis on ‘ill’” (Nussbaum 10), the state-run but privately contracted institution in *Good Kings, Bad Kings* is rife with issues, as are all of the institutions run under this ownership group. Plenty of staff members, as few as there are, have no qualms about hurting and/or neglecting the people they are employed to look after. One such

aide, a man named Louie, is a former prison guard who clearly views his job at ILLC as the same thing at a different place (he even carries a Taser at work), which is demonstrated by his constant harassment and abuse of the residents, particularly towards those whom he especially dislikes because of what he perceives as slights against himself. He is the one who eventually says, "I can be a good king or I can be a bad king" (135), although he walks away from the resident he was beating up and insulting after saying it. Acts of violence and/or withholding food at mealtimes despite not having that kind of authority are often his first, and sometimes only, resort when it comes to either discipline or someone not doing exactly what he says when he says no matter the reason. The residents regularly compare him to or directly call him a skinhead; in light of this, it should be mentioned that Louis is a white man and many of the residents are people of color. Another aide, Candy, is dismissive of the residents' overall humanity, telling Louie that "children will manipulate you if you give them a chance. They'll play you off against each other, they'll lie. And these ones'll do worse than that because they know off the bat you're gonna feel sorry for them," to which Louie agrees (203). She even smokes cigarettes inside and right outside of the facility despite the fact that some of the residents have respiratory issues that require oxygen tanks to manage, which she is definitely well aware of. On top of all that, residents note that she never seems to be around, implying that she is lazy at best and neglectful at worst.

When one of the residents, Mia Ovedio, a young Mexican-American woman, is discovered to have contracted an STD, and Mia tells the attending nurse that she got it from a male staff member who had been raping her and had since been threatening her

not to tell anyone, the very first thing she is told in response is that it would be very bad if she were lying. Another resident, Teddy Dobbs, a white man, is left alone in a shower stall while the aide who is supposed to be helping him makes a phone call to attend to a personal matter; when the water comes out so hot he gets third and fourth degree burns (a recruiter later surmises that this must have been a result of broken pipes; another resident had noted to Teddy off-page that the water there always either comes out very hot or very cold), he falls out of his wheelchair to escape from the shower stall himself, later contracts pneumonia and dies in a hospital as a result of his injuries. Out of all the harm that is caused by the aides towards the residents, this is the only accident that we see; everything else that happened was done on purpose and with purpose.

At multiple board meetings at Whitney-Palm, the private company contracted by the federal government to run several nursing homes in and around the Chicago area, one of the discussion topics are deaths that have happened at other nursing homes under their purview, including a girl who died from suffocation from being tied into a wheelchair she didn't need after being heavily drugged, and a little boy who committed suicide after being raped by another resident in front of an aide who did nothing to stop it, just to name a few. At another meeting following Teddy's death, when someone from the public relations team asks "How many deaths are reasonable? Is there a number?," one of the big bosses responds with "However many of them have died. That's the number" (Nussbaum 263). That boss, a man named Howard Anderson who is said to be absent most of the time, clearly has no idea, not even a ballpark number, how many people have died under his leadership, and he cannot even be bothered to think about it for a second.

To cap it all off, in each of these meetings, no one is concerned about how they can prevent more deaths from happening or how they have allowed so many of them to happen to begin with. That kind of morality is nonexistent. Cash flow and enough of a good public opinion to keep it going steadily is all that matters to them.

The ways in which the Whitney-Palm board members talk about the residents, whom none of them have ever met save for the director of ILLC and one “recruiter” who has only met a few of them, are also quite telling. When someone brings up that Teddy was twenty two years old and not actually a child when he died, Tim says “Yes, well. If they live at ILLC, they’re all children. Under the law,” and a doctor chimes in “If not physically, then certainly mentally” (Nussbaum 263). They take the dominant point of view that constructs disability “as a failing, incomplete and inferior, [marking] disabled embodiment as deeply devalued, not so much for what it is, but for what it fails to be. Its status and meaning are from the start relational, rather than having autonomous standing” (Shildrick 756). As a result, they make these assumptions about the residents they have never met and will never meet as though they have not spent the entire meeting debating how to deflect responsibility for deaths that happened under their watch. The residents are, to use a Foucauldian term, the “impossible subject” (Peruzzo 495) in the eyes of the board members. As M. Remi Yergeau writes in *Authoring Autism: On Rhetoric and Neurological Queerness*, “Often, the very people who diagnose others’ pathology encounter great difficulty in considering their own” (169).

Furthermore, after Teddy’s death, an ensuing wrongful death lawsuit brought on by his father, and the ensuing protests from his friends, a federal investigation finds that

the able-bodied men in charge at Whitney-Palm got kickbacks from ordering unnecessary medical tests for the residents and splitting the Medicaid and Medicare money that was supposed to be for the tests with the hospital they ordered the tests from. There were moments leading up to the climax of the novel that foreshadowed this, such as mentions of the recruiter's boss, a man named Tim, taking lavish vacations and buying expensive new cars for his wife, the hospital making a so-called private donation to the company, and a resident being taken to that hospital for x-rays one day for no obvious reason with nothing seeming to come of the results. Before any of this is revealed, however, it is made clear that the name of the facility is shown to be more of a misnomer than anything else. No one seems to truly be taught anything of use at the institute, and no one truly learns anything that will be of use in the outside world, at least not in a formal setting where learning is the point. Anything the residents do learn about their legal rights and living independently is learned through informal conversations with Joanne Madsen, a white, female, and disabled data entry clerk who is well versed in disability rights and leftist social activism. The facility clearly only exists as a means of containment and segregation, nothing more, nothing less.

The setting created in *Good Kings, Bad Kings* draws many parallels to the real life institutions that inspired it, but unlike the horror stories from those institutions, Nussbaum provides her young characters with real adult advocates and role models within her story. One of the point-of-view characters, Joanne, was born able-bodied but became paralyzed from the waist down and lost most of the use of her arms after getting hit by a bus, similar to what happened to Nussbaum in real life, and now uses a power

wheelchair to get around. The start of the novel marks the early point in her job doing data entry at the institution some time after the accident, which she has gotten after a long bout of unemployment seemingly brought on by disability discrimination. Despite being fairly new to the world of disabled people, she is able to recognize the seemingly subtle ways that the residents are dehumanized, such as Ms. Phoebe, the director of the facility, regularly calling the residents “her children or her angels” (11), which would be gross even if she actually took real steps to improve their lives, which she is shown not to do under any circumstances aside from calling the police to report a child molester. As the story goes on, Joanne begins to teach the residents what it means to think about their lives outside of the institution and helps them access resources that guide them towards independence, which she has to do without her bosses knowing about. She also starts to ask questions to her coworkers about how the institution really helps its residents improve their lives and finds that they do not, which factors into her decisions to teach the residents about their legal rights, protesting and self-advocacy.

Another point-of-view character, Ricky Hernandez, a man of Puerto Rican descent, is an able-bodied employee at ILLC whose job mainly consists of driving the residents around, usually to school and back, and supervising them. Unlike several of his coworkers, he has a lot of empathy for the kids and young adults in his care, and he goes as easy on them as he can, only disciplining them when he cannot get away with leaving them alone, and never with violence or neglect. When some of the residents stage a protest of their living conditions and the response to Teddy’s death just outside the institution, Joanne joins them and Ricky makes no moves to stop or punish them, even

though they know it could cost them their jobs, and it does lead to Joanne being fired despite her boss being told not to by the executives at Whitney-Palm. Another aide, a Black woman named Jimmie Kendricks, defends a boy named Pierre Washington from getting beaten up by Louie (Pierre still ends up with a severe injury that results in hospitalization and a transfer to a psychiatric facility, but without Jimmie's intervention, he could easily have been injured worse or killed), who gets suspended afterwards but then ends up with a new job at a group home for boys diagnosed with psychiatric disabilities; at the end of the novel, she undergoes the process of becoming the foster mother to Yessenia Lopez, the teenage girl who began the protest after Teddy's death.

An Embodied Notion of Disability and Power/Knowledge

Susan Nussbaum never explicitly cites the models of disability by name, but in one way or another, they all exist throughout the novel, especially the medical and social models. She recognizes that the medical model takes the point of view that all disabilities are illnesses that need to be managed and/or cured with the aid of medical science, that the functional model—which is somewhat related to the medical model—takes the point of view that all disabilities are an inherent deficit that greatly limit one's functionality, and that the social model seeks to dismantle the previous two models entirely by stating that Others are disabled because government and social structures deliberately exclude them by making the mainstream world inaccessible in ways that range from not having wheelchair ramps in buildings to making medical care expensive to obtain and then maintain.

The Whitney-Palm executives and board members clearly take the most dehumanizing aspects of the medical model as their worldview of disabled people and use them to their advantage. Knowing that they would be given money to conduct any medical tests, they ordered unnecessary tests for their patients at these facilities and took the money for themselves as kickbacks from a local hospital called St. Theresa, who had initially been referenced as private donors in any documentation that referred to them until the federal investigation revealed the truth. Also, they had initially planned to send Teddy to an adult nursing home upon his twenty-second birthday, after he would age out of ILLC, and when Joanne takes him and his father to meet with a disability rights lawyer about helping him stop the transfer so he can live more independently, she tells the lawyer that the same company that runs ILLC owns the adult nursing home as well, which, while it may or may not necessarily be illegal, proves that the company prioritizes its own financial interests above all else.

Another dehumanizing aspect of the medical model that *Good Kings, Bad Kings* critiques is how so many decisions made for the residents are based on the assumptions that are made based on their diagnoses (which are sometimes incorrect or inaccurate) or even just on the fact that they live at the facility. Teddy, for example, is listed as having an IQ of 74, implying a diminished mental capacity and extremely low intelligence, but he is shown to be very intelligent and certainly has the mindset and desires of a young adult around his age, such as advocating for his independence, wanting to have sex with his girlfriend Mia, and loving her to the point of actually proposing marriage, which she accepts. In fact, all of the residents are shown to be far more intelligent and thoughtful

than most of the adults around them ever seem to pick up on, not that they really try to (remember the executive and doctor who referred to them as functionally children despite never having met any of them). It is also clear that the medical model is weaponized against the residents in more direct ways besides the medical tests, and not just at ILLC. The girl who suffocated at one of the other homes did not need a wheelchair, but she appears to have been forced into one and then drugged to the point of losing all consciousness and functionality, but no one working at the home seemed to question her being in a wheelchair until they found her dead in it, and by that time, she had already been dead for several hours and had rigor mortis.

The functional model of disability has a unique presence here, one that could only be portrayed by a disabled writer like Nussbaum. A lot of the disabled characters use wheelchairs, all for different reasons. Most people's physical disabilities are not specified, but some of them are. Joanne, for instance, is quadriplegic and has limited enough use of her arms that she can only use two fingers, which, in the end, is all she really needs to do her job. Teddy has to use a wheelchair as a result of having had a tumor removed from his spine when he was younger. Pierre was hit in the head with a wrench by an aide at his previous group home, and while his file gives no indication as to whether he sustained long term damage from the impact, it would be reasonable to believe that he has some kind of traumatic brain injury as a result. Before that, he had been diagnosed with learning disabilities and attention deficit hyperactivity disorder (ADHD), and somehow with cerebral palsy despite not actually having it, and like most of his fellow residents, he uses a wheelchair. When he got to ILLC, his diagnoses were

expanded to include post traumatic stress disorder (PTSD) and oppositional defiant disorder (ODD). Mia is nearly blind and uses a manual wheelchair, but she is supposed to have a power wheelchair, and not having a proper wheelchair limits her functionality even more than it already is. While showing these physical realities, Nussbaum also seems to understand what scholar Bill Hughes takes note of in “The Constitution of Impairment: modernity and the aesthetic of oppression”: “Impairment is constructed—not discovered—in the non-disabled gaze. The invalidation and disfigurement of impaired bodies is) therefore, not simply an economic and cultural response to them, but also arises in the mode of perception which visualises and articulates them as strangers” (155). These characters may certainly be physically unable to do some things on their own, such as walking and driving, but ultimately, most of their limitations are caused by the world around them.

Finally, the mere presence of these institutions, while being a major consequence of the medical model, is also hard evidence of the social model. These places receive so much institutional and financial support in part because the people who end up in them often have nowhere else to go, or their families have nowhere else to house them. Yessenia, whose point of view opens the novel, was sent to ILLC right after being released from juvenile hall, where she was sent for breaking another girl’s jaw in a fight. Her parents are absent from her life (while she does not know her father, she has been told that he is incarcerated), and she had been under her aunt’s guardianship until she died of breast cancer some time before the story began. Although she has no love for ILCC as a facility or a place to live, her other living options are slim to none, and as a

minor with a criminal record and diagnosed disabilities, the decision is not hers, meaning she really has no choice at all. Yessenia's one time roommate, Cheri Smith, who is schizophrenic, ends up at ILLC after a recruiter meets her in a homeless shelter and convinces her and her parents that it is a good place for her to go; the so-called recruiter, Michelle Volkmann, who is also a point of view character, also knowingly lies that Cheri will have her own room there. Notably, Michelle had not actually been to ILLC at that point (and would not until later in the book), and she often stretches the truth about ILLC's living conditions when talking to potential residents in order to make a successful recruitment effort, efforts that earn her a three hundred dollar commission for each bed that she fills on top of her otherwise meager paycheck. Cheri expresses a desire to return home to her family, but while her parents seem to love and miss her, they do not seem eager to bring her back home with them, presumably due to the ways in which their lives have been impacted by decisions Cheri made while off her medication. Partway through the story, Cheri gets transferred to a mental hospital for minors (or, as Yessenia calls it, "*el manicomio*" [195]) that also happens to be contracted to and managed by Whitney-Palm after she runs away for the third time since her arrival, and when Michelle runs into her there when she goes to perform an evaluation of the facility, it is obvious that Cheri has been drugged into oblivion and stripped of her autonomy as a result. Yessenia notes that Cheri had been threatened with being sent to that facility for running away prior to it actually happening, and she is not the only resident to have been threatened with this possibility.

Other residents ended up at LLC because their families live in places that are inaccessible to them and lack the financial resources to move to places that would be. One of the reasons that Teddy was opposed to being moved to an adult nursing home, where he undoubtedly would have been the youngest resident, was because it would have meant moving much farther away from where his family lives, and his working-class family would not have the time and money to be able to visit him as often as he can at ILLC; in fact, because the facility is so far away and Teddy's father has just had his work hours reduced at the same time, he feared that his family may not have been able to visit him at all. Another resident named Bernard learns that he will likely have to move back in with his mother and siblings in an apartment that takes climbing up three flights of stairs to get to because his mother desperately needs his disability checks to pay for her diabetes medicine. Mia needs a power wheelchair, but ILLC only provides her one at the end of the novel when a lawyer tells them it is illegal for them to deny her one, which leaves them with no other choice. Phoebe, the director of ILLC, must have known that they were breaking the law by not giving her the power wheelchair, but did it anyway and did not seem to make any claims or excuses as to why she did this; the director must have also known that her bosses also owned the adult nursing home that Teddy was supposed to be transferred to. In her position, it would have been close to impossible, if not entirely impossible, for her not to have known.

Such acts of oppression and subjugation enacted by the ILLC director and Whitney-Palm executives are an embodiment of the Foucauldian idea of power/knowledge, which believes that "All knowledge, once applied in the real world,

has real effects and, in that sense at least, ‘becomes true.’ Knowledge, once used to regulate the conduct of others, entails constraint, regulation and the disciplining of practices. Thus, ‘there is no power relation without the correlative construction of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time, power relations’ (Foucault, 1977, p. 27;” *Representation* 33). More simply, “Power produces knowledge, it produces classifications, it produces measuring-instruments and, more importantly, it might also have produced ways of looking at the world and the self. It cannot be located within one individual or group of persons—be it the king, the rabble or the camp guard—nor can it be possessed. Rather, power is ubiquitous and ‘exists only when it is put into action. It is a way in which certain actions modify others’” (Foucault, 1983, p 219; Viestraete, p 59). ILLC administrators and their bosses hold and selectively produce all of the knowledge, and therefore all of the power, in the lives and wellbeing of the residents and their families, at least until an opposing entity with knowledge shares some of their own power and uses it to help them. Where there is power, there is always some kind of counter-power. Here, Whitney-Palm is the power, and the disability rights activists and lawyers are the counter-power. Those who work for Whitney-Palm produce a knowledge that claims they are doing everything in their power to ensure that the residents are living as well as possible; the residents counter by producing a knowledge that claims the opposite, which is backed up by activists and lawyers.

Power/knowledge is embodied in both formal and informal ways. For instance, when Teddy is told that nothing can be done about him being moved to an adult nursing home farther away from his family when the director and her bosses know full well that

they did not absolutely have to send him there, power/knowledge is being embodied in a formal setting. When Michelle lies to Cheri about being able to have her own room at ILLC, power/knowledge is being embodied in an informal setting. Also in a formal setting, power/knowledge is embodied as a counter-power when Joanne takes Teddy and his father to meet with the disability rights attorney, and in an informal setting when Joanne tells Yessenia and Cheri stories about disability rights advocates fighting for themselves throughout history during a discussion in her office. The nursing home executives also utilize power/knowledge in their efforts to get the parents of the residents to support them in the face of calls for closure by using fear mongering tactics to scare them into believing that their children will be left homeless and destitute if ILLC closes (which also serves to raise the stakes of so-called intervention [Disturbing Behaviors 5]). Their tactics include sending flyers to parents in the mail with panic-inducing messages and Phoebe establishing direct contact with the parents she feels that she can persuade to support them.

In the instances where power/knowledge is being wielded against the residents, besides just exercising their power, the executives are also putting into reality Foucault's assertion that a very specific kind of subjectivity was needed in order for the power structures he wrote about to be operational. While Foucault was more concerned with governmentality, successive power notions, and the practice of individualizing and dividing people, the subjection of the Other in *Good Kings, Bad Kings* is, indeed, specific, but about something else: the false binary of healthy bodies and sick bodies, something complicated by the existence of disability. Being disabled does not necessarily

mean being sick, especially since not all disabilities are medical conditions and vice versa. For example, only having one arm may be considered a disability, but it does not make one sick; on the flip side, irritable bowel syndrome (IBS) is a medical condition that affects the stomach and intestines, but having IBS does not necessarily mean being disabled. Because the nuances of disability go unconsidered so often by nondisabled people, disabled people tend to get placed on one side or the other. If disabled people are placed on the “sick” side of the healthy-sick binary, then a disabled child going to a hospital to get x-rays taken would only sound strange to someone who was paying enough attention to notice that the child in question was not actually sick and should not need them. Additionally, the residents become what Foucault calls a “dense transfer point... through which different modes of power, including disciplinary and sovereign, [begin] to operate” (Disturbing Behaviors 4). Through the subjugation of young disabled bodies, the Whitney-Palm board members, some of whom are doctors or at least have some kind of medical background, are able to exercise their power and level of control over the residents, their families, and the government paying them to do their work.

The counter-power to the nursing home employees and executives does not just come in the form of rogue aides and disability rights lawyers; it comes, most powerfully, from the residents themselves. Teddy himself voices his concerns over being transferred to the adult nursing home to someone in power, and then he meets with the lawyer and directly expresses his desire to get a job, live by himself, and make his own decisions about his life down to his own bedtime. Yessenia learns about protesting from Joanne, but Yessenia starts her own protest after Teddy dies without anyone prompting her to.

She comes to the idea all on her own and invites her friends to join her. Other disabled people in the community come to join them as well. The resulting publicity and involvement of local disability advocacy groups leads to positive changes at ILLC, including the hiring of more aides, the hiring of a new psychologist, Mia finally getting a power wheelchair, and residents being able to and knowing that they can meet with lawyers to help them exercise their civil rights and solidify their humanity. In most stories, especially stories about disabled people, this would have been the very first moment where she became a proactive subject (also from Foucault, although Foucault's notion of the proactive subject was more in the context of neoliberalism than the proactive subjects in this novel); in *this* story, Yessenia is already a proactive subject, and this moment just further solidifies it. Teddy was also a proactive subject and strived to be more proactive. Joanne's whole character arc was her becoming more proactive. Mia became more proactive as her story progressed, and she had two big moments of truth: finally telling someone she was being abused despite being threatened by her abuser, and reaching out to Teddy in the aftermath in order to reclaim her life and happiness. Most stories would also have strictly adhered to one story and one singular idea of the perception of disability, but not this one. Nussbaum understood everything that disability is and can be, that it can be medical, functional, and social, sometimes even all at the same time.

CONCLUSION

Ultimately, the most concrete statement that can be made about the three models of disability is that while their definitions can be too generalized at times, they are still very much an applicable method of viewing disability in the world as long as we remain critical of them, maintain an effort to utilize them properly, and continue to expand their overall scope. Other models of disability that were not used in this research, such as the moral model and the relational model, can seem like subcategories of the medical, functional, and social models, and some of them are at least related (e.g., the identity model is related to the social model), but those three models by themselves still have plenty of room for expansion.

Despite the many problems with the medical model and the damage its widespread adoption has caused, there are still circumstances in which it can be effectively applied. It remains true that some disabilities like cancer and diabetes can be cured and/or managed with the help of medical science; however, it also remains true that social barriers like a broken healthcare system (at least in the United States of America) keep the people experiencing those disabilities from being able to get that kind of help. Insulin has gotten so expensive in the United States that many diabetics have resorted to rationing what insulin they have until they can afford to get their next supply, often with fatal or near fatal results. In November of 2022, the *Washington Post* published a story about a study in the *Annals of Internal medicine* which claimed that an estimated 1.3 million diabetic adults in the United States, or 16.5% of those who have been prescribed

insulin, said that they had rationed their insulin in the past year. The report cited its rising costs and poor insurance coverage as the primary reason for this act, with rationing being more common among middle and lower income diabetics than those in high income brackets. Additionally, Black people were more likely to ration their insulin than White or Hispanic people. Similar disparities exist with the prevalence of HIV/AIDS.

Much of what has been said about the medical model can also be said about the functional model. Yes, it has many limitations and has caused much harm, including damaging mindsets that need to be corrected; and yes, it also has its moments where it works as a lens. Paraplegics can be and often are capable of many things, but walking is not one of them. The inability to walk or even stand does indeed limit some functionality, but one who loses that functionality can still adapt to these circumstances with the right resources, or just out of necessity. Sometimes, loss of functionality in one area has little to no effect on one's overall functionality and wellbeing. One can lose one finger or one toe, or just the use of one finger or one toe, without having to change their lives very much, if at all.

More has been said about the benefits of the social model than has been said about the shortcomings of the social model. Then again, it has come to be the preferred model among disability rights advocates, so there may be some reluctance to criticize it. That being said, the social model is becoming the preferred model for good reason. So many problems that disabled people face never had to become problems in the first place. No one would have to fight for universal wheelchair accessibility if it were just there already. Diabetics would not feel the need to ration their insulin if pharmaceutical

companies capped their price at thirty five dollars or less (either by will or by legal force), and/or if health insurance was more accessible and provided them with adequate coverage. The disability unemployment rate would be lower were it not for the presence of discrimination. Individual disabled people would not sue businesses to enforce the ADA if there were any kind of government agency that did the enforcement instead.

The implications of this research go beyond any one book or any one project. I hope that by applying these concepts to disabled characters in contemporary literature, I can make them more accessible to people who may want to understand more about the concept of disability for the sake of disabled people. I also hope for this research project to be able to provide a starting point for those who would like to study disability theory.

Going forward, there have been some calls within disability studies to expand the social model of disability, and also to create new models entirely to account for highly varied nuances between experiences with disability. For example, one scholar named Melissa Anderson-Chavarria argues for what they call a “predicament” model for autism spectrum disorder. Their claim is that such a model would reframe autism as a more individualized experience and bring the conversation beyond high and low functioning labels more commonly associated with autism; they also claim that “an advantage of the predicament model of autism is that it answers the growing call from the autism community to move beyond the ‘autism as a spectrum’ metaphor, which has been used widely to rank autistic individuals by functionality. Instead of a ‘spectrum’ of overly simplified low-to-high function, the predicament model can be used to understand autism within and beyond medical and educational realms as an individual and complex

predicament” (Anderson-Chavarria 1323-1324). In a similar vein, a different scholar named Francesca Peruzzo presents a “model of becoming aware” to create a more situational approach to looking at disability, which, again, asks us to consider more individualized experiences of disabled people (Peruzzo’s research focuses on accommodating disabled students in post-secondary education in Italy). Peruzzo uses Foucauldian philosophy to inform their work and argues for policy changes that include abandoning standardization, making academic performance more democratic, and further questioning what it means to not be disabled. Another scholar, Bill Hughes, was calling for an expansion of the social model of disability as far back as 1997, when disability studies was still a brand new addition to academia. He has written that the social model, while successful in how it has framed the experiences of being disabled as political issues, does not do enough to critique modernity even though it purports to be a part of capitalist critique. In one piece, he calls for the social model to represent an *embodied* notion of disability rather than a *disembodied* notion of disability.

It remains to be seen whether some or any of these ideas will catch on in disability studies or disability advocacy. Personally, I dislike the framing of autism as a “predicament” and “complex” because those particular words feel dehumanizing of autistic people even though the paper that argues for it attempts to do otherwise (or says it does), although I do know that the experiences of autistic people are highly varied, and I can certainly understand what Anderson-Chavarria is aiming for with the predicament model. When it comes to the models that emphasize individual experiences, there is a risk of ignoring systemic issues that affect all disabled people regardless of what kind of

disability they have. With other models that emphasize collective experiences, there is also a risk of forgetting that people with different disabilities can face different problems and have different needs as a result.

Overall, a complete model of disability is one that recognizes both the various individual experiences of disability and the collective experiences of disabled people. It should, as Pieter Verstraete says, “Instead of reducing the disabled person to his/her deficit, they emphasize the fact that every disability—as is true of gender, race and class— must be considered within the complex and intertwined framework of relations of the biological and social world: ‘Disability ... is not simply located in the bodies of individuals. It is a socially and culturally constructed identity’ (Longmore & Umansky, 2001, p. 19.”; *Towards a Disabled Past* 57). There are some models that fit this criteria, such as the human rights based model, the affirmation model, the diversity model, and the social adapted model. Most, if not all, are related to the social model, but the social adapted model has some relations to the functional model. It admits that disabled people do face some limitations that are actually related to their disability, but most of them come from the policies within the world around them while only some of them come from the body.

Models of disability aside, the best thing that can be done for disabled people is to create a better world for them, and to follow the Foucauldian dictate for “constant checking and permanent resistance” (Verstraete 59). The ADA, while transformative, did not go far enough to increase accessibility for disabled people. In *Creating a Neurodiverse World*, Devon Price lays out the shortcomings of the ADA:

“Though the law led to thousands of elevators and wheelchair ramps being built, and countless Braille signs being installed outside public restrooms, it also provided numerous exceptions to older and historical buildings. Many small businesses are still woefully inaccessible to wheelchairs and other assistive devices now, more than thirty years after the law passed. In some cases, recalcitrant cities and businesses exploited legal loopholes that allowed them to ignore ADA dictates, such as the grandfathering in of old structures and infrastructure. Throughout the 1980s, the Chicago Transit Authority refused to purchase buses with wheelchair lifts, despite repeated promises to the disabled community that all new equipment would be accessible. It took a years-long series of well-organized, disruptive protests in which physically disabled activists blocked street traffic with their wheelchairs for hours at a time before the city finally budged and agreed to acquire accessible transportation options. Even after the ADA was codified into law, this same resistance to include disabled people persisted. To this day, about a third of CTA train stations lack elevators for wheelchair users, for example. Whenever a station is remodeled to include an elevator and wheelchair ramps, local business owners and residents express outrage at the inconvenience and costliness of the improvements.”

Also greatly concerning, while scholarly definitions and understandings of disability have changed drastically since 1991, the ADA is essentially frozen in that point in time and is more concerned with a narrow definition of disability. It says nothing, for instance, about making public events safe for those with auditory processing disorders, or requiring sign language interpreters, or creating virtual options for those who cannot leave their homes. Worst of all, the only way to enforce the ADA as it stands is for individual disabled people to sue on the grounds of inaccessibility, a provision that was added at the behest of a group of pro-business politicians in office at the time. There is no agency or committee that oversees the ADA, just disabled people who have to wing it and see what happens. The act of filing a lawsuit often leads to the assumption and/or accusation from defendants, media outlets, and able-bodied people in general that the plaintiff is an ambulance chaser looking for a big payout and not someone with a

legitimate grievance against the defendant (an attitude which is not exclusive to ADA lawsuits aside from the inherent ableism), especially if the plaintiff ends up having to file multiple lawsuits on the same grounds over time, after which they are accused of gaming the system (it is unclear whether or not those who level these accusations are aware of the lawsuit provision in the ADA, but as of this writing, I have yet to see any indication that they do save for the one *New York Times* profile mentioned below).

This has been the case for a man named Albert Dytch, a therapist and disabled man who, according to a profile in the *New York Times*, has filed almost two hundred disability lawsuits over a period of several years in his home state of California (one of the most ADA compliant states where individuals can sue businesses for \$4,000 minimum in damages plus legal fees). Mr. Dytch was diagnosed with Becker's muscular dystrophy, a progressive neuromuscular disease that tends to begin developing in adulthood, in 1985. In the early stages of his diagnosis and muscular degeneration, he was still able to walk with the aid of a walking stick; as the Becker's progressed further, he had to resort to using a wheelchair and has used one ever since. Once this happened, he could no longer access many of the public places he could access before, including many restaurants and office buildings. As the progression of his muscular dystrophy kept going and further limited his mobility even with the wheelchair, the accessibility problem only got worse. He tried reaching out to these businesses directly to inform them of the problem and suggest changes to solve them, but he soon found that they did not work. Filing discrimination lawsuits against them became his last resort, and this resort worked because of the legal threat, making it clear that the possibility of being sued for damages

was the only way to get anyone's attention. Even if that attention was only the negative kind, it was better than being ignored. Often, businesses choose to settle these kinds of lawsuits before they get to trial (though they often drag on for long periods of time leading up to any kind of settlement). A primary reason cited for this is to avoid having to pay higher amounts of money in the event of losing, but a less cited, yet often true, reason is that plenty of these businesses commit real, glaringly obvious violations of the ADA that, even if they are not always certain to come up in a lawsuit, are certain to come up somewhere, and no one wants to get caught breaking the law, and worse, be forced to face the consequences, whether they be monetary losses or bad publicity.

Mr. Dyтч is not alone in his struggles to receive accommodations. When Susan L.Gabel and Maja Miskovic surveyed and interviewed disabled university students for their article "Discourse and the containment of disability in higher education: an institutional analysis," they found that the professors at this university often did not provide these disabled students with accommodations even when prompted to do so by certified letters from the school's disability resource center. They certainly received the letters from these students, but according to the students' interviews, these professors promptly ignored them afterwards. One student reported asking for more time to complete a test because of their anxiety, and the professor suggested that they try to work without accommodations first before putting them into place. Another reported not getting class notes from the professor before classes despite giving them the letter that specifically requested them and then subsequently being forgotten about entirely by the professor, thus being rendered invisible; that student had been a wheelchair user with

limited use of their arms, making it difficult for them to take notes on their own, hence the request for notes at the start of class. Some interviews with professors showed that at least one of them, possibly more, hardly remembered even having disabled students in any of their classes. Real life excerpts like these alongside fictional stories like *Parable of the Sower* and *Good Kings, Bad Kings* show that the laws surrounding civil rights for disabled people not only need to be expanded and rewritten to be more specific, they need to be directly enforced, that they need to be enforced all of the time, not just when institutions are found to have violated them with disastrous results, and that they need to be enforced by the agencies and institutions that create and put these laws in place rather than individual disabled people and their lawyers coming together to fight for themselves because no one else, individually or as part of a larger group or coalition, will advocate for them. An intersectional coalition of disabled and nondisabled people of all genders, sexualities, ethnicities, and economic classes working together at all levels of government and community will be needed to make that happen.

As far as disability representation in literature and media goes, there is still a lot of work left to do at the publishing level, the acquisition level, and the distribution level. The same is true of the ways these representations are analyzed. One has to consume these stories and hopefully walk away with a better understanding of the nuances of disability, even if they never learn about the models of disability themselves. Again, the models can provide useful lenses for viewing disability, but most people are not disability scholars who will use them in casual or painstaking research for work or out of curiosity. That being said, if at least the ideas and definitions of the models of disability can

become more common knowledge, then the names can follow, and the discourse communities surrounding these ideas can be expanded to include those who may not be scholars, but may be people just wanting to know more about disability. Literature and media often serve as people's introductions to new ideas and realities. There is no reason that literature and media, including the stories discussed throughout this project, cannot serve as an introduction to the models of disability.

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