“Abuse of the disabled”: Analyzing Disability Representation in Young Adult Literature and Disrupting Ableism in the Literature Classroom

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Doctor of Philosophy

Degree

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Dedication

Dedicated to my husband, Jared.

Thank you for the late-night dinners, your constant support, your shoulder to cry on, a push to work when I lacked motivation, and lots of laughs and distractions when I needed a break.

I couldn’t have pursued or finished this project without you.

I love you.

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Abstract

The purpose of this dissertation is to highlight an area of young adult literature (YAL) and social justice education that is often ignored: disability. Informed by a Critical Disability Studies lens, this qualitative study explores the representation of disability in YAL through three independent yet interconnected articles. Specifically, these three articles function together to answer the following guiding research questions: 1) How is disability represented in contemporary young adult literature? and 2) How do readers respond to the representations of disability in YAL and what are the effects of those responses?

First, due to historical misrepresentations of disability and the use of ableist language and stereotypes in literature, article one—"Being Sick is Not a Bad Thing": A Critical Content Analysis of Disability Representation in Young Adult Literature—presents a critical content analysis of four contemporary YA novels to examine if these issues are still present. The analyses indicate that there are still problematic portrayals of disability in contemporary YAL and that authors' positionalities as disabled insiders, or outsiders, should be considered when making text selections centering disability. The findings of this critical content analysis informed article two—"It really warmed my heart": An Instrumental Case Study of Readers' Responses to Disability in YA Literature—an instrumental case study to examine how seven first-year college students responded to representations of disability in YAL written by disabled authors. Findings from analyzing participants' written artifacts indicate that their responses to disability were largely influenced by their own ableist beliefs. Finally, inspired by problematic findings in articles one and two, article three—Understanding "Interlocking Oppressions": Toward an Anti-Ableist Frame for Literary Analysis—proposes a new Anti-Ableist Frame for literacy instruction and analyzing intersectional disabled characters in YAL and other texts. This work has

implications for the field of YAL, secondary English language arts, postsecondary English literature, and for educator preparation programs in English and literacy studies.

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Chapter 1: Introduction to the Study

I became disabled at the age of sixteen; however, it wasn't until over a decade later that I began to refer to myself as disabled. Prior to adopting this moniker, I referred to myself as "differently-abled" to indicate that I had bodily challenges while also avoiding the negative connotations associated with the word disabled. Now, I know that the negative connotations of disability are due to inherent hegemonic ableism—individual, cultural, and sociopolitical beliefs, behaviors, and policies or institutions that intentionally or unintentionally discriminate against individuals with disabilities (Pulrang, 2020)—within our society; through this dissertation, I have identified common elements of ableism and worked to dismantle them through the study of literature. This introduction chapter presents the thread—my coming to Critical Disability Studies (CDS)—that ties together the forthcoming three separate, yet congruent articles presented in this dissertation. To begin, I acknowledge that this dissertation was inspired by my personal journey from being nondisabled, to "differently-abled," to disabled through my exploration of young adult literature and my foray into CDS. Then, I outline how those experiences, my positionality as disabled, and the lens of CDS informed these three articles.

"Differently-abled"

When I was sixteen years old, I was diagnosed with Osteosarcoma—a rare, high-grade bone cancer—in my left femur. Prior to this diagnosis, I was a healthy, nondisabled teen athlete stressing over grades, homework, hallway gossip, college applications, and extracurricular clubs. However, with my diagnosis came chemotherapy, extensive surgery, physical therapy, body dysmorphia, identity crises, and a slew of long-term chronic health concerns and side effects.

I was diagnosed in the summer between my sophomore and junior year of high school; I received my first round of chemotherapy over Fourth of July weekend in 2004. I proceeded to

live in the children's hospital for about three weeks each month for nine months of my life. I do not have a lot of memories from this time, but several important moments affected my journey in understanding my own internalized ableism—how society's disability prejudice affects my physical and mental stress, my views of disability, and my own self-concept (Nario-Redmond, 2020)—and in adopting *disabled* as an aspect of my identity.

At the time of diagnosis, I was not worried about the prospect of being disabled for the rest of my life, nor was I worried about the prospect of dying; my largest concerns were losing my hair and how missing school would affect my overall class ranking. For the type of cancer I had, there are generally three surgical options: a limb salvage surgery (LSS) with a total knee replacement, a rotationplasty, and an above-the-knee amputation. I wanted to have an amputation; this surgery was the best way to ensure all cancer would be removed from my leg and it might have given me better mobility for an active lifestyle. However, my surgeon and my mom begged me to consider a LSS for two distinct reasons that I now realize were rooted in assumptions and values consistent with cultural ableism (Nario-Redmond, 2020); my surgeon stressed that professionals in the field preferred to save limbs whenever possible. He stressed that life as an amputee is difficult, so while I'd have better mobility, my "quality of life" might be better if I kept my own leg. Conversely, my mom was concerned about my ability to do things I enjoyed and how others' judgements would affect me as a young woman amputee, making it harder for me to date. I was sure I wanted an amputation, but my surgeon, again, begged me to try the LSS and promised to amputate later if I decided to go that route.

So, after three rounds of chemotherapy, I had a LSS on September 13, 2004. In this surgery, over half of my femur bone, the tip of my tibia bone, my knee, and assorted ligaments, muscles, and tendons were removed and replaced with titanium rods and plastic joints. After

surgery, I was in daily intensive physical therapy and had to relearn how to walk. Due to a complication in surgery, I encountered nerve damage that caused a condition called foot drop; this prevented me from moving my ankle or lifting my foot without the assistance of an ankle brace. Reflecting on this time from a lens informed by Critical Disability Studies (CDS), this is the first memory I have of internalized ableism from my time in treatment (Nario-Redmond, 2020). Losing the ability to move my foot was extremely difficult for me to grasp; I remember crying and feeling angry that I could not lift my ankle or foot, no matter how hard I willed them to move. This was also the first time I felt embarrassed about my appearance and physical ability. Prior to this surgery, I don't ever recall caring about others' perceptions of me or fearing that I looked disabled. I went out in public with my bald head rather than wearing scarves, hats, or wigs; I also never considered what people thought about my constant use of crutches and a wheelchair. However, this ankle brace signaled that I was unable to do something "normal" people could easily do, that I was disabled. Uncomfortable with this prospect, I received electrotherapy and worked hard with my physical therapists to regain function of my damaged nerve. After several months, I was able to regain about 75% of the mobility in my ankle, which was enough to walk without the brace. Despite my delight in regaining this function, I was left with permanent and painful nerve damage that must be managed with medication.

For all intents and purposes, my LSS was a success! The pathology report from surgery indicated greater than 98% necrosis of my tumor, increasing my chances of survival. I had regained most of the mobility in my foot; I was crushing it in physical therapy and had surpassed my surgeon's knee mobility expectations; I was adjusting to my surgical and nerve-related pain, and I had only suffered minor side effects from the chemotherapy—moderate hearing loss of high frequency sounds and chronic tinnitus.

Looking back from a CDS perspective, it wasn't until I finished treatment and was considered "better" that more aspects of internalized ableism began to appear in my life. After I finished chemotherapy, I realized I was no longer "normal." I found it difficult to relate to my same-aged peers, I no longer cared as much about my school performance, I worried about my health and my future, and I felt like no one understood what it was like to be a childhood cancer survivor. To my friends and extended family, my "sick" journey ended when I checked out of the children's hospital for the last time. However, that was not my reality. I was still frequenting the hospital for tests and check-ups, I was grappling with hearing loss and nerve pain, I was being weaned off narcotics after developing a dependency that neared addiction, I was feeling anxiety about a potential relapse or future secondary cancer diagnosis, and I was reading resource materials about all of the long-term side effects from treatment and the life-long testing to which I would have to commit.

Throughout 2005 and 2006, I experienced numerous complications that affected my health and ability. First, my after-chemo scans showed suspicious nodules in my lungs that a team of oncologists believed was evidence of metastasis. I took part in an experimental government trial to kill the presumed cancer in my lungs and then had an intensive surgery to remove the nodules. After recovering from this surgery and finding out that the nodules were not, in fact, cancer, I rapidly lost a lot of weight, started experiencing intense migraines, and slept an inordinate amount. My doctors believed I was experiencing PTSD and was struggling to adapt to life post-cancer; I then started seeing the psychiatrist who frequently visited me during treatment. I felt, sincerely, that I was not experiencing mental health concerns and that, instead, something was wrong with my physical body. Finally, after a series of falls required a minor knee surgery, my surgeon discovered that the symptoms I was experiencing were not

manifestations of PTSD but were effects of a severe staph infection that I contracted in my lung surgery. The seriousness of the staph infection led to months of antibiotic dependency and another LSS followed by the same intensive physical therapy. The events of 2005 and 2006 caused me to experience more disabling long-term conditions that will continue to affect me for the rest of my life.

Identifying My Internalized Ableism

In the years between finishing treatment and starting my doctoral journey at the University of Tennessee, Knoxville (UTK), I started to question elements of my life that I now know were effects of ableism engrained in society (Nario-Redmond, 2020). An unexpected side effect of being a kid with cancer is that everyone cannot help but tell you how sorry they are for you and how much you inspire them. You managed to change out of your pajamas? Inspirational. You went to the store without a hat so the whole town could see your bald head? Inspirational. You had to relearn how to walk? Inspirational. You went to a soccer game in your wheelchair to cheer on your old team? You poor thing, you’re so inspirational. You were caught smiling and laughing despite the possibility of dying? Truly, inspirational.

When I was first diagnosed, I was happy to hear people believed I was strong for facing my treatment and it felt good to inspire them. However, at some point, I started to feel uncomfortable. I remember talking to my mom about it and writing about it in the online blog my family kept throughout my cancer journey. I could not understand why people thought I was strong or why they thought I was inspirational. In my eyes, I was just living my life as it was normal to me at that time. I didn’t consider my cancer journey as something special or exceptional; I was just doing what I needed to in order to keep on living, just as everyone else is doing in their day-to-day lives. I now know that people who said I was strong or said I was

inspirational meant well, but that is a form of benevolent ableism. Nario-Redmond, Kemerling, and Silverman (2019) identified benevolent ableism as “pity, paternalistic protection, and unprovoked praise” for disabled people (p. 729); this causes admiration for disabled people, especially those perceived to have overcome a presumed limitation.

It wasn’t until I found Critical Disability Studies (CDS) in my first year as a student at UTK that I started to understand how I had internalized ableism through the way I talked about my experiences with cancer, my physical challenges, and my long-term health concerns (Nario-Redmond, 2020). Internalized ableism, like other oppressive manifestations, outlines how disability prejudice—or the assumption of prejudice—can cause physical and mental stress for the disabled person experiencing that prejudice, such as “depression, anxiety, paranoia, and suicidal ideation, negative moods, and lower overall well-being” (Nario-Redmond, 2020, p. 223). Thus, constantly hearing and absorbing negative messages of disability can become internalized, causing a disabled person to view disability as a negative state of existence. Put simply, I had internalized society’s deficit view of disability, which caused me to develop a negative self-concept about my own disability status. As disability is often considered a *horizontal* identity—meaning that disabled individuals may be the only disabled person in their immediate family, circle of friends, neighborhood, class, etc.—disabled people may feel especially isolated and manifest negative attributes of disability prejudice (Nario-Redmond et al., 2019; Solomon, 2012). This manifestation can include feelings of invalidation, feelings of shame and self-blame, questioning the disability validity, and questioning the need for access or accommodations (Nario-Redmond et al., 2019). For disabled individuals, social stigma and rejection can also cause variations in self-esteem and self-worth, as well as infiltrate social relationships (Solomon, 2012). I felt—and continue to feel—several elements of internalized

ableism. For example, I have often felt that I am not disabled *enough* to need or deserve accommodations (I was embarrassed to use my accessible parking pass and mobility aids), I am often the only disabled person in my immediate circle (I thought because no one could relate to my experience, they must be questioning the validity of my daily pain), and, I am aware of social stigma and rejection of disabled bodies in nondisabled spaces (while finishing this dissertation, I worried that self-disclosing my disability status in employment applications would negatively influence my opportunities).

Because society has taught us to view the term *disabled* as inherently bad (Zola, 1993), my family and I naturally avoided that term to refer to my own limitations. After my first LSS in 2004 and my second in 2006, I adapted how I did certain things because of how my new titanium knee functioned. For instance, I am unable to walk up and down stairs unless I turn my body sideways due to the lack of bend I can achieve in my knee joint. Adaptions like this led me to refer to my abilities as “differently-abled;” I believed I still had the same abilities as others, I simply approached them differently. Through my study of CDS, I now know that being disabled is *not* inherently bad, and that it is a diverse and wide-reaching identity marker (Linton, 1998; Nario-Redmond, 2020). I also know that disability euphemisms, such as “differently-abled,” are problematic and perpetuate the socially accepted view that disability is bad, or less-than (Biklen & Bodgen, 1977; Linton, 2008). As I became immersed in CDS scholarship, and later the disability justice movement, I reflected more on my experiences with cancer and the disabling long-term effects; gradually, I felt more comfortable identifying as disabled. I also reflected on how my disabling experiences affected other areas of my life, such as teaching and my interest in disability in popular media. This critical reflection and immersion in CDS scholarship reminded

me of my first experience reading a specific young adult (YA) novel that inspired the creation of this dissertation and the three studies within.

Finding *The Fault in Our Stars*

Through my hospital's "teen group," I met many other adolescents with cancer—it helped me talk about my worries and goals for my future; it gave me an outlet to bond with people who understood; and it provided me a place where I could forget about my illness and talk about non-cancer topics such as boys, high school gossip, and movies and music. After I finished treatment, however, I struggled to feel seen in the world of my friends and extended family. As I already stated, it was hard to relate to my same-aged peers and it was difficult to find people who truly understood what I had gone through. I don't think I realized it at the time, but following treatment, I found myself drawn to stories of illness in books and film. I longed for stories where I could see some of myself reflected, since I was unable to find myself reflected in my immediate social circles. Several years after I ended treatment, John Green's (2012) young adult (YA) novel *The Fault in Our Stars* was released. The protagonist in the novel has cancer, as do several other supporting characters. One character, Augustus Waters, has the exact cancer that I had, Osteosarcoma (Green, 2012).

In the novel, the teens go to "teen group;" they talk about real-world issues; they complain about life as a sick teen; they vent about their healthy friends; and they support one another (Green, 2012). I devoured this novel in 2012 and I continue to read it at least once every year. When I first read Green's novel, I thought, "Where was this book eight years ago?" Upon reflection, I know the novel is not perfect and requires a critical lens, but I also know the novel reflects one of my individual realities, one I had never seen realistically represented in fiction. I gained so much reading the novel as an adult—understanding about my lived experience, kinship

for those whose diagnoses were different than my own, empowerment as a survivor, gratefulness for my survival, acceptance of my new chronic illnesses, pride for my visible scars, and validity for my own reality—but I wonder what it would've meant to me if I had had it in my grasp as a sixteen-year-old living out that reality.

The Fault in Our Stars instantly became one of my favorite books simply because some of my individual experiences were written for the world to see. I recommended it to everyone in my group of friends and family and after others read it, I was asked questions such as, "So is this how you felt?" or "Was it really like this?"; my resounding "Yes!" created a new bond of understanding within my relationships. Knowing that millions of people have read this novel since its publication in 2012 (and have also seen the movie, which came out in 2014) gives me a personal level of satisfaction because, while not everyone who reads it has cancer or knows someone who does, they may gain awareness for the stress, pain, and reality of being a teen living with cancer. Thus, they may be more understanding when they encounter someone living a different reality than themselves, such as a girl without hair, asking you to repeat yourself due to her hearing loss, or limping as she walks with her nondisabled peers.

My positive experience reading *The Fault in Our Stars* made me wonder how others would feel, as well. It was amazing to have my experience validated in a novel, but I also felt a kinship for people living with conditions different than my own. Additionally, I considered individuals in my life who have other physical disabilities, chronic illnesses, psychiatric disorders, or have otherwise invisible illnesses. While I cannot claim to have read every YA novel in circulation, my responses to *The Fault in Our Stars* led me on a journey to explore the representation of various disabilities in YA texts. What I found was, in my opinion, largely problematic and disheartening. Experiencing popular tales that perpetuated deficit views of

disability and did not dispel negative stereotypes made me consider how the topic of disability is similar or different to other issues of diversity. I thought about false binaries such as ability/disability, normal/abnormal, and pondered how disability lies within the body *and* within social constructions. My experiences with problematic YAL and musings about disability eventually inspired this dissertation: I aimed to locate authentic adolescent disabled experiences in YAL, analyze effects of these representations on readers, and propose a tool for analysis of disability in YAL and other literature studied in an English education classroom.

Purpose of this Dissertation

The purpose of this dissertation is to highlight an area of young adult literature and social justice education that is often ignored: disability. Historically, examining disability in literature highlighted negative depictions and stereotypical tropes (Markotić, 2016; Mitchell & Snyder, 2000); this emphasis on negative attributes of disability was standard because, often, disabled characters served as narrative props meant to illicit reader sentimentality, teach an important life lesson, or to help other characters with a moral dilemma (Dyches & Prater, 2000; Meyer & Wender, 2017). Similarly, in society and education, disability has often been relegated to the outer fringes of social justice and diversity endeavors (Connor & Gabel, 2010; Erevelles, 2000; Goodley, 2007; Nario-Redmond, 2020). As disabled protagonist Maeve states in *This is Not a Love Scene*, this pervasive exclusion and stigmatization, as well as the sentimental objectification of disabled bodies might be considered “abuse of the disabled” (Megale, 2019, p. 2, p. 63). This dissertation, then, attempts to remedy this systemic exclusion of disability and center it as a valuable topic for exploration and discussion in the classroom. Through the forthcoming articles, I highlight how this “abuse” may appear in YAL and influence our reading of disability and

suggest how we can reject problematic tropes, dispel the use of ableist metaphors, and demand authentic portrayals highlighting disabled narratives.

Thus, the purpose of my work is three-fold: 1) to critically analyze the representation of disability in YA novels written by disabled and nondisabled authors, 2) to explore readers' responses to the representation of disability in YA novels, and 3) to develop a theoretical frame in which English and literacy educators can use to analyze disability in classroom texts to highlight this element of diversity and to dismantle effects of ableism.

Research Questions

This three-article dissertation was guided by the following research questions:

1. How is disability represented in contemporary young adult literature?
2. How do readers respond to the representations of disability in YAL and what are the effects of those responses?

The first research question was explored through a critical content analysis in article one and the second research question was addressed through a case study in article two. While there were no guiding research questions for article three, the findings from questions one and two informed the theoretical development of a new frame for literary analysis that is outlined in article three.

Defining Key Terms & Concepts

For the sake of consistency and coherency, I have defined and described several terms and concepts related to disability which are repeated and referenced throughout my work. The conceptualizations and use of these terms are informed by my own positionality as a member of the disabled community whose beliefs about disability align most closely with a social model of disability, meaning I believe the disadvantages a disabled person experiences are *largely* a result

of societal biases and limitations, but I also acknowledge that biological differences can cause challenges that cannot be a consequence of socio-political efforts (i.e., pain).

Disability. I rely upon the World Health Organization's ([WHO], 2022) definition of disability, in which "disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support" (para. 2). This definition recognizes the importance of context, disability type, subjective experiences, accessibility, and oppression as disabling factors. Further, disability is a socially constructed "historical, social, political, and cultural phenomenon" (Bialka, 2015, p. 143) encompassing diverse short- and long-term and invisible or visible traits and conditions (e.g., neurological conditions, sensory functions, psychiatric disorders, limited ability or inability to perform cognitive tasks, chronic illness or disease, absence or loss of limb). A more detailed explanation of disability is provided in this next section.

Disabled. Nondisabled people generally use person-first language (i.e., person with a disability) or rely upon disability euphemisms (i.e., special needs, exceptional, differently-abled) (Linton, 2008); scholars of CDS and disability justice advocates prefer identity-first language (i.e., disabled person, Deaf person) (Garland-Thomson, 1997; Linton, 1998; Smith & Erevelles, 2004). Due to the social and historical significance of the disability rights and justice movements, an understanding that disability is a marker of identity (Brown, 2011), and my positionality as an insider in the community, I have deliberately chosen to use identity-first language when referring to disability in this dissertation.

Nondisabled. The term nondisabled is used deliberately throughout to represent people without disabilities. Historically, the terms able-bodied and abled were used to represent "corporeal normativity" (Quayson, 2007, p. 4). However, that usage perpetuated the stereotype that disability is non-normative and a less-than status. Thus, nondisabled is used throughout my work to center disability and reject "normate" assumptions that to be nondisabled is preferential (Garland-Thomson, 1997; Linton, 1998).

Ableism. In this dissertation, ableism represents the individual, cultural, and structural levels of prejudice, stereotyping, discrimination, and oppression of people with disabilities (Bogart & Dunn, 2019). Further, I recognize that ableism results in disabled people being "*excluded, ignored, misunderstood, rejected, dismissed, avoided, pitied, envied, objectified, dehumanized, manipulated, shamed, mocked, stereotyped, overprotected, condescended to, and/or provided with unwanted help*" (Nario-Redmond et al., 2019, p. 739, emphasis in original). A more detailed exploration of ableism and how it influences this work is provided in the next section.

Anti-Ableist. In my work, I take a deliberate anti-ableist stance. Anti-Ableism places a focus on "theories, actions, and practices that challenge and counter ableism, inequalities, prejudices, and discrimination based on any type of disability" (Byrne-Haber, 2020, para. 2). To adopt this stance, I recognize that ableism is the root of "all of our movements because ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (Mingus, 2011, para. 11). Thus, I understand that centering disability perspectives, critiquing ableism, and disrupting every-day instances of ableism is necessary to challenge the

normative status quo and to dismantle the social injustices faced by disabled people who are more marginalized by their compounding identities.

Theoretical Framework

To analyze the representation of disability in young adult literature (YAL) and the effects those representations have on readers, this dissertation is comprised of three autonomous yet theoretically aligned articles. While each article incorporates different qualitative methods for exploration, all three articles are informed by Critical Disability Studies (CDS) as a theoretical frame, are grounded in understanding ableism, and are rooted in assumptions about literature stemming from Bishop's (1990) foundational metaphor, "mirrors, windows, and sliding glass doors."

Critical Disability Studies

Disability studies emerged as a field for academic research and professional education in the 1980s as a direct result of the Critical Legal Studies movement that also informed Critical Race Theory (Meekosha & Shuttleworth, 2009). Critical Disability Studies (CDS) emerged as a response to critiques and limitations of disability studies. Amongst critical scholars in the field, CDS is not considered a separate area of study than traditional disability studies; however, it signifies a "radical paradigm shift or simply signifies a maturing" of disability studies (Meekosha & Shuttleworth, 2009, p. 48). CDS scholars recognize disability as a concept encompassing many short- and long-term and visible or invisible characteristics and diverse conditions, such as: absence or loss of limb, sensory functions, progressive neurological conditions, chronic diseases, inability or limited ability to perform cognitive tasks, psychiatric disorders, etc. Scholars of CDS understand that disabled people's experiences and bodies are as diverse and varied as those among people without disabilities (Markotić, 2016).

Critical Disability Studies (CDS) signifies that the field has shifted to include more focus on critical theory (Meekosha & Shuttleworth, 2009). This new engagement with critical theory allows more openness to perspectives, embraces more of an individual view of disability as a lived experience, and attempts to transform the oppressive circumstances through critical and intersectional analyses (Goodley, 2012; Meekosha & Shuttleworth, 2009). Thus, by using CDS as an interpretive lens for this dissertation, I engage in critical analysis to address the representation of disability in YAL.

Scholars of CDS offer models of disability as approaches or standpoints to conceptualize the construction of disability in the world and to examine disability as a “historical, social, political, and cultural phenomenon” (Bialka, 2015, p. 143). The models of disability serve as approaches for understanding the relationship between biological factors and social barriers; furthermore, the models represent different views about the impact of disability on well-being, how disability is relevant to human rights and social policy, and how individuals and society respond to disability (Wasserman et al., 2016). Scholars began to reject the notion of disability as human defectiveness in favor of a socially constructed view of disability; this created a false dichotomy between two contrasting approaches, or models, of disability within disability studies: the medical model and, later, the social model (Barnes et al., 2010; Donoghue, 2003; Gilson & DePoy, 2002; Terzi, 2005; Zola, 1989).

The medical model of disability views both physical and mental differences to separate individuals diagnosed with a disability apart from those who are not. Initially, the social model was developed in response to criticism of the limitations and deficit views of the medical model, and the older more archaic moral model (Olkin, 2002), emphasizing social limitations and barriers which disable bodies. Similarly, ongoing criticism about limitations and exclusions of

the social model—through what is known as the critical realist turn (Goodley, 2012)—began to consider pain, other biological impairments, and broader conceptualizations of disabilities as fundamental elements of human difference (Gilson & DePoy, 2002; Goodley, 2012). These ongoing critiques of the social model have caused theoretical expansions towards other conceptual models of disability: the minority group model (Hahn, 1994), the human variation model (Higgins, 1992; Scotch & Schriner, 1997), and the affirmation/identity model (Brewer et al., 2012; Swain & French, 2000). More detailed attention to these models and their effects on our understanding of disability is provided in the forthcoming articles. For the purposes of this work, I rely upon a broad social model of disability which recognizes that people can be disabled because of biological differences, but what is *more* disabling is the effect of socio-political biases, limitations, and barriers.

Disability & Ableism

How we define disability, what counts as a disability, and who can qualify as disabled is highly contested; numerous definitions exist, and conceptualizations of disability vary by field of study, intent, closeness to disability, and social beliefs (McDermott & Turk, 2011). For example, many disability-focused organizations use disability as an umbrella term to represent the complexity and variation of conditions and disabling effects (Jelsma, 2009); however, most nondisabled Americans—who also do not have a close relationship with someone disabled—do not agree that so many variable conditions should qualify as disabilities (Shannon-Missal, 2015). As Nario-Redmond (2020) suggested, this continued disconnect between public perception—especially amongst the nondisabled—and disabled reality makes the study of disability prejudice—ableism—“ripe for investigation” (p. 6). As previously mentioned, I rely upon the World Health Organization’s ([WHO], 2022) definition of disability, in which “disability results

from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support" (para. 2). This definition recognizes the importance of context, disability type, subjective experiences, accessibility, and oppression as disabling factors. Further, disability is understood as a socially constructed "historical, social, political, and cultural phenomenon" (Bialka, 2015, p. 143) encompassing diverse short- and long-term and invisible or visible traits and conditions.

The culturally dependent dominant assumption—*master narrative* (Bamberg, 2004)—of disability characterizes disability as "something to be cured, eliminated, fixed, or overcome, and depict life with a disability as tragic, pitiable, and burdensome" (Baglieri & Lalvani, 2020, p. 2). This dominant narrative results in disabled and nondisabled people viewing disability as inferior and undesirable; furthermore, disability is "a social status that incites both hostile and benevolent forms of prejudice" and a "group that provokes stereotypes of incompetence and dependency, and behaviors that range from staring and unwanted assistance to abandonment, dehumanization, and hate crimes" (Nario-Redmond, 2020, p. 3). These beliefs and prejudices lay the foundation for ableist ideology and oppression toward a significant percentage of the global population (Campbell, 2009).

Disability is the largest marginalized group in the world and there are disabled people in every other marginalized group; further, disability is unique because people can enter—and exit—disabled status at any point in life. In fact, Nario-Redmond (2020) posited that this "open enrollment" of disability status may explain why "ableism has been such a contentious topic, even among the experts who study stereotyping and prejudice" (p. 4). Chodorow (1999) also

identified ableism as a "permissible prejudice," often unacknowledged and generally accepted in society that privileges nondisabled experiences (para. 2).

The term ableism has evolved from the social rights movements within disabled communities of the 1960s and 70s and is historically associated with disability prejudice (Albrecht, 2006). The definition of ableism varies, but is generally understood as the prejudice, stereotyping, discrimination, and oppression of people with disabilities (Bogart & Dunn, 2019; Campbell, 2001; Chouinard, 1997). I specifically rely upon, lawyer and disability advocate, Lewis's (2022) updated working definition of ableism:

> A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism. (para. 3)

This conceptualization of ableism is important to highlight the relationship between disability and other identity markers for intersectional considerations, as well as to help understand that context can be disabling. As Tremain (2017) and Lewis (2019, 2022) have outlined, the propagation of ableist assumptions about disability provided the necessary foundation for a widespread system of oppression that is inextricably rooted in and linked to other systems of oppression (e.g., racism, heterosexism, classism), which are grounded in beliefs of inherent superiority and inferiority based on arbitrarily identified traits. Disabled writer, educator, and

disability justice trainer, Mia Mingus (2011), outlined numerous examples of ableism's roots in various oppressions, stating:

> Ableism set the stage for queer and trans people to be institutionalized as mentally disabled; for communities of color to be understood as less capable, smart and intelligent, therefore "naturally" fit for slave labor; for women's bodies to be used to produce children, when, where and how men needed them; for people with disabilities to be seen as "disposable" in a capitalist and exploitative culture because we are not seen as "productive;" for immigrants to be thought of as a "disease" that we must "cure" because it is "weakening" our country; for violence, cycles of poverty, lack of resources and war to be used as systematic tools to construct disability in communities and entire countries. (para. 11)

Society has devalued disability in its assumption that it is "better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids" (Hehir, 2002, p. 3). As Chodorow (1999) explained, devaluing disability—and privileging ability—is pervasive and situates ableism as a "permissible prejudice" (para. 2), allowing ableism to operate "below our cultural radar and remains socially acceptable" (Derby, 2016, p. 106). Thus, ableism functions to stigmatize disabled experiences and can have detrimental effects. For example, Olkin (1999) found that disabled people are often the only member of their family with a disability; this may result in a sense of isolation from the disabled community and a lack of role models who may offer coping mechanisms to deal with daily forms of ableism. Further, without exposure to positive sentiments toward disability, disabled people may internalize ableist ideas and see their own lives as "tragic," "defective," and "in need of cure" (Nario-Redmond et al., 2019, p. 727).

Just as all other forms of social oppression, prejudices, and biases function at the individual, cultural, and structural level, so too does ableism (Baglieri & Lalvani, 2020). Moreover, ableism includes negative prejudices—hostile ableism—and "positivity biases"—benevolent ableism (Nario-Redmond et al., 2019, p. 729). More often, however, ableism includes a mixture of negative and positive feelings—ambivalent ableism—that shift depending on the situation (Nario-Redmond et al., 2019). Regardless of the type of ableism, there are three related components, what Nario-Redmond (2020) labeled as the ABCs of ableism: "affective emotions or attitudinal reactions; behavioral actions/practices; and cognitive beliefs/stereotypes that go beyond general negativity" (p. 6). Like other "isms" in society, effects of oppression from ableism can also be internalized by disabled people.

Throughout this dissertation, these conceptualizations of disability and ableism inform my reading and analyses. Specifically, my work highlights how ableism appears through representations of disability in YAL, how ableist assumptions, beliefs, and understandings influence our reading of disabled YA characters, and, thus, how ableism/anti-ableism must be considered as a frame for analysis when reading disability narratives.

Mirrors, Windows, and Sliding Glass Doors

My experiences with *The Fault in Our Stars* (Green, 2012) provided a reflection of life as a teen with cancer. While I didn't know it when I first read that novel in 2012, my engagement with it reflects what I now know is supported by Rudine Sims Bishop's (1990) oft-cited metaphor considering books as "windows, mirrors, and sliding glass doors." Bishop suggested books serve as "mirrors" when readers see themselves represented on the page; "windows" when books allow readers to gain understanding and empathy for others' lives, experiences, and cultures; and "sliding glass doors" when readers imagine themselves walking into the world of a

novel. Bishop argued that mirrors are needed to help young readers develop a sense of self-worth and positive personal identity, and windows and sliding glass doors are essential for inspiring perspective-taking and creating a more empathetic world. She explained books offer "views of worlds that may be real or imagined, familiar or strange" (1990, p. ix). Bishop's work was foundational to the field of YAL and education as a rationale for diverse literature inclusion and influenced many of the claims that literature can elicit empathy to affect readers' pro-social behaviors (Cart, 2006; Connors, 2014; Connors & Rish, 2015; Djikic et al., 2013; Nussbaum, 1997; Trites, 2000).

In the three decades since Bishop articulated her metaphor, numerous scholars have taken it up, expanding it to include more liberatory perspectives. Christopher Myers (2014) expanded the metaphor when he stated young readers "see books less as mirrors and more as maps" (n.p.). He suggested children use the maps as they are "searching for their place in the world, but they are also deciding where they want to go. They create, through the stories they're given, an atlas of their world, of their relationships to others, of their possible destinations" (C. Myers, 2014, n.p.). Toliver (2021) added telescopes as an extension to the original metaphor to help readers envision their futures. She suggested:

> Mirrors transform the human experience and reflect it back to the reader, and telescopes use multiple mirrors to gather light from hazy futures and clouded otherworlds to make faraway, liberatory ideas clearer and brighter. Windows offer views of real, imagined, strange, or familiar worlds, and telescopes provide views of liberating futures and otherwise worlds. (p. 30)

While scholars have added to the original metaphor, they have also complicated it. Bishop (2012), herself, complicated the metaphor by reflecting that, sometimes, a locked "window could

be a barrier, allowing children to look in but not be a part of the observed audience" (p. 9). Reese (2016) stated a danger of windows and mirrors; she posited that by solely looking through the windowpane, readers may misunderstand and misrepresent what they have observed. She offered a warning about "fun house mirrors, which throw back a distorted portrait of reality" (p. 1). Reese expressed the detrimental effects these distorted mirrors can have on readers whose experiences are misrepresented. Toliver (2018) has further problematized the metaphor with concern for "broken mirrors" (p. 2), which may reflect inauthentic representations of marginalized people that can be internalized by readers. Thus, the expansions and complications of the windows, mirrors, and sliding glass doors metaphor indicates the importance of authentic portrayals that dispel common stereotypes and reject misrepresentations of marginalized people, such as the disabled.

Article Summaries and Dissertation Overview

This dissertation is comprised of three independent articles focused on the representation of disability and ableism in young adult literature (YAL) as informed by a Critical Disability Studies (CDS) lens. This format allowed for an in-depth exploration of three varied yet complementary studies including a critical content analysis, a case study, and a theoretical proposal for anti-ableist literary analysis. Below is a brief outline of the three articles explored within this dissertation; a conclusion chapter is provided at the end to consider how the findings and implications from each individual article should be considered together.

Article 1: "Being Sick is Not a Bad Thing": A Critical Content Analysis of Disability Representation in Young Adult Literature

Historically, disability in literature has been represented from a deficit perspective that reinforces negative stereotypes. These negative representations can have detrimental effects;

however, by reading young adult literature (YAL) that emphasizes authentic portrayals of disability and challenges dominant deficit views, people may develop critical literacy skills that allow them to reflect on their own experiences and the world at large.

In this literary study, I draw upon tenets of Critical Disability Studies theory to inform a critical content analysis of four contemporary young adult novels: *A Time to Dance* (Venkatraman, 2014), *Marcelo in the Real World* (Stork, 2009), *Sick Kids in Love* (Moskowitz, 2019), and *This is Not a Love Scene* (Megale, 2019). Specifically, through multiple iterations of analysis, I identify instances of disability in YAL that either uphold or contest deficit views of disability to answer the following questions: a) How is disability represented in young adult literature? b) What implications do these representations have for readers? and c) How do authors' positionalities as disabled or nondisabled affect how disability is represented in their texts?

Article 2: "It really warmed my heart": An Instrumental Case Study of Readers' Responses to Disability in YA Literature

The purpose of this article is to explore readers' responses to disability in YAL through an instrumental case study design. This study grew naturally following the findings of the critical content analysis in article one to discern the effects of reading authentic disability portrayals. To examine the possibilities of including disability in classroom discussion and analysis, college freshmen enrolled in a first-year studies course in YAL read and responded to three YA novels written by disabled authors about disabled protagonists, *Sick Kids in Love* (Moskowitz, 2019), *The Silence Between Us* (Gervais, 2019), and *This is Not a Love Scene* (Megale, 2019). Thus, the purpose of this study is to explore how these readers responded to depictions of disability through a Critical Disability Studies (CDS) informed lens, and to consider if readers might

question dominant narratives of disability through the reading experience. The following research question is addressed: How do readers respond to representations of disability in YAL and what are the effects of those responses?

Article 3: Understanding "Interlocking Oppressions": Toward an Anti-Ableist Frame for Literary Analysis

As a result of the findings in articles one and two, I determined it would be necessary to offer pedagogical suggestions for educators hoping to include disabled texts in curricula, as well as for educators intending to address disability and ableism in anti-oppressive pedagogy. To address issues identified in articles one and two, I take the stance that recognizes "ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (Mingus, 2011, para. 11). Further, I posit that we must emphasize novels by and about disabled people, and we must build students' foundational knowledge about disability and ableism's wide-reaching roots in systemic oppression. Specifically, through this article, I suggest that through an explicitly Anti-Ableist Frame (AAF) for literary analysis, the concept of ableism—and its relationship to other "isms"—can serve as a useful "tool" in ELA classrooms for encouraging critical exploration of oppressive ideology and analysis of texts representing intersectional disabled characters. First, I elucidate foundational knowledge that informs the creation and use of an AAF. I also outline how the lens can be used for literary analysis. Then, I provide an example to demonstrate how educators might apply the AAF to the critical study of a contemporary YA novel featuring a disabled protagonist, *Darius the Great is Not Okay* (Khorram, 2018). I close with implications of the AAF for the analysis of YA and other texts, as well as to posit how the principles of an AAF could be expanded into a full framework with

further implications in secondary English instruction and pre-service teacher education programs.

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Chapter 2: Article 1

"Being Sick is Not a Bad Thing": A Critical Content Analysis of Disability Representation in Young Adult Literature

Abstract

Historically, disability in literature has been represented from a deficit perspective that reinforces negative stereotypes. These negative representations can have detrimental effects; however, by reading young adult literature (YAL) that emphasizes authentic portrayals of disability and challenges dominant deficit views, people may develop critical literacy skills that allow them to reflect on their own experiences and the world at large. In this article, tenets of Critical Disability Studies theory are used to inform a critical content analysis of four contemporary young adult novels: *A Time to Dance* (Venkatraman, 2014), *Marcelo in the Real World* (Stork, 2009), *Sick Kids in Love* (Moskowitz, 2019), and *This is Not a Love Scene* (Megale, 2019). Instances of disability in YAL that either uphold or contest deficit views of disability are analyzed to answer the following questions: a) How is disability represented in young adult literature? b) What implications do these representations have for readers? and c) How do authors' positionalities as disabled or nondisabled affect how disability is represented in their texts? Findings of these analyses indicate that disability is still largely written from a deficit perspective, relying on historical stereotypes and narrative tropes. Further, findings highlight that authors' positionality as disabled or nondisabled may influence reinforcement or rejection of disability stereotypes in their writing.

In *Sick Kids in Love*, Sasha, a teen protagonist with Gaucher's Disease, states, "you know there's nothing wrong with being like me, right?" (Moskowitz, 2019, p. 122) as he proudly claims his chronic illness as an integral facet of his identity, much to the chagrin of "healthy people" (p. 44) who may not be able to relate to positive views toward disability and illness. Throughout the novel, Sasha and Ibby, a teen with Rheumatoid Arthritis, contend with their identities as "sick kids" living in a world that assumes individuals with disabilities desire to be "normal" (Garland-thomson, 1997). Sasha and Ibby's experiences highlight a portrayal of disability in fiction—and in society—that is atypical; disabilities are often framed as a "biomedical 'problem' assumed to lower an individual's quality of life" (Chrisman, 2018, p. 54). As common depictions of disability in fiction include awe-inspiring and child-like characters who triumph over their abnormal physical and/or mental bodies (Markotić, 2016), Sasha and Ibby's perspectives on disability illustrate that without an introduction to positive views of disability, individuals may unintentionally reinforce ableist ideology—individual beliefs or

behaviors, and sociopolitical policies or institutions that intentionally or unintentionally discriminate against individuals with disabilities (Pulrang, 2020)—such as myths or misunderstandings, stereotypes, microaggressions, biases, and prejudices about disabled people. However, by reading young adult literature (YAL) that emphasizes disability and challenges dominant deficit views, people may develop critical literacy skills that allow them to reflect on their own experiences and the world at large.

Critical approaches to representation of disability in YAL are imperative because disability is a common element of human diversity in the social world. Currently, 61 million adults in the United States live with a disability, making up 26% of the overall population (Centers for Disease Control and Prevention [CDC], 2020) and approximately 1.3 million young people live with some form of disability or chronic health concern (Erickson, Lee, & von Schrader, 2016). Furthermore, in the 2015-2016 academic year, approximately 6.7 million K-12 students in the United States received special education services (National Center for Educational Statistics [NCES], 2018). According to the National Alliance on Mental Illness (NAMI) (2019), approximately 1 in 5 adults over age 18 and 1 in 5 youth aged 13-18 experiences a serious mental illness, with approximately 50% of all lifetime cases of mental illness beginning by the age of 14. Additionally, young adults with disabilities, chronic illness, and mental illness are more likely to be socially stigmatized and "othered" in society (U.S. Dept. of Health & Human Services, 2020). So, whether society, educators, and readers explicitly understand and address issues regarding disability and illness, these issues exist and are prevalent in the lives of individuals, in politics, in popular media, and in literature. However, despite the prevalence of disability, and the awareness of disabled peers, youth tend to think about it as an individual problem; disability, then, is something a person "has" and is stigmatized, or disability

describes someone suffering a deficit or loss which needs to be pitied, cured, or treated, and most prevalently, disability results in someone be treated differently than the nondisabled "normal" people (Kennedy & Menton, 2010).

This deficit view, however, is extremely damaging and perpetuates negative biases and prejudices against people who live with disabilities. While these issues must be addressed through multiple levels of society, one way to help contest deficit views is for educators to ask students to examine and reflect upon the common perceptions of disability and to engage with issues of disability critically. As Kennedy and Menton (2010) stated, teachers must "help students better analyze the language/rhetoric of disability, understand how disability is represented in literature, and uncover how the media (e.g., TV/movies and websites) depict people with disabilities" (p. 62). Similarly, Cart (2006) asserted that "kids need to learn empathy. They need to learn how the *other* can become *us*" (p. x). By reading young adult (YA) novels that authentically capture the experiences and circumstances of individuals with disabilities, we can help shift the view away from "othering" those with disabilities.

In this literary study, I draw upon tenets of Critical Disability Studies Theory to inform a critical content analysis of four contemporary young adult novels: *A Time to Dance* (Venkatraman, 2014), *Marcelo in the Real World* (Stork, 2009), *Sick Kids in Love* (Moskowitz, 2019), and *This is Not a Love Scene* (Megale, 2019). Specifically, through multiple iterations of analysis, I identify instances of disability in YAL that either uphold or contest deficit views of disability to answer the following questions: a) How is disability represented in young adult literature? b) What implications do these representations have for readers? and c) How do authors' positionalities as disabled or nondisabled affect how disability is represented in their texts?

Disability in Literature

Historically, examining disability within literature focused on classical texts featuring characters with disabilities, such as the one-legged "mad" Captain Ahab, the vengeful and deformed Captain Hook, the hunchbacked King Richard III, the courageous Colin Craven, or the sentimental Tiny Tim (Markotić, 2016; Mitchell & Snyder, 2000). Traditionally, characters with disabilities were represented in a negative, restrictive view, or they were meant to elicit reader sentimentality and pity, or to teach readers—assumed to be nondisabled—concepts of acceptance, kindness, and tolerance (Markotić, 2016; Meyer & Wender, 2017). Oftentimes, a character with a disability served as a source of moral symbolism essential to the development of other characters (Dyches & Prater, 2000). As there are "overwhelming impulses—to regulate, normalize, and regiment the (human) body," (Markotić, 2016, p. 2) disabled bodies are often unfairly used to teach lessons or invoke empathic responses from readers without a disability (Meyer & Wender, 2017).

Depictions of characters with disabilities often emphasize narrative conventions and stereotypical tropes. For example, tropes allotted to disabled individuals include pathetic victims, courageous protagonists, avenging villains, freaks, and innocent or "special" people (Garland-Thomson, 1997; Markotić, 2016). Two common narrative tropes include the "super-crip"—a representation of a character with exceptional abilities or powers that function in relationship with or in contrast to a disability—and the myth of a cure—a representation of a character who either dies or is cured of their disability by the end of the narrative (Couser, 2009; Dolmage, 2014; Schalk, 2016). Within these awe-inspiring and extraordinary narratives, protagonists are seen as brave, courageous, and noble for "cop[ing] with what 'normal' people would find too difficult or overwhelming to handle" (Markotić, 2016, p. 4).

Within the last two decades, however, the focus has shifted from studying negative portrayals of disabilities to stressing the importance of accurate representations of individuals with disabilities (Heim, 1994; Prater, 2003). In the past few years, disabled adolescent characters have increasingly been included in broad diversity discussions (Whaley, 2016). Additionally, social media movements, such as #WeNeedDiverseBooks and #OwnVoices—emphasizing novels written by and about people from the same marginalized populations—have increased awareness of authentic disabled voices in YAL (Whaley, 2016). These movements have been vital for increased publication of books that emphasize a disability perspective—for disabled authors and disabled characters—to create visibility, give voice to oft-ignored or erased experiences, and to ask readers to question dominant social and political views (Fox, 2017).

Theoretical Framework

For the purposes of this study, I apply a critical literacy approach to consider how disability is represented in YAL through a Critical Disability Studies (CDS) lens. Luke (2012) defines critical literacy as the analysis, critique, and transformation of "norms, rule systems, and practices governing the social fields of everyday life (p. 5). Critical literacy focuses on an ideological "critique of the world portrayed in" popular media, literature, and other texts (Luke, 2012, p. 7). According to Shor (1999), "when we become critically literate, we examine our ongoing development, to reveal the subjective positions from which we make sense of the world and act in it" (p. 2). Thus, my critical orientation will draw from Critical Disability Studies as I analyze representations of disability in YAL as they align with the models of disability and how those representations may draw upon ableist ideology in life.

Critical Disability Studies Theory

Traditional disability studies emerged as a field for academic research and professional education in the 1980s as a direct result of the Critical Legal Studies movement that also informed Critical Race Theory (Meekosha & Shuttleworth, 2009). Critical Disability Studies (CDS) emerged as a response to critiques and limitations of disability studies. Amongst critical scholars in the field, CDS is not considered a separate area of study than traditional disability studies; however, it signifies a "radical paradigm shift or simply signifies a maturing" of disability studies (Meekosha & Shuttleworth, 2009, p. 48). Within the field of CDS, "disability" is a concept that encompasses many short- and long-term and visible or invisible characteristics and diverse conditions, such as absence or loss of limb, sensory functions, progressive neurological conditions, chronic diseases, inability or limited ability to perform cognitive tasks, psychiatric disorders, etc. Scholars of disability studies understand that variation exists among "disabled" people's experiences and bodily states just as often as variation among people without disabilities (Markotić, 2016).

Critical Disability Studies (CDS) signifies that the field has shifted to include more focus on critical theory (Meekosha & Shuttleworth, 2009). This new engagement with critical theory allows more openness to perspectives, embraces more of an individual view of disability as a lived experience, and attempts to transform the oppressive circumstances through critical and intersectional analyses (Goodley, 2012; Meekosha & Shuttleworth, 2009). Thus, by using CDS as an interpretive lens, we can engage in critical literacy practices to reflect upon and address models of disability in YAL to examine authentic and problematic representations of disability.

Models of Disability

Critical Disability Studies scholars offer models of disability as approaches or standpoints to conceptualize the way disability is constructed in the world and to examine disability as a "historical, social, political, and cultural phenomenon" (Bialka, 2015, p. 143). The models of disability serve as approaches to understanding the relationship between biological impairments and social limitations; furthermore, the models represent different views about the impact of disability on well-being, how disability is relevant to human rights and social policy, and how individuals and society respond to disability (Wasserman et al., 2016). Scholars began to reject the notion of disability as human defectiveness in favor of a socially constructed view of disability; this created a false dichotomy between two contrasting approaches, or models, of disability within disability studies: the medical model and, later, the social model (Barnes, Mercer, & Shakespeare, 2010; Donoghue, 2003; Gilson & DePoy, 2002; Terzi, 2005; Zola, 1989).

The medical model of disability views both physical and mental differences to separate individuals diagnosed with a disability apart from those who are not. Initially, the social model was developed in response to criticism of the limitations and deficit views of the medical model, and the more archaic moral model (Olkin, 2002), to emphasize social limitations which function to disable bodies. Similarly, ongoing criticism of limitations and exclusions of the social model—through what is known as the critical realist turn (Goodley, 2012)—began to consider pain, other biological impairments, and broader conceptualizations of disabilities as fundamental elements of human difference (Gilson & DePoy, 2002; Goodley, 2012). These ongoing critiques of the social model have led to theoretical expansions towards other conceptual models of disability: the minority group model (Hahn, 1994), the human variation model (Higgins, 1992;

Scotch & Schriner, 1997), and the affirmation/identity model (Brewer et al., 2012; Swain & French, 2000). Table 1.1 below defines and outlines common understandings of these models of disability. Through this content analysis of the selected YAL, I will identify how these models of disability appear in the narratives of disabled characters and the implications of these portrayals on readers.

Methodology: Critical Content Analysis

In this study, I draw on qualitative critical content analysis as a research method to explore the representation of models of disability as they appear in young adult literature (YAL). Content analysis is a broad term used to indicate research methods for analyzing, describing, and interpreting texts (White & Marsh, 2006). According to Short (2017), content analysis involves multiple readings of a text to make inferences and to, then, make sense of those inferences within the context that surrounds the text. By adding "critical" to content analysis, researchers signal a political stance aimed at locating social power and practices to understand and challenge inequities embedded within those practices (Short, 2017). Thus, critical content analysis prioritizes a critical lens to guide the researcher's questions, the text selection, and the findings (Willis et al., 2008). In this critical content analysis, I apply the models of disability—just as CDS scholars apply them as frames or approaches to conceptualize the way disability is understood and constructed (Altman, 2001; Bialka, 2015)—as an analytical frame to explore underlying messages of disability within selected YA texts (Short, 2017). This analysis focuses specifically on how the models of disability are represented in YAL and how these representations either support or contest disability stereotypes and tropes within four YA novels.

I must note that using the models of disability as an analytical frame to determine if representations of disability are "good" or "bad" is subjective based upon my own positionality

as a member of the disabled community and my positive views of disability as an identity marker. Thus, my analyses and interpretation of disability in these four texts is informed by my own personal alignment with a broad social model of disability which recognizes that the disadvantages a disabled person experiences are *largely* a result of societal biases and limitations, but also acknowledges that biological differences cause challenges that cannot be a consequence of socio-political efforts (i.e., pain).

Text Selection Criteria

Data for this study come from YA texts featuring disabled protagonists. For inclusion, the selected novels needed to meet several criteria. First, the book must be considered Young Adult Literature as aligned with the broad definition that the book is written for and marketed to an audience aged 12-18 and features an adolescent protagonist (Bushman & Haas, 2006; Cole, 2009). Additionally, when selecting texts with representations of disability, one must be aware of issues that include stereotypes, didacticism, sentimentality, and the use of disabled characters as either a "vehicle for the growth of the main character" (Tal, 2001, p. 31) or as "catalysts" for community change (Coats, 2001, p. 16). Tal (2001) also suggested books written from a first-person perspective of disabilities are preferable to books written from the perspective of a friend or caretaker. Thus, only novels featuring a protagonist with a disability were considered; novels with a parent, sibling, or secondary character with a disability were not included in the analyses.

I conducted an advanced search for sample YA novels cross-referencing national book award lists, starred reviews (e.g., Kirkus, Booklist, and Publishers Weekly) and recommended reading lists from blogs such as Book Riot and We Need Diverse Books, and Young Adult Library Services Association (YALSA), Goodreads, and Amazon. While I considered award winning novels from well-known authors, I also wanted to include new disabled perspectives and

did not exclude unknown novels or first-time authors from my search. At the time of this research, I collected and read ten YA novels featuring disabled characters and then narrowed my selection to four texts. To narrow my selection, I first eliminated texts in which the disabled character died or received a fatal diagnosis. Next, I eliminated texts featuring health conditions that are less conventionally understood as disabilities, although they technically fall under the disability umbrella (e.g., transplant recipients and heavily burned or scarred individuals). Further, I selected books I felt had the most to offer for an in-depth analysis of diverse disability experiences. I landed on the following four texts: 1) *A Time to Dance* (Venkatraman, 2014), which received starred reviews from Kirkus, Booklist, BCCB, VOYA, and SLJ; 2) *Marcelo in the Real World* (Stork, 2009), the 2010 Schneider Family Book Award winner for teen disability experiences; 3) *Sick Kids in Love* (Moskowitz, 2019), which received a starred review from Kirkus and won the Sydney Taylor Book Award in 2020; and 4) *This is Not a Love Scene* (Megale, 2019), a non-award winning debut novel.

As I was narrowing my text selection, I intentionally chose four novels to analyze the portrayal of disability in two texts published prior to 2015 and two texts published after 2015; this date was specifically chosen to coincide with the introduction of the #WeNeedDiverseBooks initiative that may have influenced increased publication of disability narratives in YAL (Whaley, 2016). Additionally, although award winning novels are important to see the types of disability narratives being celebrated in literary communities, I purposefully selected one text by a debut author—Megale—which had not received any starred reviews or awards at the time of study. Similarly, I deliberately chose two texts written by self-identified disabled authors—Moskowitz and Megale—and two authors who are nondisabled—Venkatraman and Stork. For the purposes of this analysis, I consider disabled authors as insiders (Short & Fox, 2003) because

they have the same or a very similar disability as the protagonist in their novel (Whaley, 2016); thus, while Venkatraman and Stork both self-identify as having a mental illness and/or invisible disability (Stork, 2017; Venkatraman 2021), they do not have the same or similar disabilities as their characters—a limb amputation and a cognitive disorder, respectively—and are considered outsiders to those experiences (Short & Fox, 2003; Whaley, 2016).

Methods

Each of the four selected novels was closely read twice. For my initial close reading, I relied upon Botelho and Rudman's (2009) call to focus on several broad critical issues within the novels, as well as to consider language use and narrative strategies. I used open coding (Saldaña, 2016) to identify and highlight all phrases connected to elements of the character's disability. My second reading involved a closer examination of those situations of disability already highlighted, dividing the previously identified instances of disability into categories informed by the models of disability as outlined by CDS scholars to conceptualize the way disability is constructed within the novels (Bialka, 2015). I then used these categories—the models of disability (as outlined in Table 1.1)—to identify which model(s) appeared most prevalently to determine with which model of disability each novel best aligned. See Table 1.2 for an example of how initial codes were later arranged into categories.

I also identified and evaluated either content that reiterates negative assumptions or deficit views of disability—support of the super-crip, myths of a cure, claiming people with disabilities are brave or courageous, etc.—aligned with a medical model—or content that challenges negative views of disability in favor of a positive portrayal—aligned with a social, minority, human variation, or affirmation model.

Two novels—*Sick Kids in Love* and *This is Not a Love Scene*—center white disabled characters in the U.S.; *Marcelo in the Real World* centers a disabled Hispanic American in the U.S.; and *A Time to Dance* takes place in India, centering the experience of a disabled Indian. This is significant because, in the US, many People of Color are less likely than white people to seek treatment or help for an illness or disability; this reluctance is partially due to long-standing cultural beliefs around stigma and openness (Armstrong, 2019). Furthermore, different racial and cultural groups—both domestically and internationally—have their own conceptions of health and illness, which influences "what gets defined as a problem, how the problem is understood, and which solutions to the problem are acceptable" (Hernandez et al., 2009, p. 1047). As a white cultural outsider, I do not claim to speak to the nuance of how these cultural definitions of health affect individual families and their willingness to seek help and/or support disabled family and friends; however, an influence of cultural beliefs around disability should be considered when analyzing the experiences of disabled characters within *Marcelo in the Real World* and *A Time to Dance*. Although cultural differences and intersectional identities of the characters will be briefly considered in my analysis, my primary focus is the representation of disability and the experiences of the protagonist living with said disability rather than their gender, race and/or cultural beliefs; consequently, an in-depth intersectional analysis of issues of a character's race or gender rests outside the bounds of this study. This was a purposeful decision to answer my first and third research questions: How is disability represented in young adult literature? and How do authors' positionalities as disabled or nondisabled affect how disability is represented in their texts? Thus, the overall representation of disability and the authors' disabled/nondisabled identities take precedence over other identity markers of the characters. Also, while every novel included at least one secondary character who ascribed to stereotypical views and a medical

model of disability, those issues were largely excluded from analysis if they did not align with a model that was featured more prevalently through the protagonist's own experiences.

Findings

In my analyses, I found that models of disability appear in young adult literature (YAL) through the same tropes previously described as recognizable in classic literature. Additionally, common portrayals by outsider authors align with the medical model, wherein the protagonist has changed in a major way or recovered from their disability by the end of the novel; furthermore, problematic language used by the authors within the peritext reinforces the idea that people with disabilities must overcome their limitations (e.g., *A Time to Dance* and *Marcelo in the Real World*). Depictions of disability in YAL are often stories of heartbreak, misfortune, tragedy, or triumph and align closely with the deficit views ascribed to the medical model (Carey, 2009; Garland-Thomson, 1996; Olkin, 1999).

However, narratives of disability written by disabled authors use beliefs aligned with social models—as well as minority, affirmation, and human variation models—to explicitly address deficit views of disability (e.g., *Sick Kids in Love* and *This is Not a Love Scene*). Table 1.3 presents an overview of my findings after employing critical content analysis methodology using CDS as a theoretical frame to illustrate how the models of disability are constructed and questioned within four YA novels: *A Time to Dance*, *Marcelo in the Real World*, *Sick Kids in Love*, and *This is Not a Love Scene*; an in-depth analysis of my findings in each novel follows.

In *A Time to Dance*

The portrayal of disability in *A Time to Dance* aligns most prevalently with the medical model as the plot is heavily driven by Veda's pride—and eventual disdain—for her bodily ability. The dedication appearing at the beginning of the novel emphasizes stereotypes of

disabled nobility (Markotić, 2016) by addressing “the courageous people […] whose spirit triumphs over terror and tragedy” (n.p.). The protagonist, Veda, is a prize-winning dancer recognized for the “skillful mastery over her body” (Venkatraman, 2014, p. 23). Within the first thirty pages of the text, Venkatraman uses verse to reiterate Veda’s abled-ness, such as this stanza from the poem “Dancing My Body Beautiful:”

> Both feet on the ground again, I pirouette and leap,
> rejoicing in the speed at which
> my body obeys my mind’s commands,
> celebrating my strong, skilled body—
> the center and source of my joy,
> the one thing I can count on,
> the one thing that never fails me. (p. 13)

After a bus accident leaves Veda with a below-the-knee amputation on her right leg, the focus shifts to how she can “recover in no time” (p. 39). While many in Veda’s life emphasize her ability to surpass her limitations, Veda internalizes fears that she is “too crippled to dance again” (p. 60) and that she is “the star attraction at a freak show” (p. 73). While these messages of a disabled body are problematic and emphasize a lesser-than view of disability, Veda’s reactions of fear and uncertainty to her new appearance are a good representation of common and natural reactions to an unexpected limb amputation (Walton, 2016).

In line with the medical model of disability, the plot moves from Veda’s hatred for her new reality to emphasize her strength as she attempts to re-learn the traditional Bharatanatyam dance as well as her capacity to “be brave enough” to overcome her limitations (p. 204) and “inspire [others] to work harder” (p. 186). This element of Veda’s story perpetuates the myth of a

cure, wherein readers are meant to be inspired by Veda's diligence to improve the new perceived limits of her body (Couser, 2009; Dolmage, 2014; Schalk, 2016). The medical model often assumes that people with disabilities desire to be "normal" (Markotić, 2016); Veda exhibits this when she says, "I'm not sure I can empty myself of wishing for those able bodies I don't own" (p. 146). Additionally, both Veda and secondary characters within the text often use derogatory terms born from ableist ideology—"cripple," "lame," "freak," "handicapped," "stump," "monster," "beast"—showing how language has come to perpetuate deficit views of disability. By the end of the text, Veda has relearned how to dance, has received public praise for her regained skill, has come to appreciate "both [her] beautiful feet" (p. 307), and has overcome her disability when her "ghost limb fades" completely from her life (p. 301). So, by the end of the novel, Veda has been objectified by using her triumph over her disability as "inspiration porn" for nondisabled readers who hold underlying assumptions about disabled incompetence (Beller, 2020, n.p.). Inspiration porn refers to the objectification of disabled people, who are "portrayed as specimens of wonder and amazement—perhaps as a way to motivate those without disabilities to self-improve" (Nario-Redmond et al., 2019, p. 729). Through Veda's perseverance and triumph over her bodily limitations, she is viewed as an inspiration to her peers—and to readers—because her narrative is typical in its reliance on stereotypical tropes of disability that stem from the medical model of disability.

Veda's story also aligns with a moral model of disability when secondary characters imply that her disability is a result of bad karma inherited from an unknown action in her previous life (Olkin, 2002). A "beggar" near the Shiva temple even prays for Veda so she isn't "a cripple in [her] next life" (Venkatraman, 2014, p. 97). Veda questions the role of God in her disability when she frustratingly asks her grandmother, "why did He take away my leg? Is God

punishing us for sins we committed and bad Karma we built in a past life?" (p. 98). Veda's stream of thought is a direct reflection of the moral model, stating that disability is a punishment from a higher entity (Black, 1996). Veda grapples with the moral model's concept of disabled redemption (Henderson & Bryan, 2011; Niemann, 2005) when she continues to wonder about the root of her disability and how she must contend with karma, stating that "good actions result in rewards, sooner or later. If you cause suffering, instead, something bad will return to you" (p. 213). Veda even believes her amputated leg is "an invisible reincarnation taunting" her (p. 233). While Veda believes strongly that her disability is a result of God's will, so too do her neighbors, the Subramaniams, who prayed for Veda's recovery throughout the text and "offered thanks" to Buddha for allowing Veda to have the opportunity to dance again (p. 268). These common beliefs about Veda's disability carried throughout the novel are indicative of the moral model of disability; Veda's amputation served as a source of shame for her until Buddha allowed her to overcome the limitations of her disability (Henderson & Bryan, 2011; Niemann, 2005).

Although an alignment with the moral model and the overall implications of Veda's disability as a punishment are problematic, I recognize that my interpretation of this novel and my analysis is informed by a white, westernized disability perspective (Goodley, 2012; Meekosha, 2004). Critiques from a global disability frame may not be as critical as I have been about the influence of the moral model on Veda's experience. Analysis of *A Time to Dance* from the "Indian perspective" on disability might examine how "tradition, history, (post-)colonization and (post)modernity [affect] the Indian psyche of disabled and nondisabled people" (Goodley, 2012, p. 639). Ghai (2006), a disability scholar from the Indian perspective, expressed that the internalization she felt in India "accustomed her to seeing [her] disability as a personal quest and tragedy to be borne alone" (p. 14); thus, the setting of India and the complex realities of poverty,

religion, and colonization may account for Veda's negative view of her amputation and the belief that God gave her a punishment she must overcome.

In *Marcelo in the Real World*

In *Marcelo in the Real World*, readers learn Marcelo experiences an unnamed cognitive disorder, likely autism spectrum disorder, as Marcelo says, "the closest description of [his] condition is Asperger's syndrome" (Stork, 2009, p. 55). At the beginning of the novel, Marcelo's experiences with his disorder, his family, and his friends positively align with the affirmation model of disability. Marcelo goes to a school for the disabled, has a steady job working with his school's equine-therapy horses, and is generally very happy with his life and his major differences. Marcelo's individual characteristics and unique abilities—he can hear what he calls "internal music" (Stork, 2009, p. 5) within his body—are acknowledged and appreciated by his mother when she says, "you are who you are" (p. 32); he also embraces his differences while frequently questioning the concept of normality. In alignment with the affirmation/identity model of disability, Marcelo pushes against the idea of "regular people" by stating that "the children who ride the ponies at Patterson are regular people" (p. 27). Additionally, Marcelo starts the novel with a fairly keen sense of personal identity, and he critiques his father's, and society's understanding of what it means to be "normal" when he says, "Arturo is basically asking me to pretend that I am normal, according to his definition… This is an impossible task… especially since it is very difficult for me to feel that I am *not* normal" (p. 23; emphasis in original). Marcelo continues his critique of society by emphasizing his father's deficit views on his "cognitive disorder;" Marcelo states, "explanations about my condition are based on the assumption that there is something wrong with the way I am […] I view myself as different […] but not as someone who is abnormal or ill" (p. 55).

While the novel starts with this positive and accepting portrayal of difference and Marcelo often offers a critique of society's problematic view of disability, the narrative ultimately falls victim to views aligned with the medical model of disability. Throughout the novel, Marcelo must grow and change who he is to fully integrate into society; these are themes that draw from the belief that disabilities must be cured or remedied (Couser, 2009; Dolmage, 2014; Schalk, 2016). He is constantly pressured by his father, Arturo, who forces Marcelo to choose between leaving his school for the disabled in the fall or quitting his job at the stables for the summer. A major element that propels the plot of this novel is when Marcelo makes the choice to become fully immersed in the "normal environment" (p. 20) of the mailroom at Arturo's law firm for the summer. While Arturo's ultimatum for Marcelo is bad enough, he goes so far as to deny Marcelo's disabled identity multiple times by stating "there's nothing wrong" (p. 20) with him and that he is "not disabled" (p. 40). Further alignment with the medical model of disability is seen through the characterization of Marcelo, which is representative of the super-crip trope. This trope is commonly found in stories of disability where the character's abilities function with or against their disability through the text (Couser, 2009; Dolmage, 2014; Schalk, 2016). Early in the novel, Marcelo is judged negatively for representations of his presumed ASD: his special interests in religion, morals and rules, and his obsession with fine details. However, just as a super-crip is later celebrated for the very characteristics that were used to identify them as "abnormal," Marcelo's intense sense of morality and his keen attention to detail allows him to save the day for Ixtel, a secondary character who has been wronged by Arturo's law firm.

Throughout the novel, Stork does offer frequent critiques of society's understandings of disability and normalcy; these critiques are important and may cause nondisabled readers to feel the novel is a positive representation of disability. However, these critiques do not do enough

because Marcelo is still forced to change fundamental elements of his disabled identity by the novel's conclusion. Additionally, while Marcelo does embrace his own differences at times, he also holds problematic views of disability. He expends much effort throughout the novel separating himself from other people with disabilities; he even goes so far as to say people with disabilities "need help" (p. 6) and "truly suffer" (p. 55) from their diagnoses. These beliefs about disabled people are perpetuated by ableist ideology that disabled people are either awe-inspiring or incompetent (Beller, 2020; Markotić, 2016). Furthermore, through Stork's broad critique of society's problematic views of disability, he fails to acknowledge the influence of Hispanic culture's views of disability and how Marcelo's existence as a Hispanic male further disabled him. For example, Zuckerman et al. (2014) found that amongst Latinx families, having a child with ASD is associated with feelings of embarrassment, rejection, and familial burden. Additionally, through pressures placed on Marcelo by his father, Arturo, and Arturo's explicit denial of Marcelo's disorder, we see evidence that Hispanic and Latinx men often look at pain as a sign of weakness and believe that seeking help makes one less of a man (Cabarello, 2011). This alignment with traditional machismo values and a sense of embarrassment of Marcelo's ASD-like disorder could have heavily influenced the decision forced upon him to leave his summer job and school for disabled youth. By the end of the novel, Marcelo has changed many elements of his identity to conform to the "normal" environment of his father's desire. The assimilation is so successful that Marcelo "can't find" (p. 159) his internal music and remembering, suggesting that individuals on the autism spectrum can and should improve with enough time and pressure (Smith, 2013). Like Venkatraman's dedication in *A Time to Dance*, Stork's (2009) author's note perpetuates the problematic language of a medical cure by dedicating the novel to his nephew's "ability to overcome the negative aspects of autism" (p. 313).

In *Sick Kids in Love*

Sick Kids in Love acknowledges the multidimensionality of disability aligning with both the human variation model—which acknowledges that everyone has or will have a limitation that is disabling in certain settings—and the affirmation/identity model—which promotes a positive disabled identity. From the very first page of chapter one, we learn that Isabel ("Ibby") is comfortable with her treatments for her rheumatoid arthritis (RA) and that she recognizes some disabilities are more disabling than others. Ibby claims her disability as an integral part of her identity and chooses the moniker "sick girl" (Moskowitz, 2019, p. 5) for her advice column in the school paper, *Sick Girl Wants to Know*. When Ibby meets Sasha, who is receiving treatments for his own chronic illness, Gaucher's Disease, the two bond over their shared experiences and their confusion over healthy people's discomfort with their illness. In line with the idea from the human variation model that disability is a universal human experience and a collective identity (Davis, 2002; Zola, 1989), Ibby and Sasha view their conditions as "the same" (p. 134). Ibby suggests numerous times that Sasha and she are alike because they are both "sick people" (p. 68) who do not need to "establish some hierarchy of who's sicker than who" (p. 135). According to Zola (1993), disability is a sign of human variation, a source of vulnerability or disadvantage in certain settings; Sasha expresses the reality of this claim when he says, "I certainly find that being sick only affects me in really specific situations" (p. 72).

Frequently throughout this novel, disabled author Hannah Moskowitz (2019) blatantly calls out stereotypical tropes of disability, elements of ableism and inspiration porn, and problematic views in line with a medical model in support of an affirmation/identity paradigm. For instance, in a discussion about not looking "sick enough" (p. 2), Sasha claims that his low pain tolerance turns him into a "total sick caricature" (p. 8) who is pathetic and demanding

whenever he is admitted to the hospital for Gaucher's-related symptoms. In a poignant exchange between Ibby and Sasha, Ibby explains that her dad doesn't want her to "define" herself by her illness because he knows how disabled people are stigmatized in society (p. 44). Sasha furthers this sentiment when he proclaims that "healthy people are *so weird* about that" (p. 44, emphasis in original) and suggests that society believes it's only acceptable to "define yourself by your illness…as long as you're an Olympic athlete who's overcoming it" (p. 45). Ibby and Sasha believe healthy people do not see illness as "an important part of your identity that you're just living with" because they "can't imagine it" (p. 45). Consistent with Garland-thomson's (1997) view that nondisabled people have no concept of being okay with a disability and hold the belief that all people with an impairment desire to be "normal," Ibby says:

> They think it's completely ridiculous that a person can just…have a sick life and be fine with it. So they have to build this story around you kicking illness' ass. You can't coexist with it. You can't incorporate it into yourself. Because they don't. So you can't. (p. 45)

Both Ibby and Sasha proudly claim their illnesses as vital parts of their identity, but they also discuss the "annoyances [their] chronic illness[es] decide to throw at [them]" (p. 182) and allow themselves to acknowledge the feelings of frustration and anger aligned with the affirmation model of disability (Swain & French, 2000). While Sasha declares "you know there's nothing wrong with being like me, right?" (p. 122), Ibby hates feeling "frustrated and pressured" (p. 132) by her friends who do not understand the pain associated with her "invisible illness" (p. 51, p. 81) and who do not "get" that "being sick is not a bad thing" (p. 258). This pendulum swing between pride and frustration is reminiscent of the affirmation/identity model of disability because Sasha and Ibby have acknowledged the social construction of disability, fostered a collective identity with one another, collectively experienced "frustration and anger," and

embraced the right to be an "insider" in the disabled community rather than an "outsider" (Swain & French, 2000, pp. 577-578).

Sick Kids in Love also functions as a counter-narrative to the two most common literary tropes for disabled characters, the super-crip and the myth of cure (Couser, 2009; Dolmage, 2014; Schalk, 2016); Sasha and Ibby make it through the entire novel without being extraordinary and without curing their disability. While neither Sasha nor Ibby are expected to grow or overcome their illnesses as a major plot point—in fact, both characters remain relatively the same from start to finish—Ibby does begin to vocalize her identity more openly. She has always considered her RA to be part of her identity, but she avoided talking about it out of perceived inconvenience to her healthy friends. However, towards the end of the novel she finally vocalizes her affirmative stance about her illness by saying, "I'm sick… And I don't wish that I wasn't. And I don't really care how uncomfortable that makes you anymore" (p. 276). Thus, through Sasha and Ibby's positive interpretations of their chronic illnesses, readers can learn that not every disabled person desires to be nondisabled, which is key to rejecting this common myth in ableist ideology (Garland-thomson, 1997). In comparison to *Marcelo in the Real World* and *A Time to Dance*, Ibby and Sasha's acceptance of their illnesses illustrates a positive portrayal of disability that rejects the typical stereotypes, ableist ideas, and deficit views commonly identified in fiction (Chrisman, 2018).

In *This is Not a Love Scene*

Of the selected YAL, *This is Not a Love Scene* is the only novel featuring a protagonist who uses a wheelchair. Maeve is a funny and honest teen who positively identifies as a person with muscular dystrophy while also pointing out the shortcomings in her environment that make it challenging for her to get around; for these reasons, this novel best aligns with the views of the

minority (social) model and the affirmation/identity model. Throughout the novel, Maeve takes pride in what she is capable of—while also acknowledging and working around her bodily limitations—and she is often angered when nondisabled people automatically do things for her. Maeve often proclaims, "abuse of the disabled" (Megale, 2019, p. 2, p. 63), when she feels a nondisabled person has stepped out of bounds to perceive her as incompetent or "thinks [she] need[s] help when [she's] just sitting somewhere doing nothing" (p. 111).

Maeve and her doctor also help to dispel any myths about her disability and quality of life. Rejecting the myth of cure and the need to overcome the disease, Dr. Clayton reiterates, "there's no treatment" and "*cure* wasn't even on the table" (p. 90, emphasis in original). Instead, Dr. Clayton focuses his energy on Maeve's lung function, which is a constant source of frustration, anger, and worry for her—aligning with an affirmation/identity model of disability (Swain & French, 2000). Maeve and Dr. Clayton also emphasize her ability to have "typical" teenage experiences, like exploring her sexual desires with her new romantic interest. In exploring Maeve's experiences, readers may learn the important lesson that disabled people can have a positive identity formation *and* be frustrated by their disability as the two are not mutually exclusive (Swain & French, 2000); furthermore, Maeve represents an example of a disabled person who does not wish to be nondisabled (Garland-Thomson, 1997).

Several scenes in the novel point to how Maeve needs accommodations that ableist society does not allow her. For example, she remarks on the problematic height of standard secretarial counters when she attempts to reach a clipboard with her "weak" arm, but instead "[her] arm fall[s] like a trapeze artist who missed his swing midair" (p. 32); this requires her to ask the secretary—who is now full of apology and "offensive" (p. 32) pity—to push it three inches closer. Maeve faces another frustration with accessibility when she goes to the movies

and spots, per "usual, two able-bodied people" sitting in the only two wheelchair accessible seats in the theater (p. 64). She draws attention to the fact that "this happened a lot" because nondisabled people don't ever expect "disabled people to come and take the fun out of disabled spots" (p. 65). In yet another issue of accessibility, Maeve visits the town ice cream parlor with her friends; she remains at the bottom of the exterior steps with her service dog, François, because there is no wheelchair accessible entrance or even a "ramp into a sketchy back entrance" for her (pp. 74-75). She even comments that "usually, in a situation like this, [she]'d write a letter and toss in the Americans with Disabilities Act threat" (p. 75). The minority and social models of disability emphasize how society contributes to and shapes disability through prejudice and discrimination, lack of accommodations, and inaccessibility (Hahn, 1994; Longmore, 2003). For example, Maeve believes she could do more for herself if her social and physical environments were more accommodating to her wheelchair. *This is Not a Love Scene* functions as an exemplar text aligned with both the minority and affirmation/identity models of disability as it offers a glimpse into systemic ableism—through the avenue of limited accessibility—readers may have previously never needed to think about (Pulrang, 2020).

Implications & Conclusion

Lee & Low Books' (2020) annual diversity data indicated that only 11% of YAL published in 2019 featured characters with disabilities, which is just a 4% increase from 2015. While the visibility of disability in YAL is gradually growing, we must analyze the representations of disability in these texts for progressive and/or problematic ideologies. Thus, by using Critical Disability Studies as a theoretical lens, I engaged in a critical content analysis to identify models of disability in YAL that included both positive and negative portrayals of disabled experiences.

The purpose of this analysis was to explore the representation of disability in YAL, to determine the implications of those representations—whether they be positive or problematic—and to determine if authors' positionalities affected disability representation. By employing Critical Disability Studies as a theoretical frame and the aligned models of disability as an analytic tool to guide this analysis, I have drawn attention to the ways in which positive disabled identities and stereotypical tropes of disability operate in four YA novels; my findings indicate that two novels by insider disabled authors presented more positive portrayals of a disabled experience. By reviewing only four texts, I do not wish to overgeneralize that nondisabled authors *always* present stereotypical disabled experiences, nor do I wish to leave the impression that the disabled-authored texts are the best books for disability representation. However, I offer a word of caution to readers and teachers as they select novels from an outsider perspective because we cannot deny that there remains a dependency on the medical model and problematic tropes of disability in YAL.

In *A Time to Dance* and *Marcelo in the Real World*, outsider (Short & Fox, 2003) or nondisabled authors present disabled characters who must improve or overcome the situations of their disability by the end of their narrative. By engaging with these texts, nondisabled and disabled readers alike may internalize a medical model of disability or develop a problematic ableist view of disability in which they view disability as an individual problem that can and should be cured through perseverance (Couser, 2009; Dolmage, 2014; Schalk, 2016). Thus, if educators wish to use these texts in a classroom environment, they must screen books in advance (Prater, 2003) and draw on critical literacy to guide students' analysis in unearthing problematic tropes of disability. First, teachers might consider how disabled characters are portrayed within the text; for example, are they seen as sad, helpless, and pathetic; are they seen as heroic,

inspirational beings with remarkable success despite their disability; are they "cured" or dead at the end of the novel? Answering "yes" to either of these questions might indicate that a text does not authentically portray a disabled experience and aligns with stereotypical tropes common in fiction. If these stereotypes exist in a text selected for inclusion in the classroom, teachers should then ask students to consider what underlying message the author is delivering through this portrayal of disability. Further, Dunn (2015) posed numerous questions that may help teachers when selecting texts featuring disability and engaging in critical conversations about disability with students:

- Who gains and who loses by the representations that appear in these texts?
- How is disability represented in this text?
- What are some implications of those representations for individuals in the real world?
- What "cultural work" does this text do? In other words, to what extent are harmful stereotypes about disability cultivated, disrupted, or both?
- How might hidden, harmful assumptions about disability be recognized so that students might become "resisting readers"?
- If this text cultivates harmful assumptions about disability, but the text is going to be read anyway, what questions can be posed about this book to get readers to re-think those assumptions? (pp. 9-10)

Conversely, the disabled authors of *Sick Kids in Love* and *This is Not a Love Scene* present realistic first-person narratives of teens living with a disability to which each author is personally familiar. These two narratives take readers on a journey of self-empowerment, positive disabled identity formation, and offer a critique of disabling elements of social and

physical environments (Swain & French, 2000). By selecting disabled authors' depictions of disability, teachers may help students question the status quo and how society views disabled people (Mathis & Vaughan, 2018). Nondisabled readers engaging with these two texts may explore embedded ableism in our sociopolitical climate and may develop a richer, more justice-oriented view of disability (Loewen & Pollard, 2010). Similarly, disabled readers may experience an increased sense of agency and positive identity formation when seeing realistic portrayals of disability. To further explore issues of ableism in society and disability justice movements, teachers should highlight real-life examples for students to explore. For example, teachers might ask students to read articles such as "What You Need to Know About Ableism" (Finkelstein, 2020) to help students see how ableism appears in real life, as well as to learn actionable steps they can take to limit their own ableism. Teachers might also choose to show the 2020 Netflix documentary *Crip Camp: A Disability Revolution* or highlight videos available on YouTube such as "Social Justice: What's disability got to do with it?" to highlight significant figures and actions in the historical movement for disability rights in the US. Furthermore, teachers might ask students to listen to episodes from Podcasts such as "From the Throne" or "Barrier Free Futures," and showcase non-fiction texts and social media feeds for disability justice advocates and authors such as Alice Wong or Shane Burcaw to introduce students to real-life disabled advocates who share their daily lives with the public.

The findings from these analyses call for disability representation in YAL "which challenges, resists, and transgresses an interpellated norm, whether that norm be social, physical cultural, or aesthetic [because] how bodies get read, assessed, and interpellated through literature continues to inform, determine, regulate, and govern how bodies get treated in the world" (Markotić, 2016, p. 10). Furthermore, findings indicate that publishers, readers, and educators

should consider the positionality of the author—as disabled or nondisabled—when effectively selecting books that feature characters with disabilities. As we begin to see increased publication of YA novels featuring disabled protagonists, we must center YA novels that authentically portray disabled experiences so that we may move away from "othering" those with disabilities (Hughes, 2017; Silverstein, 2019); then, nondisabled and disabled readers alike may develop necessary critical literacy skills to interrogate disability, allowing them to reflect on their own experiences with and relationship to sociopolitical ableism in the world at large.

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Appendix

Table 1.1: *Models of Disability*

Disability Model	Definition/Explanation
Moral	● The moral model is the oldest model of disability and is rooted in spiritual and religious traditions (Olkin, 2002). ● Disability is viewed as an individual problem and carries a degree of stigma and pathology (Olkin, 2002). ● Disability is ascribed as a direct effect of sin or social immorality that must be healed or redeemed through perseverance (Black, 1996); this view may imply that a disability is deserved, is a punishment from God (or other entity) for past indiscretions, is a test of faith in what one can handle (and how to redeem oneself), or is a curse bringing shame to oneself and one's family (Henderson & Bryan, 2011; Niemann, 2005). ● The moral model uses individuals with disabilities as life-lessons for non-disabled people, either as a warning away from sin or to develop patience, courage, and perseverance.
Medical	● Supporters view disability as "a long-term to permanent physical, behavioral, psychological, cognitive, or sensory impediment" that renders someone as other and less-able (Gilson & DePoy, 2002, p. 154). ● Disability is an individual problem and those identified as "disabled" must "overcome" their disability through personal perseverance; disabled people are defined only by their abnormal condition, defect in, or failure of the body (Olkin, 1999).
Social & Minority Group	● All physical and mental differences are an element of human diversity and *society* is responsible for placing negative connotations and stigmas on these differences; therefore, any meaningful "solutions" must be driven by societal change rather than individual perseverance (Barnes, Mercer, & Shakespeare, 2010). ● Supporters are "concerned with the social processes that 'disable' people" and how this process informs the development of disability identity (Gabel & Peters, 2004). ● The minority model folds into the social paradigm as it identifies social stigmatization, prejudice, exclusion, and institutional or legal constraints as the root cause of disability (Putnam, 2002; Scotch & Schriner, 1997).

Table 1.1 Continued

Human Variation	• The human variation model was born from the social model but addresses the multidimensionality of disability depending on the social and physical settings in which certain impairments become relevant (Higgins, 1992; Scotch & Schriner, 2002). • Within the human variation model, challenges faced by people with disabilities do not result from their deliberate exclusion, but from the mismatch between their characteristics and their physical or social environment (Higgins, 1992; Zola, 1993). • Supporters believe all humans have—or will experience—a physical or mental variation that can become a source of vulnerability or disadvantage in certain settings.
Affirmation/Identity	• The identity—or affirmation—model shares the social model's view that disability is socially constructed; however, it differs in its emphasis of positive identity formation. • Disability is defined by one's experience in the world and is viewed as a marker of membership for a minoritized identity, like gender and race, with shared experiences (Brewer et al., 2012). • Supporters believe a positive disabled identity is fostered by a) acknowledging the social construction of disability, b) fostering a collective identity (such as through campaign groups), c) collectively experiencing "frustration and anger," and d) embracing the right to be an "insider" rather than an "outsider" (Swain & French, 2000, pp. 577-578).

Table 1.2: *Sample Codes from* Sick Kids in Love *(Moskowitz, 2019)*

Excerpt from Text	First Round – Open Coding	Second Round – Category – Model of Disability
"I wake up at noon on Saturday feeling like I've been run over. My whole self is throbbing. A full-body sprained ankle." (p. 55)	Pain associated with RA.	N/A – This excerpt simply explains a side effect of RA for the reader; thus, it was excluded from further analysis.

Table 1.2 Continued

"'And I had the Sick Girl thing, but they thought that sounded… I can't remember the word they used. Like it would only be applicable in certain situations.' 'I mean, I certainly find that being sick only affects me in really specific situations,' he says and the relief of hearing someone call that out, of someone just grabbing that and pouncing on it and identifying it as the bullshit that is... God, it's like coming up for air." (p. 72)	Certain situations are more challenging—more disabling—for Ibby & Sasha due to their diseases.	Human Variation – Acknowledges that disability is multidimensional and is influenced by a mismatch of biological impairment and setting (Higgins, 1992; Scotch & Schriner, 2002).
"'No,' I say. 'No, it's the same. It's not… It's not identical, but it's the same experience. And it's not something that healthy people understand.' My dad doesn't say anything. 'I'm sick,' I say. 'And I don't wish that I wasn't. And I don't really care how uncomfortable that makes you anymore.'" (pp. 275-276)	Ibby finally claims her disease as a part of her identity after being scared to discuss it with her father.	Affirmation/Identity – Disability is a marker of one's identity and signifies a shared lived experience with other disabled people (Brewer et al., 2012).

Table 1.3: *Models of Disability in 4 Contemporary Young Adult Novels*

YA Novel	Synopsis & Identified Disability	Other Identity Markers	Models of Disability
A Time to Dance (Venkatraman, 2014)	Veda is a national prize-winning Indian Bharatanatyam dancer who values the physical prowess of her body. When a bus accident results in a below-the-knee amputation and Veda's dance instructor no longer believes she is teachable, her world is turned upside down. A new dance teacher helps Veda relearn the most basic of dance steps to reclaim her passion and skill.	Name: Veda Gender: Female Race/Ethnicity: Indian (South Asian)	Medical Model Moral Model

Table 1.3 Continued

Marcelo in the Real World (Stork, 2009)	Marcelo has an unnamed cognitive disorder closely related to autism spectrum disorder. He is able to hear music and interpret the world in ways that "normal" people cannot identify. Under pressure from his father, Marcelo leaves his school to join "the real world." New friends and experiences in this environment change Marcelo immensely.	Name: Marcelo Gender: Male Race/Ethnicity: Unspecified Hispanic	Affirmation/Identity Medical Model
Sick Kids in Love (Moskowitz, 2019)	Isabel ("Ibby") and Sasha meet in the hospital while receiving treatment for their chronic illnesses, rheumatoid arthritis and Gaucher's Disease, respectively. The two form a friendship—and eventually fall in love—over their experiences and shared identity as a "sick" teen.	Name(s): Isabel & Sasha Gender(s): Female & Male Race/Ethnicity: White Jewish	Human Variation Model Affirmation/Identity Model
This is Not a Love Scene (Megale, 2019)	Eighteen-year-old Maeve has two wishes: to be a successful filmmaker and to finally land a hot boyfriend. However, her rare form of muscular dystrophy and the loud mechanics of her wheelchair tend to stand in the way of typical romances. When she develops chemistry with the lead actor in her latest film production, she must decide between what she wants and what she needs.	Name: Maeve Gender: Female Race/Ethnicity: White	Social/Minority Model Affirmation/Identity Model

Chapter 3: Article 2

"It really warmed my heart": An Instrumental Case Study of Readers' Responses to Disability in YA Literature

Abstract

The purpose of this article is to explore readers' responses to disability in YAL through an instrumental case study design. To examine the possibilities of including disability as a diverse topic for classroom discussion and analysis, seven first-year college students enrolled in a YAL course read and responded to three YA novels written by disabled authors about disabled protagonists, *Sick Kids in Love* (Moskowitz, 2019), *The Silence Between Us* (Gervais, 2019), and *This is Not a Love Scene* (Megale, 2019). Students adopted a critical literacy stance informed by a Critical disability Studies lens to interrogate disability representation and share their personal experiences with the reading. The following research question is addressed within this case study: How do readers respond to representations of disability in YAL and what are the effects of those responses? Findings indicate that readers' responses to disability narratives are largely influenced by their own ableist beliefs and assumptions about disability; thus, adopting an explicitly anti-ableist lens for reading may be necessary.

Disabled characters have been discriminated against and oppressed in literature for nearly as long as humans have been writing and creating art (Gallagher, 2020; Shortley, 2018). In fact, scholars believe the first example of disability in literature was blindness in Sophocles' *Oedipus Rex* around 430 BC (Bowman & Jaeger, 2004). Historically, film and literature has included disabled characters to teach life lessons or elicit sentimentality from a presumed nondisabled audience (Dyches & Prater, 2000; Markotić, 2016). Within the last three decades, however, there has been a call for increasing visibility for authentic and diverse disabled experiences, especially in children's and young adult literature (CYAL) (Heim, 1994; Kingsbury, 2021; Prater, 2003; Silverstein, 2019). Despite this call, representations of disability remain difficult to find in CYAL, especially authentic intersectional representations written by disabled authors (Kingsbury, 2021; Whaley, 2016). According to the Cooperative Children's Book Center's ([CCBC], 2020) study on diversity in publishing, only 3.4% of CYAL in 2019 featured a primary character with a disability. Similarly, Lee & Low Books' (2020) annual diversity data indicated that only 11% of responders working in the publishing industry (e.g., executives, editors, agents, and authors) self-reported as living with a disability. Compare these publishing statistics with

disability prevalence in the real world and it becomes evident that disability is sorely underrepresented in books published for young people.

According to the World Health Organization ([WHO], 2021), over 1 billion people—about 15% of the global population—experience disability. That percentage is higher in the US, specifically; the Center for Disease Control and Prevention (CDC) reported in 2020 that 61 million adults—26% of the overall population—live with some form of disability. Further, an estimated 1.3 million youth in the US experience disability or chronic illness (Erickson et al., 2016). Within the 2015-16 academic year, approximately 6.7 million US K-12 students received special education services (National Center for Education Statistics [NCES], 2018). The number of individuals who experience disability is gradually increasing, yet social stigmatization, access to resources, and inclusion efforts are severely lacking (WHO, 2021). This is especially evident in school settings, where disability remains stigmatized and often ignored as a diversity topic outside special education environments (Baglieri & Lalvani, 2020; Donovan & Weber, 2021; Erevelles, 2000; Goodley, 2007).

Disability remains stigmatized because of the cultural hegemony that reifies widely accepted ableist infrastructures, which keep disabled people at the bottom of the social hierarchy (Cherney, 2011; Hardin & Hardin, 2004). Highlighting these cultural norms, Ware (2001) posited that critical scholars "avert their gaze" from disabled people as well as issues of disability in education, "as if to suggest that liberatory praxis would naturally exclude the disabled" (p. 113). Scholars of young adult literature (YAL) and education advocate for the inclusion and analysis of novels featuring disability to create visibility, to give voice to oft-ignored or erased experiences, to reconsider our understanding of diversity, to destigmatize disabling conditions, and to ask readers to question dominant sociopolitical views about

disability (Donovan & Weber, 2021; Dunn, 2015; Fox, 2017; Heim, 1994; Prater, 2003; Silverstein, 2019). Although overwhelming claims suggest literature—and especially YAL—can lead readers to become better citizens, to become more empathetic and compassionate, to dispel prejudices, and to motivate social change, there are very few empirical studies with direct outcomes supporting this claim, and even fewer specifically focused on readings of disability (Bishop, 1990; Connors, 2014; Connors & Rish, 2015; Djikic et al., 2013; Mar et al., 2006; Nussbaum, 1997; O'Donnell, 2011; Pinker, 2004; Richmond, 2014; Shanahan & Dallacqua, 2018; Trites, 2000).

The purpose of this study is to examine the possibilities for and outcomes of including disability in classroom discussion and analysis with college students enrolled in a first-year studies YAL course as they read and responded to three novels written by disabled authors about disabled protagonists. Thus, I explore, through a Critical Disability Studies (CDS) lens (Meekosha & Shuttleworth, 2009), how readers responded to depictions of disability and whether readers question dominant narratives of disability through their reading experiences. I address the following research question: How do readers respond to representations of disability in YAL and what are the effects of those responses?

Related Literature

Disability in Literature

While disabled characters have appeared in texts since approximately 430 BC, depictions of disability have not often been positive or realistic. In classical texts, readers encountered characters such as the hunchbacked Quasimodo and King Richard III, Lenny who dies because of his disability, Colin Craven who overcomes the bounds of his wheelchair, the one-legged and "mad" Captain Ahab, the evil and deformed Captain Hook, and the sentimental innocent Tiny

Tim (Leduc, 2020; Markotić, 2016; Mitchell & Snyder, 2000; Shortley, 2018). Traditionally, a disabled character was used to propel the plot forward or to show important character development for nondisabled characters (Biklen & Bogdan, 1977; Dyches & Prater, 2000; Heim, 1994). Furthermore, disabled characters have been historically—and are still—presented in one-dimensional, negative, and restrictive views; they are often meant to elicit sentimentality and pity, or to teach assumed nondisabled readers about tolerance and acceptance (Biklen & Bogdan, 1977; Heim, 1994; Markotić, 2016; Meyer & Wender, 2017). Just as Bishop (1990) outlined in her oft-cited metaphor, books centering disability can serve as “mirrors” when disabled readers can see themselves represented on the page; “windows” when books allow nondisabled readers to gain understanding and empathy for others’ lives, experiences, and cultures; and “sliding glass doors” when all readers can imagine themselves walking into the world of a novel. This emphasis is especially important for a social status and group such as disability, whose existence and historical movements remain stigmatized and ignored in classrooms and society.

Perhaps correlating with the passage of the Individuals with Disabilities Education Act (IDEA) in 1975 and the Americans with Disabilities Act (ADA) in 1990, more books have been published within the past three decades featuring characters with a diverse range of disabilities and more scholars have stressed the importance of both accurate and authentic representations of disability (Gallagher, 2020; Heim, 1994; Prater, 2003; Silverstein, 2019; Ware, 2001). Furthermore, authors seem to be making a more concerted effort to reject deficit views of disability to capture a more realistic depiction of disabled experiences (Wopperer, 2011). Social media movements, such as #WeNeedDiverseBooks and #OwnVoices, have also helped to draw attention to authentic disabled narratives in YAL (Whaley, 2016). The initial conversation about #OwnVoices was inspired by YA author Corinne Duyvis’s frustration in lacking authentic

representations in YAL as a bisexual disabled person. She suggested that instead of simply emphasizing diverse books and characters, we must emphasize diverse authors who write about that same diverse group. Thus, #OwnVoices raised questions of authorial identity and stressed the importance of marginalized authors having the space to create stories from their own marginalized identities (Whaley, 2016). While #OwnVoices may have positively influenced an increase in disability representation in CYAL publishing by 4% between 2015 and 2019 (Lee & Low Books, 2020), it also became a "catch all" term that raised critical issues about vagueness and who has the right to define an #OwnVoices experience (Lavoie, 2021). Largely driven by the folx at We Need Diverse Books, the term #OwnVoices is not generally used in 2022 to discuss books by and about marginalized experiences, but an emphasis on authors' positionality in relation to the characters in which they write remains important for consideration (Lavoie, 2021).

Disability Stereotypes & Narrative Tropes

Representations of disabled characters often fall into one of several stereotypical categories, or narrative tropes. For example, a common disability trope is that of a pathetic victim, a sinister villain, a helpless innocent, or a courageous overcomer (Baglieri & Shapiro, 2012; Biklen & Bogdan, 1977; Garland-Thomson, 1997, 2008; Markotić, 2016; Quayson, 2007). Numerous typologies have been developed since as early as 1977 with Biklen and Bogdan's exploration of 10 disability stereotypes found in fiction. More recently, Baglieri and Shapiro (2012) identified 9 categories into which disabled characters fall: the object of pity, the subhuman organism, the sinister or evil, the unspeakable object of dread, the eternal child or holy innocent, the object of comedy, ridicule, or curiosity, the burden, the victim of violence, and the super-crip or extraordinary. In the content analysis of article one within this dissertation, I identified how two common tropes exist within contemporary YAL, including the super-crip—a

character with exceptional abilities despite their disability—and the myth of a cure—a character who must get "better," overcome an aspect of their disability, or die by the end of their narrative (Couser, 2009; Dolmage, 2014; Schalk, 2016). *Marcelo in the Real World* (Stork, 2009), for example, features Marcelo, a character who must overcome symptoms of his Autism-like disorder to appear more "normal" by the end of the novel and who is celebrated, despite his cognitive disorder, for his extraordinary sense of morality and attention to detail. Within super-crip and myth of a cure narratives, disabled characters are portrayed as noble, courageous, and brave because they can "cope with what 'normal' people would find too difficult or overwhelming to handle" (Markotić, 2016, p. 4). Stereotypes and tropes function to dehumanize disabled people and separate them from nondisabled readers; reading these stereotypes can have detrimental effects for readers' prejudices about corporeal disabled individuals (Markotić, 2016; Shortley, 2018). To limit negative effects, Ware (2001) demanded researchers shift their examination of disability to consider it through a cultural lens wherein "ability is interrogated in much the same way that gender is interrogated by feminist studies scholars and Whiteness is interrogated by ethnic studies scholars" (p.110).

Without an awareness for disability stereotypes, nondisabled readers might not realize the harmful implications of these depictions. An emphasis on novels depicting disability written by disabled authors with the same or a similar disability to their protagonists is especially important considering disability is socially stigmatized and relegated to the outer fringes of diversity and social justice work (Baglieri & Lalvani, 2020; Donovan & Weber, 2021; Shortley, 2018). Further, Quayson (2007) posited that "disability representation is seen as having a direct effect on social views of people with a disability in a way that representations of other literary details, tropes, and motifs do not offer" (p. 19). Thus, novels with stereotypical or ableist representations

of disability have the power to alter "perceptions of people with disabilities and helps maintain biases and myths about disabilities" in corporeal situations (Myers & Bersani Jr., 2008, para. 1); these depictions can also perpetuate the further stigmatization of disabled people in society (Heim, 1994). Within the field of literary theory, cognitive poetics and narrative empathy scholars posit that we process fiction and reality in the same way, which explains why fiction can emotionally and tangibly affect readers. This emotional effect from literature has the potential to affect how we act and think in real-world situations (Cheyne, 2019; Keen, 2007; Stockwell, 2002). Because of how our brains process fiction, readers interact with fictional characters as if they were real people with complex backgrounds, personalities, and motivations (Nikolajeva, 2014; Zunshine, 2006). Readers "wonder not only about the motives, views, and values of the writer as possibly reflected in the text, but also about oneself in response to that representation of reality" (Soter, 1999, pp. 31-32).

This can be problematic, however, because as "literary characters do not necessarily have to behave the way real people do, and they do not necessarily follow the prescribed behavioristic patterns or the observed course of mental disturbances" (Nikolajeva, 2002, p. 9), readers may ascribe inaccurate or incomplete fictional characteristics to people in the real world. This may be particularly harmful if a fictional character represents a marginalized socio-political or cultural group (i.e., disabled, BIPOC, and LGBTQIA+) and readers ascribe negative representations to corporeal individuals in those same groups. To mitigate this possibility concerning disabled people, Heim (1994) outlined four criteria for evaluating representations of disability in fiction that emphasize counter-storytelling—sharing stories that challenge common myths and biases, or stories from populations that are often not told (Delgado & Stefancic, 2017; Solórzano & Yosso, 2002)—to disrupt disability stereotypes: 1) accurate information; 2) absence of stereotypes; 3)

rich plot and disabled character development; and 4) sensible disability confrontation "that a child would be likely to experience in real life" (p. 139). As Delgado and Stefancic (2017) stated, because stories have a "valid destructive function," we must attack "embedded preconceptions that marginalize others or conceal their humanity" through fiction (pp. 49-50). To disrupt the manifestation of problematic disability tropes and preconceptions, scholars in the fields of YAL and education have recognized the need to include accurate and authentic depictions of disability, to approach the texts from a critical perspective, and to study readers' responses to those depictions.

Readers' Responses to Disability in YAL

While an abundance of scholarship on critical questions and conversations around issues of race, gender, and class exists, I am particularly interested in how readers can critically engage with YAL representing disability. The goal of enacting critical readings of disability involves critiquing how language within a text can unearth prejudices or disrupt deficit views toward disabled people (Erevelles, 2000; Lewison et al., 2002; Richmond, 2014; Silverstein, 2019; Ware, 2001). Although there are numerous theoretical studies exploring perceived student outcomes and possible implications for readers' responses to YAL featuring characters with disabilities (Bass, 2015; Chrisman, 2018; Darragh, 2016; Groenke et al., 2010; Hayn et al., 2009; Hazlett et al., 2011; Henderson, 2009: Kennedy & Menton, 2010; Meyer & Wender, 2017; Richmond, 2018; Tsumoto & Black, 2015) and numerous content analyses with similar implications for readers (Curwood, 2012; Koss, 2015; Matsumoto & Black, 2019), I noticed a gap of empirical research dedicated to students' and teachers' responses to disability, especially when compared to criticality and responses to issues of race, gender, and class in YAL. Below, I

include a review of empirical studies that explore readers' responses to disability with youth, college students, and with preservice teachers.

Using mixed methods, Cameron and Rutland (2006), studied the effects of extended contact with literature emphasizing disability with young readers; they conducted a six-week study analyzing the effects of reading books featuring disabled characters on nondisabled students. Their results indicated that extended contact, classroom practices, and discussions reduced prejudice towards disabled individuals. Darragh (2010) used quantitative methods to examine how reading YAL featuring people with disabilities affected the perceptions of 229 eighth grade students. Darragh's study found no statistically significant differences between students' attitudes prior to and following the reading of the novels. Again, Darragh (2015) expected that reading a YA novel featuring a disabled character would help students develop positive views for and positive behaviors toward disabled people. Comparatively, some students read YAL without a disabled character, and unfortunately, no statistical differences were found between the groups. Mathis and Vaughan (2018) used a Disability Studies lens to examine the effects of two YA novels featuring characters with emotional and behavioral disorders for male adolescents who self-identify as having similar disorders. Through book community discussions, they found the teens were able to connect with the characters, "the societal 'other'" (p. 301), and with the plot, themes, and situations on a personal and individual level; furthermore, the characters reflected the participants' individual fears, joys, beliefs, and values which helped them understand their individual identities as they are situated among family, friends, and society. Additionally, they found that "hearing the varied perspectives within this reading community enlightened readers' own understandings of self and others" (p. 300).

Cypher and Martin (2008) explored college students' responses to disability in children's literature in a college course. They found that their students strongly rejected critiques of Helen Keller's common portrayal as an inspirational disabled public figure as those critiques "proved to contain a significant threat to their own subject formations" (n.p.). Their work highlighted the effect of students' personal histories and beliefs that may influence their reading of disability. Donovan and Weber (2021) conducted surveys and interviews to explore "how preservice teachers read and plan to teach literature featuring characters with disabilities" (p. 205). They found that YAL allowed participants to consider the social construction of disability; however, when it came to planning for instruction, many participants' "framing of disability in unit planning offered a limiting view of disability" (p. 217). Menchetti, Plattos, and Carroll (2011) studied the role book and movie portrayals of developmental disabilities have on preservice special education teachers. Their findings indicated that the impact of disability representation is influenced by whether the portrayals were positive or negative, and accurate or inaccurate. Olan and Richmond (2020) used RRT as a framework for analyzing preservice teachers' responses to post-traumatic stress disorder (PTSD) in YAL. They found that both students in urban and rural settings increased their understanding of and empathy for PTSD in the novel, as well as to "imagine the characters are living, breathing human beings" with real emotions (p. 54). Ware (2006) fostered critical conversations about disability through YA and canonical literature in a summer institute with in-service teachers and in a college course for preservice teachers. First, she found that students were, unfortunately, more likely to pathologize disabled characters and that they favored medical terminology and accuracy of disability. However, when reading texts against one another and answering critical questions, she found students understood how disability is socially constructed. White and Dunn (2015) read YAL with preservice English

teachers to explore how society constructs disability. By studying the disabled character' social status, they noted readers analyzed the character's challenges to identify social assumptions as a larger barrier than the character's disability.

Finally, Ware (2001; 2002) explored how both students and educators responded to disability representation in poetry, short stories, and film within a 9th grade classroom. By the end of the unit, she found that students recognized problematic patterns for disabled representation in the media and critiqued how concepts of normalcy and difference are socially constructed. Conversely, Ware (2002), found that the participating teacher and school social worker felt numerous tensions regarding the unit, including: uncomfortable memories about interactions with disabled people; feeling unqualified to teach about disability; worrying that disabled students would feel marginalized by studying disability; and believing disability was a dangerous topic for class discussion. Ware's study highlighted the importance of teachers' reflection on their own disability histories and ableist biases, so they can understand the value in including disability to benefit *all* students' learning experiences.

This study builds upon this existing work by exploring readers' responses to YAL featuring disability. Dunn (2015) warned that while combining "high-quality disability-themed fiction" with critical discussion can help students disrupt the "us/them dichotomy," of disabled and nondisabled, discussions that lack "well-placed critical questions" can, in turn, exacerbate existing stereotypes. (Dunn, 2015, p. 2). Further, "inaccurate, dismissive, stereotypical, or other problematic depictions of disabilities in fiction can be useful in helping students understand issues associated with disabilities" and by highlighting "problems in inaccurate portrayals, students can gain a deeper understanding and appreciation for human experiences and diversity" (Menchetti et al., 2011, p. 63). While I agree with Menchetti, Plattos, and Carroll (2001) that

classrooms may inspire "spirited conversations" about "bad" disability books (p. 63), I also recognize that for readers who have limited experiences with disability or who might hold ableist views, reading stereotypical tropes can reinforce prejudice and stigma when interacting with corporeal disabled individuals (Myers & Bersani Jr, 2008). If ableist beliefs inform students' readings of stereotypical portrayals, they will see situations that reinforce their own views rather than disrupt them. Thus, Menchetti, Plattos, and Carroll (2001) suggested "the best place to start will be books that have both literary quality and accurate portrayals" (p. 62). This is also important because readers might completely miss an instance within the text where they are meant to recognize and critique a negative disabled representation (Dunn, 2015). Therefore, I only centered YA novels that—from my perspective as a disabled reader and scholar—feature authentic disabled experiences from disabled authors.

Theoretical Perspectives

This study draws on theoretical perspectives from the field of Critical Disability Studies (CDS) and Rosenblatt's (1938/1968) Reader Response Theory (RRT). Within the context of the freshman-level college course, CDS was drawn upon as an interpretive lens for critically reading YAL featuring protagonists living with a disability; specifically, students were asked to consider the conceptualizations of disability and ableism as informed by CDS. RRT informed the analysis of study participants' responses to the YAL and their thoughts regarding corporeal disability issues in society.

Critical Disability Studies

Critical Disability Studies (CDS) emerged as a field for academic research and professional education in the 1980s as a direct result of the Critical Legal Studies movement that also informed Critical Race Theory (Meekosha & Shuttleworth, 2009). Scholars of CDS offer models

of disability as approaches or standpoints to conceptualize the construction of disability in the world and to examine disability as a "historical, social, political, and cultural phenomenon" (Bialka, 2015, p. 143). The models of disability serve as approaches to understanding the relationship between biological and social conditions; furthermore, the models represent different views about the impact of disability on well-being, how disability is relevant to human rights and social policy, and how individuals and society respond to disability (Wasserman et al., 2016). Scholars began to reject a medical model of disability—the notion of disability as human defectiveness—in favor of a socially constructed view of disability; this created a false dichotomy between two contrasting approaches, or models, of disability within disability studies: the medical model and, later, the social model (Barnes et al., 2010; Donoghue, 2003; Gilson & DePoy, 2002; Terzi, 2005; Zola, 1989).

The medical model of disability views both physical and mental differences as justification for separating individuals diagnosed with a disability apart from those who are not. Initially, the social model was developed in response to criticism of the limitations and deficit views of the medical model (Olkin, 2002) to emphasize social barriers which function to disable bodies. I adopt a broad social model of disability and asked students to consider how both biological differences *and* social barriers affected disabled characters within the novels they read, as well as to consider corporeal implications.

Disability & Ableism

How we define disability, what counts as a disability, and who can qualify as disabled is highly contested; numerous definitions exist, and conceptualizations of disability vary by field of study, intent, closeness to disability, and social beliefs (McDermott & Turk, 2011). For example, many disability-focused organizations use disability as an umbrella term to represent the

complexity and variation of conditions and disabling effects (Jelsma, 2009); however, most nondisabled Americans—who also do not have a close relationship with someone disabled—do not agree that so many variable conditions should qualify as disabilities (Shannon-Missal, 2015). As Nario-Redmond (2020) suggested, this continued disconnect between public perception—especially amongst the nondisabled—and disabled reality makes the study of disability prejudice—ableism—"ripe for investigation" (p. 6). For the purposes of this study, I adopted the World Health Organization's ([WHO], 2022) definition of disability, in which "disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support" (para. 2). This definition recognizes the importance of context, disability type, subjective experiences, accessibility, and oppression as disabling factors. Further, disability is understood as a socially constructed "historical, social, political, and cultural phenomenon" (Bialka, 2015, p. 143) encompassing diverse short- and long-term and invisible or visible traits and conditions.

Disability is the largest marginalized group in the world, and there are disabled people in every other marginalized group; further, disability is unique because people can enter—and exit—disabled status at any point in life. In fact, Nario-Redmond (2020) posited that this "open enrollment" of disability status may explain why "ableism has been such a contentious topic, even among the experts who study stereotyping and prejudice" (p. 4). Further, Chodorow (1999) identified ableism as a "permissible prejudice," often unacknowledged and generally accepted in society that privileges nondisabled experiences (para. 2).

Disability is both "a social status that incites both hostile and benevolent forms of prejudice" and a "group that provokes stereotypes of incompetence and dependency, and

behaviors that range from staring and unwanted assistance to abandonment, dehumanization, and hate crimes" (Nario-Redmond, 2020, p. 3). Just as disability is defined in numerous ways, so too is ableism. Ableism represents the individual, cultural, and structural levels of prejudice, stereotyping, discrimination, and oppression of disabled people (Bogart & Dunn, 2019). Further, I recognize that ableism results in disabled people being "*excluded, ignored, misunderstood, rejected, dismissed, avoided, pitied, envied, objectified, dehumanized, manipulated, shamed, mocked, stereotyped, overprotected, condescended to, and/or provided with unwanted help*" (Nario-Redmond et al., 2019, p. 739, emphasis in original). Just as all other forms of social oppression, prejudices, and biases function at the individual, cultural, and structural level, so too does ableism (Baglieri & Lalvani, 2020). Moreover, ableism includes negative prejudices—hostile ableism—and "positivity biases"—benevolent ableism (Nario-Redmond et al., 2019, p. 729). More often, however, ableism includes a mixture of negative and positive feelings that shift depending on the situation (Nario-Redmond et al., 2019). Regardless of the type of ableism, there are three related components, what Nario-Redmond (2020) labeled as the ABCs of ableism: "affective emotions or attitudinal reactions; behavioral actions/practices; and cognitive beliefs/stereotypes that go beyond general negativity" (p. 6). I will explore examples of these presentations of ableism later to aid in understanding participant responses to YAL depictions of disability.

In adopting CDS as an interpretive lens, I asked study participants to embrace these conceptualizations of disability and ableism to inform their reading and analysis of disability representations in YAL. However, if students have limited experience with the disabled community and if they possess ableist views, these conceptualizations may be hard for them to

grasp and to identify within the texts. Thus, we must consider prior experiences and awareness of disability and ableism that students bring with them to the reading context.

Reader Response Theory

To understand how participants are responding to representations of disability in the selected novels, I will draw upon a transactional theory of reader response (Rosenblatt, 1938/1968). According to Rosenblatt's (1938/1968, 1985) Reader Response Theory (RRT), readers' individual experiences and background knowledge interact with a text to influence comprehension and understanding. Rosenblatt (1985) emphasized the importance of the reader-text-context relationship; she claimed "the same text may give rise to different works in transactions with different readers, or with the same reader at different times. This leads to rejection of the notion that there is a single 'correct' reading of a literary work of art" (p. 36). Thus, the meaning of a text is not naturally bound by the text or the reader, but instead "comes into being during the transaction between the reader and text" (Rosenblatt, 1994, p. 929).

Furthermore, Rosenblatt (1990) asserted RRT encompasses critical reading in that it includes the questioning of social, cultural, and political assumptions. Moreover, Lewis (2000) argued reader response is a social act that requires us to consider the transaction between a reader and a text as well as to examine the social conditions that shape how a reader interprets and responds to literature. As the reader actively constructs meaning, they draw on their prior knowledge and experiences as well as on the text and context "where support is provided by knowledgeable peers and a teacher who mediates learning and encourages shared knowledge and social interaction" (Möller & Allen, 2000, p. 148). This close consideration and examination will make visible issues of status and power that align with critical literacy and invite readers to question the socio-political discourses that shape their own experiences and assumptions of

disability (Lewis, 2000; Möller & Allen, 2000). Thus, while applying CDS as an interpretive lens, participants' personal perspectives undoubtedly influenced how they read disability, considered social implications for disabled people, examined ableism, and responded to the selected novels.

Methodology

Informed by CDS and understandings of RRT, I developed a qualitative instrumental case study (Stake, 1995, 2008) to examine readers' responses to disability representation in YAL within the specific contextual boundaries (Hatch, 2002) of a freshman-level college course. According to Yin (2018), a case study is an in-depth empirical qualitative method used to investigate a phenomenon (the "case")—such as a program, an institution, a person, an event, or a process—within the bounds of specific contextual conditions. Furthermore, Stake (2008) noted that case study is classified by an "interest in an individual case" (p. 443) and that "the object of study is a specific, unique, bounded system" (p. 445).

Case study methodology is appropriate because I am interested in both the uniqueness and the commonality of a people within a phenomenon or "case" (Stake, 1995), which for the purposes of my work is an 18-person freshman-level college course. Thus, instrumental case study design clarifies the uniqueness of each participant's personal experiences—as well as shared experiences across participants—with the phenomenon under study, reading and responding to disability in three YA novels within a freshmen course context.

In this context, however, the case is further bounded to only include written artifacts for the seven students who consented to participate in the study. These factors serve as the shared boundaries for the case (Willig, 2008). Because my research questions seek to explain the "how" of the social phenomenon of my participants' experiences and to focus in-depth on my case,

instrumental case study is a relevant method (Stake, 1995, 2008; Yin, 2018). The following question guided this case study: How do readers respond to representations of disability in YAL and what are the effects of those responses?

I must also acknowledge that my analyses of participants' written artifacts in this case study is subjective based upon my own positionality as a member of the disabled community. As someone who became disabled as a teen, I have grappled with issues of ableism for much of my life. I also have a positive view of my own disabled identity, which influences my reading of others' remarks regarding the disabled community. Because of this positionality and the subjective nature of qualitative research, I recognize that a nondisabled scholar, or one with a different disability, may have analyzed participants' data differently.

Course Context & Participants

I used data collected in a first-year studies course in YAL during the fall semester of 2020 at a large land grant university in the southern United States. This course was pitched as a broad YAL class, focused on the theme of representation, which included the reading of six "social issues" novels (Lewison et al., 2002, p. 384). Due to university guidelines in response to the COVID-19 pandemic that began in early 2020, this course was delivered fully online via one-hour synchronous weekly Zoom sessions. Eighteen incoming freshmen were enrolled in the course and eight gave their consent to formally participate in this study. As student artifacts were the primary data source for analysis, I excluded one student due to numerous missing assignments. The remaining students were given pseudonyms to protect their anonymity in this case study. Of the seven participants, all identified as female, one as Asian, one as Asian American, and five as white.

To help position students in relation to the disabled community and to determine if students might have ableist assumptions, they answered three questions on a pre-reading questionnaire. I asked students to define disability, disclose any connections to the disabled community, and share their understanding of the concept of ableism. No students reported having a disability, themselves; however, four students had family or friends with various disabilities and three students had no established connections to the disabled community prior to this class. Nearly all responses indicated that students may have entered the course with a deficit view of disability, and they may not have readily recognized ableism. Beth and Tabby, specifically, expressed extremely negative views, describing disability as not "normal." Thus, students' conceptualization of disability and ableism influenced how I analyzed their reading responses throughout. See Table 2.1 for an overview of each participants' answers to the pre-reading questionnaire.

Materials

Students read six YA novels focused on "social issues" (Lewison et al., 2002, p. 384), such as the #MeToo movement, police brutality and white allyship, and LGBTQ rights. Although students read and responded to each of these novels, only data pertaining to three texts centering the representation of disability were included in this case study. Below is a brief synopsis of the three novels about disability that were selected for inclusion in the YA course syllabus for fall 2020. These novels were written by disabled authors who have lived experiences like the protagonists of their novels to serve as effective counter-stories (Solórzano & Yosso, 2002) to the typical disability tropes present in literature. Students read each book over a span of two weeks and alternated their reading of a nondisabled and disabled novel. The novels are listed in the order they appeared on the course schedule; students alternated the reading of disabled

texts with nondisabled texts. This order was random and was just meant to break up the disabled texts.

Sick Kids in Love (*SKIL*) by Hannah Moskowitz (2019) follows Isabel and Sasha who meet in the hospital while receiving treatment for their chronic illnesses—rheumatoid arthritis and Gaucher's Disease, respectively. The two form a friendship—and eventually fall in love—over their experiences and shared identity as a "sick" teen. This novel, inspired by Moskowitz's own experiences with chronic illness, outlines life for a teen balancing looking "normal" while always experiencing symptoms of invisible illnesses.

The Silence Between Us (*TSBU*) by Alison Gervais (2019) tells the story of Maya who is forced to leave Pratt School for the Deaf and begin her senior year at Engelmann, a hearing school. As a proud member of the Deaf community, Maya struggles with forming relationships with her new hearing peers. When she begins to bond with Beau, the hearing boy who went out of his way to learn sign language, Maya begins to rethink her idea that Deaf and hearing relationships never work. That is, until Beau is unable to understand why Maya would not want to receive a cochlear implant to improve her hearing. This novel was inspired by Gervais's identity as a Hard of Hearing person living in a proud Deaf community; it won the 2020 Schneider Family Book Award Teen Honor title given to authors who embody "an artistic expression of the disability experience for child and adolescent audiences" (American Library Association, 2020, no para.).

This is Not a Love Scene (*TINALS*) by S. C. Megale (2019) outlines eighteen-year-old Maeve's two wishes: to be a successful filmmaker and to finally land a hot boyfriend. However, her rare form of muscular dystrophy and the loud mechanics of her wheelchair tend to stand in

the way of typical romances. When she develops chemistry with the lead actor in her latest film production, she must decide between what she wants and what she needs.

Procedures

I grounded the course design in RRT and aimed to offer students multiple opportunities to reflect on their backgrounds and personal reading experiences, participate in regular discussions, and consider how our class and our social contexts influence their readings (Rosenblatt, 1994). In the first Zoom session of the course, following general introductions, I introduced my personal interest in the theme of disability representation in YAL. Asking students to respond to issues of disability representation required them to adopt a critical literacy stance informed by Critical Disability Studies (CDS), which I briefly introduced to students via a short slide deck. Prior to reading the first novel, I provided a brief overview of important concepts of CDS, including: the social model of disability, what counts as disability, ableism, impairment, and limitation. Students also learned several examples of disabled stereotypes and literary tropes to which they might encounter in their reading. I reminded students of these stereotypes throughout the semester as they encountered new disabled characters.

I also introduced RRT, acknowledging that everyone in the class brought with them individual experiences, knowledge, beliefs, and questions that influenced how they interpreted the selected texts. The course asked students to first consider who they are and the context of our course as they engaged with three YA novels written by disabled authors and about disabled protagonists; then, they responded to incorporated activities including pre- and post-reading questionnaires, whole-group discussions, written reflective responses, and short essays near the end of the course.

Data Collection and Analysis Methods

Data sources included students' individual written responses to each novel. Thus, numerous artifacts were analyzed and coded for each of the seven participants, including:

- 1 Pre-reading questionnaire
- 3 During-reading discussion posts
- 3 Post-reading reflections
- 1 End-of-Course reflection
- 1 Post-reading questionnaire

Informed by CDS and RRT, I read data sources repeatedly with attention to moments that highlighted students' feelings toward and understandings of the protagonist's experiences and disability. By reading the data multiple times, I identified recurring patterns across participants' responses that were eventually used as open codes (Saldaña, 2016). These initial patterns centered students' ability to identify disability tropes and stereotypes across the novels. Relying heavily upon scholarship delineating the nuance of ableism (Nario-Redmond, 2020; Nario-Redmond et al., 2019), I also noticed early patterns where students both identified and overlooked examples of ableism within the three texts. Further, initial patterns indicated that students entered the novels with assumptions and myths of disability; for example, believing that a Deaf person would prefer to be hearing. To help code student data, I also drew upon larger course context. For example, I considered students' pre-reading questionnaires and comments made during class discussion to influence how I read each students' responses. See Table 2.2 to locate initial codes and how they were combined into three themes.

Drawing on Yin (2003), I reviewed the initial codes and conducted a second round of coding using thematic analysis identifying commonalities between and across students' artifacts.

I used these thematic codes to refine, combine, or eliminate existing initial codes to create three overarching themes. For example, when reading *Sick Kids in Love* (*SKIL*), Annie stated that she found "it so admirable that Sasha takes care of his family even when he's hurting himself." This comment was initially coded as *stereotype/benevolent ableism* and then was grouped under the theme *Possessing Disabling and Ableist Assumptions* as it indicated ableist views aligned with "inspiration porn" (Grue, 2016), declaring Sasha as amazing and exceptional because he is a good older brother *despite* being chronically ill. The three overarching themes (possessing disabling and ableist assumptions, identifying disabled tropes and ableism, and overlooking ableism and disability stereotypes) guide the findings outlined below. To further validate the identification of these three themes and the overall analysis of participant data, I conducted member checking in which participants were given the opportunity to review this article to determine if I had accurately portrayed them and their responses to the novels (Birt et al., 2016).

Findings

I began this study with the question: How do readers respond to representations of disability in YAL and what are the effects of those responses? I found that readers' responses were overwhelmingly contradictory. I also found that, despite a grand claim in the field of YAL (Connors, 2014; Connors & Rish, 2015; Djikic et al., 2013; Mar et al., 2006; Nussbaum, 1997; Pinker & Goldstein, 2004; Richmond, 2014; Shanahan & Dallacqua, 2018; Trites, 2000), it seems as though my participants did not demonstrate feelings of empathy for disabled characters or people, but rather exhibited sympathy and pity. I do not wish to proclaim that this finding indicates my participants are *bad people*; rather, I believe this finding is consistent with scholarship about insider familiarity biases that serve as roadblocks to empathic responses for people to which we cannot relate (Hoffman, 2000; Nikolajeva, 2014; Keen, 2007). Further, their

responses led me to reconsider how we in the field of YAL and education might engage with the topic of empathy, especially regarding disabled individuals; I explore this reconsideration in more detail in the forthcoming discussion.

In coding participant artifacts, I discovered readers' responses are largely influenced by seemingly unconscious ableist views; these underlying ableist ideas may also explain their deficit conceptualizations of disability outlined in Table 2.1. The personal ableist views influenced how students entered the reading situation, as well as how they reflected on the reading experience. Participants shared several assumptions about disabled people, in general, and how they expected authors to write about disability for their—assumed nondisabled—readers. Although I believe these responses and assumptions were made innocently rather than maliciously, they unfortunately stem from ignorance to disability, aligning with benevolent and ambivalent ableism, functioning unconsciously at personal, cultural, and structural levels (Nario-Redmond et al., 2019). Conversely, many students successfully identified examples of disability stereotypes within the texts, and they were able to discuss the use of overtly problematic disability tropes. Despite this success, it remained difficult for participants to recognize subtle examples of ableism within the texts, nor did they connect those examples to corporeal issues for real-life implications. Using participants' responses to the three novels—abbreviated as *SKIL*, *TSBU*, and *TINALS*, respectively—I identified three overall themes to describe their reading responses: possessing disabling and ableist assumptions, identifying disabled tropes and ableism, and overlooking ableism and disability stereotypes.

Possessing Disabling & Ableist Assumptions

Although students didn't explicitly say "I assumed…" in their responses, their statements indicated they had preconceived notions about disabled lives and reading disability. For example,

when discussing *SKIL*, Tabby said, “I like how [Ibby] has healthy friends… because I think typically when you think of a sick character their friend group usually always tends to be other sick people.” Similarly, Sarah said, “I love that [Ibby] has other friends and actually hangs out with them.” Tabby’s and Sarah’s comments indicate they assumed disabled people only interact with other disabled people; this view may be influenced by how disabled people are excluded in many social situations and how they’re stereotypically portrayed elsewhere in media as only having friends with similar life experiences (Markotić, 2016; Nario-Redmond, 2020); Beth made a similar comment, specifically calling attention to other popular YA novels which show disabled people mostly interacting with other disabled characters, such as *The Fault in Our Stars* and *Five Feet Apart*. In her response to *TINALS*, Annie said, “I did think it was interesting that KC asked Maeve to go ice skating. I would have thought in that scenario Maeve would not have agreed to go and would be offended by that.” Annie’s response indicates that she lacks awareness of accommodations to allow individuals with mobility aids to participate in activities that are perceived to be meant for nondisabled individuals, like ice skating (Baglieri & Lalvani, 2020).

Many of the students’ responses aligned with benevolent ableism, the tendency to exhibit “pity, paternalistic protection, and unprovoked praise” for disabled characters (Nario-Redmond et al., 2019, p. 729). When talking about *SKIL*, Annie, said “I feel sorry for [Ibby],” which is indicative of feelings of pity; Beth also indicated feelings of pity for Ibby when she stated, “I can’t imagine needing to take medicine daily and monthly or weekly trips to a doctor.” Beth furthered this sentiment when she responded to Maya in *TSBU*; she said, “I would hate to have to worry about getting interpreters and other accommodations.” The implication of these statements is that taking daily medication, visiting doctors often, and relying upon accommodations to go

about your daily life is "inherently and naturally horrible" (Amundson & Taira, 2005, p. 54). This view aligns with feelings of ableist admiration, which is "really pity in disguise," because "disabled people must be noble or especially spirited in order to cope with what 'normal' people would find too difficult or overwhelming to handle" (Markotić, 2016, p. 4). Thus, Annie and, to a greater extent, Beth do not seem to be attempting to imagine what it must be like for Ibby and Maya, they are simply implying that living a disabled life would be undesirable, which stems from benevolent ableism's "perceptions of astonishment" regarding the day-to-day lives of disabled people (Nario-Redmond et al., 2019). Similarly, but slightly differently, Tabby said "I feel bad of [Ibby] because she does not know if she is actually feeling pain from her RA or if she is just feeling normal everyday pain. I think that would be very confusing." Again, Tabby indicated she was feeling sympathy for Maya in *TSBU* when she said, "I can kind of see Maya's perspective about how that might be an offensive question because Maya knows how to do a lot of typical things that everyday teenagers do… I understand why Maya would get mad." Tabby's comments, unlike Annie's and Beth's, indicate that she feels sympathy for Ibby and Maya; she acknowledges that she cannot relate to their disabilities, but she attempts to understand their perspectives, recognizing that it must be confusing at times and difficult to deal with nondisabled peers' offensive remarks and ableist assumptions.

Students exhibited ableist views in several other ways, such as stigmatizing disabled experiences in favor of a nondisabled norm. For instance, Annie centered nondisabled experiences when she responded to TSBU and stated, "[Beau] might have reacted in an ignorant way when Maya first spoke, but if you look at it from another perspective he genuinely didn't know." This argument is consistent with the "permissible prejudice" (Chodorow, 1999) that allows ableism to be easily excused because nondisabled people lack knowledge; this implies

that the onus is on a disabled person to educate a nondisabled person in these situations. Annie continued to center nondisabled experiences as "normal" when she said, "going back to the term 'ableism,' I feel like under certain circumstances it's human nature." She then centered her own nondisabled experiences when she said she "didn't fully agree with the notion" that Ibby's doctors were not doing enough for her severe pain (which was Ibby's perspective throughout *SKIL*). Annie's statements highlight the common ableist tendency to discount the lived experiences of disabled people (Nario-Redmond, 2020).

Nario-Redmond, Kemerling, and Silverman (2019) identified ambivalent ableism, wherein nondisabled people respond differently to disabled people depending on if they are perceived as nice or rude. Several students' responses supported their findings that niceness is expected and more valued. For instance, nearly all the students liked Sasha and Ibby in *SKIL* because of how nice and kind they were to each other and secondary characters. However, nearly all students felt differently about the disabled characters in *TSBU* and *TINALS*, Maya and Maeve, respectively. Garland-Thomson (1997) called characters like Maya and Maeve misfits, meaning reader expectations and what the text does do not align according to existing tropes and disability stereotypes; these misfits cause readers to feel discomfort and surprise.

For instance, Annie said, "I really don't like Maya. It kind of bothered me how much she would get mad at Beau over things such as his initial shock of her speaking. She's overreacting in some situations." Emma echoed this opinion when she said she "noticed that Maya does have quite an attitude and [she] think[s] Maya could've been nice to Beau." Beth felt similarly about Maya, stating, "I do not like Maya. [She] seems to be looking for problems with her new school… she seems to constantly complain." Beth also extended her displeasure by connecting Maya's experiences to "a lady who is both blind and mostly deaf" in Beth's personal life; Beth

stated that this woman "still manages to get along well with others who can see and hear." Beth's response to Maya and her comparison to another person who happens to be Deaf reinforces ableist assumptions that disability is a monolithic experience, meaning all Deaf people are believed to experience life similarly (Baglieri & Lalvani, 2020; Nario-Redmond, 2020).

Every student mentioned at least once an assumption that a novel was meant to teach them about the disability represented. For example, Tabby stated she found *TSBU* "interesting and informative" because she "learned more about the deaf community by reading this book." Similarly, Annie said, "I like how informative [*TSBU*] has been. I think it's a great way to learn about certain topics rather than just research or something." Liz admitted having little experience with chronically ill people prior to the course and said reading *SKIL* "has been a sort of learning experience" for her. Conversely, students responded negatively to *TINALS* because it did not meet their expectation to be educated about Maeve's disability. For example, Tabby expressed that she hoped "to learn more about Maeve's disability and how it affects her." Emma seemed to view this lack of education as a flaw on the author's part when she exclaimed, "I do not believe the author informed the readers about the disability as much as the other books we have read in this class. It did have a disabled main character, but we did not receive much more on the background of Maeve's disease." These responses may represent the ableist view that the onus falls on disabled people to educate nondisabled people; further, this supports the view that readers interacting with these texts are assumed to be nondisabled (Dyches & Prater, 2000; Markotić, 2016).

Students' assumptions and ableist views were particularly illuminating regarding *TINALS*. One of the core plot points of this novel is Maeve's attempt to pursue a sexual relationship with a nondisabled male, Cole. Students readily shared their dislike for Cole as he

was sometimes nice to Maeve and seemed to care about her, and other times seemed to feel anxious and uncomfortable; in fact, Cole's characterization is a representation of the most common type of ableism: ambivalent ableism (Nario-Redmond et al., 2019). As Emma pointed out, Cole's sexual intentions seemed very "sketchy" toward Maeve; but the students failed to identify his behaviors as a subtle form of ambivalent ableism. Although that lack of insight is problematic, the larger issue rests in students' ableist views about Maeve's sexual intentions toward Cole. For example, Beth said, "I was not expecting the dirty jokes and the characters to be discussing sex… At times it would feel weird hearing some of the things about Maeve's sex life." Tabby said, "I think Maeve *thinks* she wants this to feel like a typical 18-year-old relationship, but I do not think she is completely thinking it through." Students' responses aligned with a common ableist myth that disabled people are child-like innocents, asexual beings who do not have "normal" desires, nor are they found desirable by nondisabled people (Nario-Redmond, 2020). Because students cannot imagine an interabled sexual attraction, when those "stereotypes are violated," by Cole and Maeve, they felt uncomfortable (Nario-Redmond et al., 2019, p. 731).

Several students also used ableist language that stigmatizes disability or stems from ableist stereotypes (Baglieri & Lalvani, 2020). For example, Sarah said she found the characters in *SKIL* to be "motivating and inspiring… resilient… very admirable" and exuding great "strength." Similarly, Mary said "it really warmed my heart" when discussing Ibby's pride and acceptance of her sick identity throughout *SKIL*. These comments perpetuate benevolent ableism through "unprovoked praise for everyday activities" (Nario-Redmond et al., 2019, p. 729). Further, this is a manifestation of "inspiration porn" (Grue, 2016), the tendency for nondisabled people to admire disabled people as "specimens of wonder and amazement" if they surpass low

expectations and, in turn, inspire or motivate nondisabled people to self-improve (Nario-Redmond et al., 2019, p. 729). Students also used disability metaphors that are frequently co-opted as everyday language in our society (Baglieri & Lalvani, 2020); for example, Liz expressed her surprise for a plot point in *TINALS*, talking about "how absolutely insane it is."

Identifying Disability Tropes & Ableism

Several students identified overt examples of ableism from secondary characters within the texts. For example, many students focused on the characters of Jackson and the charity representative in *TSBU* and *TINALS*, respectively. Annie noted she was surprised "how society can be when it comes to having connections to the disabled. Jackson's attitude throughout the entire book just bothered me and really made me think, 'wow this is really how people act?'" Similarly, Beth proclaimed, "I hated Jackson. I hated him based on the fact that he was a fuck boy before I even realized how much of an ableist douche he was." Within *TINALS*, students easily identified "the wheelchair lady"—who used Maeve's image for a charity event—as a representation of ableism. Beth said, "I do not like the wheelchair lady who lied about Maeve… It seems like she was using Maeve." Sarah also disliked her and identified her motives as wrong because they "portrayed [Maeve] as the poster girl for being 'inspirational.'"

Several students also identified how social barriers negatively affected the characters. For example, regarding *SKIL*, Liz mentioned how Ibby was forced "to advocate for herself in a world that simply does not try to accommodate for her illness." Similarly, although she didn't use the term *benevolent ableism*, Mary said *SKIL* taught her that disabled people can be "offended with over niceness." Annie condemned a lack of accommodations after she learned that Maya's deafness may have influenced her inability to get a job in *TSBU*; she expressed, "to me, I feel like anyone in society should have an equal opportunity, and maybe it's 'inconvenient' for the

business to hire an interpreter, but I think that's a little pathetic." Liz, again, made connections between Maya's experiences in *TSBU* and the social barriers in the real world; she said:

> This book has also opened my eyes to the lack of accommodations for deaf people in everyday life. I had no idea how important lip reading was to a deaf person's understanding of a hearing person, and I'm now wondering how the current pandemic has affected deaf people's ease of going about life, as masks now make lip reading impossible.

Many students also identified how plots and characters helped dispel ableist beliefs in society and historical disability tropes in literature. For example, Tabby discussed how Sasha and Ibby in *SKIL* taught her that "it is okay to be sick and be happy about it." Similarly, Mary stated that *TSBU* is a good counter-story to common Deaf narratives in that "Maya's deaf pride is something really good to read because it seems more often than not, in the media, a deaf person detests their disability." Both Tabby and Mary's points disrupt a common ableist myth that disabled people would choose to be nondisabled if given the opportunity (Garland-Thomson, 1997; Nario-Redmond, 2020). Similarly, Liz pointed out that *SKIL* dispelled the common disability trope of a myth for cure where a "major character death in a story about illness feels like it's only a cheap device for making your audience cry." Mary also identified the problematic trope of disability as tragic when she said, "it was always frustrating to see movies depict sick people as sad people who sit around and cry." Again, Mary expressed how "refreshing" she found Maeve's characterization in *TINALS* because she is very confident and outspoken, which "doesn't keep her the 'shy' girl that so many novels portray the disabled person to be."

Overlooking Ableism & Disability Stereotypes

Despite participants' success in identifying problematic tropes and overtly ableist characters, they overlooked many other disability stereotypes and subtle examples of ableism. For example, as I presented above, Annie condemned Jackson's extreme ableist behavior towards Maya in *TSBU*; however, she failed to understand that ableism is often more subtle. She explained, "the thought never crosses my mind to bully them." Although overt hostile ableism and hatred of disabled people does exist (Nario-Redmond et al., 2019), the issue of bullying that Annie mentioned is much more nuanced and prevalent in society (Baglieri & Lalvani, 2020). For example, providing context to the nuance of bullying and hostile ableism, take this tweet from a self-identified Autistic lesbian activist, Charlie:

> If you say, "but I would NEVER bully an autistic person," but then you make fun of people that don't get jokes, get easily upset, have "cringe" interests, are "weird," don't understand social cues/expectations, etc. … Sorry to say it, but you would bully an autistic person. (@cmackenzies, 2021)

Charlie's tweet is important because, like Annie stated in her written response, most people would not openly declare that they hate disabled people and intend to bully them (Nario-Redmond et el., 2019); however, ableist assumptions and stereotyping does affect treatment toward disabled individuals whose biological traits and/or mannerisms go against a perceived norm (Garland-Thomson, 1997; Saylor & Leach, 2009). Furthermore, while readers were quick to hate Jackson's overt ableism in *TSBU*, they failed to notice Beau's benevolent ableism. Throughout the novel, Beau patronized Maya, made assumptions about her Deafness, and offered her unwanted help (Baglieri & Lalvani, 2020; Nario-Redmond et al., 2019). However, students were more likely to condemn Maya's negative response to him rather than condemn

Beau's behavior; more often, students like Emma were quick to defend how "he was just trying to help her." Tabby also expressed, "Beau has always been a good person, even though he messes up sometimes he has the best intentions." These responses support the evidence that subtle examples of ableism—especially benevolent and ambivalent ableism—may be hard to discern in people with little experience with the disabled community and/or discussing ableist prejudice because it is "often misunderstood, sympathy and well-intentioned, favorability biases" (Nario-Redmond et al., 2019, p. 727).

Annie discussed that in *SKIL*, Ibby "doesn't want to be an inconvenience, she still feels like she's a bit separate from her friends… I feel sorry that she still feels somewhat of an outsider… It was sad to see that Isabel never thought she had a major disability." This response is a bit complicated because Annie recognizes that Ibby feels her disability is minor, even though it separates her from her peers; however, Annie feels pity for Ibby and fails to recognize that often disabled people feel like an "inconvenience" or an "outsider" because of social attitudes and barriers (Nario-Redmond, 2020). Similarly, Beth discussed how Ibby feels that she "looks too healthy" at her RA treatment infusions. Beth noticed this scene made her "feel bad" for Ibby, but she failed to identify how Ibby's emotions stem from social attitudes about what counts as a disability, ideas about disability hierarchies, and the assumptions that disabled people must always look and act sick (Nario-Redmond, 2020).

Discussion

Through analyzing written responses to the three novels centering disability, I found that students' own ableist views and their experiences, or lack thereof, with disabled people informed their reactions. Findings from this analysis also support the call from many in the field to broaden critical conversations in the classroom to include disability and ableism. Many

participants' responses indicated that they had ableist assumptions about disabilities going into the readings, as well as expectations for how authors would write about disabilities for a presumed nondisabled audience. Many of these assumptions influenced what they—nondisabled readers—assumed disabled people can do (e.g., ice skating as a wheelchair user), how they should act (e.g., being nice and appreciative of unprovoked help from nondisabled people), how they should feel (e.g., desiring to be nondisabled), and the role the author plays in their reading (e.g., providing disability information). The assumptions readers displayed are rooted in the individual, cultural, and structural ableism engrained in our sociopolitical environment that continues to center a nondisabled norm (Baglieri & Lalvani, 2020; Garland-Thomson, 1997; Nario-Redmond, 2020). Further, many students casually used ableist language and metaphors, as well as made statements indicating their own ableist views; as detailed above, many of their comments are consistent with benevolent and ambivalent ableism (Nario-Redmond et al., 2019).

Within participants' responses, there were numerous problematic tropes of disability they identified within the texts. They also harshly critiqued characters who demonstrated overt ableism in their interactions with the disabled character(s). Similarly, they identified if a certain character dispelled or was written to counter a common trope of disability. Despite this success, students also overlooked several examples of subtle ableism and failed to make connections to real sociopolitical issues affecting disabled people. Interestingly, almost all students explained their hatred of Jackson in *TSBU*, but only one student recognized Jackson's extreme treatment towards Maya is not representative of everyday treatment toward disabled people. Liz said, "he lacks any sort of nuance and is written to be as unbearable as humanly possible, while also representing ableism. I understand a lot of ableist people may be annoying and creepy, but I think this caricature of ignorance does more harm than good and perpetuates the attitude that

those who hold bigoted mindsets are easily identifiable as all-around bad people." Finally, many students exhibited contradictory responses, meaning within the same response they critiqued an ableist example from the text, but made a statement that indicated their own ableist views. This suggests students can identify others' examples of ableism but struggle to locate ableism within themselves. As previously stated, I believe these statements were made innocently, not maliciously and I do not believe the comments make my participants bad people; however, I must acknowledge that even innocent comments can be harmful and indicate problematic or biased views. As disabled writer, Presley (2008) stated, "the power of ignorance can kill" (p. 177). Think comparatively to a white person who uses a racial microaggression against a Black person; their comment may have been made innocently enough, but that innocence is rooted in ignorance and the comment can still do harm (Kanter, 2020; Nario-Redmond, 2020). Because these participants all identified as nondisabled, I am led to believe that they are simply ignorant to issues relating to disabled people, the existence of ableism in US society, and how those systems influenced their own views. Thus, these findings indicate readers may need more explicit instruction on ableism—especially subtle, benevolent and ambivalent ableism—and tools to aid in reading from an explicitly anti-ableist perspective.

There were also two general findings that did not align with any theme above but are important for consideration: author's positionality and disability as an avoided topic of discussion. At the start of the course, I explained to students that every novel was written by a disabled author who identified with the same—or a similar—disability to the protagonist of the novel. Students recognized the importance of this insider status throughout their responses. For example, Beth said, "[*SKIL*] focuses on their lives in a way that only someone living that life could describe." Liz expressed a similar sentiment when she said, "the novel feels more authentic

because it was written by a sick person." These sentiments reinforce the importance of marginalized authors having the space to create stories from their own marginalized identities (Whaley, 2016).

Additionally, in their final reflection at the end of the semester, numerous students indicated these books are important because they realized disability is often a topic avoided in conversation and education. For example, Annie said, "I never want to be ignorant… but I never discussed these topics with my friends or family or classmates." Beth expressed a similar sentiment when she stated, "These novels gave me insight into issues that I don't talk about or have to deal with in my daily life." Finally, Sarah indicated that "before this class, [she] definitely was not well informed about the disability community… reading and talking about books from perspectives of people who live with these disabilities allowed [her] to gain a deeper understanding of what they face." These comments indicate that students are very aware that disability and issues of ableism remain an avoided and ignored topic for discussion; it also highlights their belief that they benefited from reading and discussing those issues (Baglieri & Lalvani, 2020; Donovan & Weber, 2021; Erevelles, 2000; Goodley, 2007).

Discussion on Empathy

My findings indicate that we may need to rethink how we conceptualize empathy, sympathy, and pity and the purposes we see in eliciting empathy, preferably, from fiction. Typically, these emotive reactions are placed along a linear scale, indicating that emotions naturally progress and become more complex as you move from pity to sympathy, to empathy (Burton, 2015). First, many can agree that pity is the least desirable emotive response to fiction and corporeal others, especially regarding disabled people. As Presley (2008) stated, "When people pity a person or group of people, it may seem like they care about them and are interested

in improving their lives. But beneath this seeming benevolence actually lies rejection, fear, discomfort, and a strong sense of inferiority of the person being pitied" (p. 176). Conversely, modern conceptions claim sympathy allows us to understand others, empathy asks us to "stand at the center of [someone's] social world and get a sense of the surrounding conditions" (Lanzoni, 2018, p. 162). Similarly, Wispé (1986) explained that empathy is more complex than sympathy because it requires perspective-taking or role-taking. Thus, the difference between empathy and sympathy—with the belief that empathy is a more complex than sympathy—could be understood as the difference between emotional identification *with* someone ("I feel your pain") and emotional support *for* someone ("I feel sad for your pain") (Keen, 2007, p. 5).

As detailed above, my students' responses indicated they often exhibited feelings of pity or sympathy (e.g., "I feel bad for…")—aligned with benevolent ableism—for disabled characters. While this is problematic as a manifestation of benevolent ableist views and does not lend itself to pro-social change, I believe YA scholars' call for disabled texts as a site for empathetic responses is potentially problematic, as well. As a society, we value empathy for others as a skill and trait because we believe empathy leads us to dispel prejudice through social action (Djikic et al., 2013; Hoffman, 2000; Mar et al., 2006; Nussbaum, 1997; Pinker, 2004); however, others—like Suzanne Keene (2007) and Sophie Ratcliffe (2008)—dispel "empathy-altruism" and believe social action as an outcome of empathy, *while possible*, is an exception, not a rule (p. vii). Moreover, we must also consider that sometimes empathizing can further marginalize people, especially disabled individuals. As Baglieri & Lalvani (2020) outlined, empathy-driven classroom assignments generally rely upon "patronizing" lessons intended to inform children about broad disability issues; however, they suggested these lessons "end up, at best, presenting 'feel good' moments for the nondisabled, and at worst, reinforcing ableist

stereotypes" (p. 7). Desired responses to disabled people center compassion and inspiration rather than providing opportunities "to think critically about issues related to identity, community membership, and civil rights" (Baglieri & Lalvani, 2020, p. 7).

If we consider ableism is an oft-ignored form of social oppression which needs to be dismantled (Baglieri & Lalvani, 2020; Donovan & Weber, 2021; Erevelles, 2000; Goodley, 2007), empathy may successfully function at that individual level, or for the short term, but may fail to consider ableism as a systemic-level oppression or to spark long-term motivations toward pro-social change. Aiming for empathy reinforces the idea that "disability is located within individuals and discussed as an individual difference, rather than inextricably linked to ableism, which operates at individual, cultural, and structural levels (Baglieri & Lalvani, 2020, p. 7). Thus, it may be more worthwhile to ask students to react to disability assumptions and prejudice with consideration for sociopolitical implications than to react empathetically to an individual's situation. Comparatively, think about this in relation to race; Dwayne Reed, a teacher, author, and motivational speaker tweeted "white supremacy won't die until white people see it as a white issue they need to solve rather than a Black issue they need to empathize with" (@TeachMrReed, 2020). The goal should not be just for a nondisabled person to feel for a disabled person—further stigmatizing their existence against a nondisabled norm—but we should, instead, want nondisabled people to recognize their complicity in ableism and then work to dismantle existing ableist systems.

Next, I believe we need to reconsider how we conceptualize empathy as the be-all, "holy grail" emotive response to fiction and reality (Koopman, 2015, p. 77). Again, while "empathy-altruism" (Ratcliffe, 2008, p. vii) is a *possible* effect of reading, it is not a guarantee, especially when considering limitations to empathic response, such as insider familiarity bias (lack of

empathetic response for "outsiders") and "here and now" bias (empathetic responses for issues nearest us) (Hoffman, 2000; Nikolajeva, 2014; Keen, 2007). My reconsideration for the conceptualization of empathy for disabled people was inspired by two students' responses to the Deaf character, Maya, in *TSBU*. First, Sarah said, "I don't think we can grasp what it feels like to be Deaf but hearing about Maya's struggles can help put things into perspective so we can try to understand." And most influential to shifting my beliefs was the following proclamation from Mary:

> I realized that I have no place to identify how she should feel about a disability I do not have. I cannot make any type of judgement on her actions when I myself cannot imagine myself having a hearing disability. I love getting to read through Maya's world, but I cannot put myself in her shoes. It frustrated me hearing people heavily judge her… We are not her. No one in the class is hearing impaired, so what gives them the right to pass judgment on this girl when they cannot remotely relate to her?

As these two participants' responses indicated, it may be impossible for someone to "stand at the center of [someone else's] social world" (Lanzoni, 2018, p. 162) if they are "outsiders" and have no personal experience or even a frame of reference from which to do so (Koopman, 2015; Nikolajeva, 2014). Moreover, Nario-Redmond, Gospodinov, and Cobb (2017) warned against a common element of empathy as it pertains to disabled people, particularly; they posited that we should be concerned about asking students to "try on" disabled experiences through the role-taking and perspective-taking scholars claim makes empathy a complex emotion (Wispé, 1986). Further, without a frame of reference for outsider experiences, empathy can yield a response that is like pity. Just as Baglieri & Lalvani's (2020) warned against empathy toward disabled people as it may reinscribe narratives of individuals' inspiration and overcoming, Vidali et al. (2008)

posited how empathy can be problematic when pertaining to the disabled community through what they identified as the "enlightenment narrative," which reinscribes a binary of disabled and nondisabled and relies on assumptions that "disabled persons exist in order to serve as educational devices" (para. 7).

Implications & Conclusion

The purpose of this study was to explore how readers respond to representations of disability in YA novels and the effects of those responses. I found that through their transactions (Rosenblatt, 1994) with three novels centering disability counter-stories, students identified problematic stereotypes and ableist views toward disabled individuals. Further, students sympathized with the disabled characters, acknowledging that while they cannot fully relate, they can try to understand ableist barriers that affect disabled people. Although I consider many of the findings to be positive and worthwhile to the field, there were also problematic findings that need further exploration; specifically, students' inability to recognize subtle ableism within the texts and within themselves indicates that more in-depth and explicitly anti-ableist literature instruction is required.

The findings from this study hold implications for further research in the fields of reader response and YAL, especially considering disability as a topic for diversity exploration in the classroom and as a source to elicit readers' empathy. Much consideration is needed for future studies. For instance, my participants were adult readers of YAL who enrolled in a college-level course; I—and other future researchers—would need to consider the importance of readers' age when studying if and how readers are affected from reading YAL featuring characters with disabilities. It would be important to replicate the study with young adult readers and pre-service educators, as well. Additionally, because all participants in this case study identified as

nondisabled, it might be helpful to replicate this study or expand research to include disabled participants. Further investigations are also necessary to determine if there is a difference in responses from readers in school—who are asked to complete class assignments—and out of school—who read YAL for pleasure—since this case was bound by the course design; as RRT demonstrates the importance of context in the reading relationship, it is necessary to discern how different reading contexts affect readers' responses to disability narratives.

Although we still need more visibility of characters with disabilities in YAL to provide those necessary "windows" and "mirrors" for readers, we must consider how nondisabled readers may misinterpret what they see through the window (Reese, 2016), especially when ableist views muddle the glass. We must also understand the value of these novels for both disabled and nondisabled readers. As I outlined above, my students did not feel empathy for the disabled characters—which requires more reconsideration and problematizing in future studies—they did, however, reach new levels of understanding for three disabilities to which all seven participants expressed lacking prior knowledge: chronic illness, Deafness, and muscular dystrophy. While the bounds of this study did not allow me to determine if students' experienced lasting effects from this new disability knowledge and sympathy for those experiences, I believe they left the course context with a bit more information about ableism and some of the social barriers that function to disable people. As Emma aptly stated, the students "were able to see the difficulties in the characters' personal lives which helped inform us more about situations we do not see in our everyday lives." Moreover, my goal was to feature authentic disabled perspectives, to create visibility for oft-ignored experiences, to destigmatize disabling conditions, to ask readers to reconsider our understanding of diversity, and to ask readers to question dominant sociopolitical views about disability (Donovan & Weber, 2021; Dunn, 2015; Fox, 2017; Heim,

1994; Prater, 2003). While I believe I was successful in reaching that goal, my students share in that belief and see value in their experience; as Mary proclaimed, “I think these books and our class meetings really speaks to how people can have these hard discussions instead of pretending they are not real. Having discussions, while it may be hard, solves problems.”

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Appendix

Table 2.1: *Overview of Participants' Connection to and Understanding of Disability*

Student Name (Pseudonyms)	How do you define disability?	Are you or anyone you know connected to the disabled community?	What is ableism?
Annie	"I don't know how I would define it."	"No, I am not connected."	"I don't know."
Beth	"When someone has lower than normal physical or mental abilities."	"I have had ADHD and dyslexic teachers. My family takes a blind lady to church. One of my cousins is on the spectrum."	"When people don't take those with disabilities into account and think less of them."
Emma	"Something that takes away a person's ability to perform certain tasks."	"No."	"I'm not sure."
Liz	"A physical or mental condition that prevents or limits a person's functions."	"One of my best friends is disabled."	"Discrimination against people with disabilities."
Mary	"Something that limits the abilities of another."	"I am not connected personally."	"Treating another person differently and not giving them the same opportunities because of their disability."
Sarah	"A physical or mental setback that disrupts daily functions."	"I have a few family members with chronic and mental illnesses."	"Social discrimination towards people with disabilities."
Tabby	"When someone cannot function normally according to society."	"I have a cousin that has to [wear] hearing aids because he was born deaf."	"I do not know."

Table 2.2: *Themes & Initial Codes*

Themes	**Initial Open Codes**
Disabling Assumptions & Ableism	What disabled people can/cannot do
	How disabled people should act/feel
	Authors expected to educate assumed nondisabled readers
	Sympathy & Pity
	Using ableist language
	Discounting/judging disabled characters
	Disability as a monolithic experience
Identifying Disability Tropes & Ableism	Inspirational themes
	Shy and withdrawn themes
	Death, cure, and overcoming themes
	Sad and suffering themes
	Recognizing structural barriers
	Character’s dispelling tropes
Overlooking Ableism and Disability Stereotypes	Disabled hierarchies & being “disabled enough”
	Benevolent and ambivalent ableism
	Social implications of fictional portrayals

Chapter 4: Article 3

Understanding “Interlocking Oppressions”: Toward an Anti-Ableist Frame for Literary Analysis

Abstract

Due to continued deficit views of disability in YAL and ableist reader responses to disability representation in YAL, this article outlines pedagogical suggestions for educators hoping to include disabled texts in curricula, as well as for educators intending to address disability and ableism in anti-oppressive pedagogy. This article explicitly adopts the stance that recognizes "ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (Mingus, 2011, para. 11). This article emphasizes the use of novels by and about disabled people and building students' foundational knowledge about disability and ableism's wide-reaching roots in systemic oppression. Specifically, this article posits a new lens for reading: an explicitly Anti-Ableist Frame (AAF) for literary analysis. Through this frame, the concept of ableism—and its relationship to other "isms"—can serve as a useful "tool" in ELA classrooms for encouraging critical exploration of oppressive ideology and analysis of texts representing intersectional disabled characters. First, foundational knowledge that informs the creation and use of an AAF is provided. Next, three levels of critical questions—textual-, analytical-, and real-life implication-based questions—for the analysis of ableism as it pertains to common literary elements are outlined. Then, an example is given to demonstrate how educators might apply the AAF to the critical study of a contemporary YA novel featuring a disabled protagonist, *Darius the Great is Not Okay* (Khorram, 2018). The article closes with implications of the AAF for the analysis of YA and other texts, as well as posits how the principles of an AAF could be expanded into a full framework with further implications in secondary English instruction and pre-service teacher education programs.

Talila A. Lewis (2019), a social justice lawyer and disability advocate, stated:

> Ableism & racism have always been inextricably linked. Each of these oppressions informs the other and depends on the other to survive and thrive. Therefore, it is impossible to end racism without ending ableism, and impossible to end ableism without ending racism. Ableism is also at the root of every other oppression. (para. 3)

Given this statement, we might presume ableism is centered in equity, diversity, and inclusion initiatives and is a focus for social justice in education and society; however, that is not the case. Due to historical hegemony surround disability, ableism and disability has been historically "turned away from the table" (Connor & Gabel, 2010, p. 202) of social justice education and diversity endeavors (Buffington-Adams & Vaughan, 2019; Gibson, 2015; Liasidou, 2012, 2014), has been excluded from attention to intersectionality (Erevelles & Minear, 2010), and has been

ignored as a critical perspective in education (Erevelles, 2000; Goodley, 2007). By acknowledging that ableism is at the root of "all of our movements because ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (Mingus, 2011, para. 11), I understand centering disability perspectives and critiquing ableism is necessary to challenge the normative status quo and to dismantle the social injustices faced by people whose compounding identities cause further marginalization.

The Time is Now

Disability and ableism are often ignored in talks of diversity and social justice (Erevelles, 2000; Goodley, 2007); however, we are at a sociopolitical crossroads that proves, now more than ever, disability deserves a seat at the table. The events starting in 2020, often called the double pandemic, highlighted the intersection of anti-Black and anti-Asian racism, and ableism through the COVID-19 pandemic, both of which "isms" have roots tied to white supremacy (Kennedy, 2021; Mingus, 2022; Starks, 2021). These events increased public attention to issues of ableism; in fact, Google searches in the US for "what is ableism" doubled in 2020 (Google Trends, 2020). Rhetoric in news and social media, as well as scribed on protest signs in 2020 and 2021 compared white supremacy to a pandemic, virus, or illness, and described acts of racism as a symptom of that illness. Although this seems an apt metaphor that is easy to grasp, it inherently perpetuates ableism and racism. In a Twitter thread published on March 18, 2021, Dr. Subini Annamma tweeted:

> Fam, racism is not a virus. White supremacy is not a pandemic. Using illness & disability as a metaphor situates white supremacy & racism as passively spreading. These metaphors evade the way white supremacy & racism are purposefully built into structures

> & strategically enacted… Naming racism & white supremacy as a virus or pandemic also positions those with illnesses, viruses, and disabilities as deficit, less than. It can in fact demonize disabled people which makes them more susceptible to harm. (@DrSubini)

Through her tweets, Annamma suggested we rethink language use, consider who is harmed by that language, and ponder how language supports systems of power. The events of 2020 through 2022 have highlighted issues of race *and* disability in the United States, which has increased awareness for these "interlocking oppressions" (Annamma et al., 2018, p. 52).

This heightened awareness might be advantageous, providing a space for educators to begin including disability in classroom discussion and analysis (Baglieri & Lalvani, 2020). According to the National Alliance on Mental Illness (NAMI) (2019), 1 in 5 adults *and* 1 in 5 youth experience a mental illness, with the onset of about 50% of all mental illnesses occurring before age 14. In 2020, the Center for Disease Control and Prevention (CDC) reported that 61 million adults—26% of the overall population—in the US live with a disability and about 1.3 million young people in the US live with a disability or chronic illness (Erickson et al., 2016). Additionally, approximately 6.7 million US students in K-12 settings received special education services in the 2015-16 school year (National Center for Educational Statistics [NCES], 2018). Further, in December 2021, the US Surgeon General released an advisory to highlight a youth mental health crisis as an effect of the COVID-19 pandemic (US Dept. of Health and Human Services, 2021). Thus, we can assume our schools include many youths and adults living with diverse disabilities; despite this, disability remains stigmatized in school settings and is often a taboo topic of discussion and analysis outside of special education environments (Baglieri & Lalvani, 2020).

Continued media coverage of the COVID-19 pandemic, particularly about the disabling effects and persistent symptoms of long-COVID, as well as highlighting inequities and the lack of resources, has increased awareness of the rampant ableism embedded in the sociopolitical climate of the US (Briggs & Vassall, 2021; Marshall, 2020; Mingus, 2022; Pomeroy, 2021). I argue that this increased awareness of ableism—and its relationship to other "isms" in US society—provides a valuable entry-point for introducing issues of disability and intersectionality (Crenshaw, 1991) in our public and higher education systems, specifically through the analysis of disability in texts used within English classrooms.

A Need for Anti-Ableism in ELA Instruction

I draw upon my findings in article one and article two of this dissertation to advocate for the inclusion of disability as a topic for discussion in the English language arts (ELA) classrooms. Through the lens of Critical Disability Studies (CDS) (Meekosha & Shuttleworth, 2009), I found that ableist stereotypes are ever-present in contemporary young adult (YA) novels and I found that readers may overlook those stereotypes when reading and analyzing disabled characters. Further, I found that readers' responses to disability in YAL is largely influenced by their own ableist views; thus, while CDS as a critical lens was beneficial to help readers identify overtly ableist textual elements, it was not enough to help them explore subtle ableism or connect textual issues to reality. To address these issues, I posit we must emphasize novels by and about disabled people, and we must build students' foundational knowledge about disability and ableism's wide-reaching roots in systemic oppression. Specifically, through this article, I suggest that through an explicitly Anti-Ableist Frame (AAF) for literary analysis, the concept of ableism—and its relationship to other "isms"—can serve as a useful "tool" in ELA classrooms for encouraging critical exploration of oppressive ideology and analyses of texts representing

intersectional disabled characters. Fully integrating a critique of ableism in the classroom will help students "recognize social injustices" and will allow them "to challenge and resist ableism and other systems of oppression in which we are all implicated, participate in, and contribute to" (Podlucká, 2020, p. 80).

Thus, the purpose of this article is to introduce and describe the Anti-Ableist Frame (AAF) as it applies to analyses of YA and canonical literature, and to provide implications for secondary ELA pedagogy, pre-service English education, and scholarship. To begin, I elucidate foundational knowledge that informs the creation and use of an AAF. I then outline how to use the lens for literary analysis. Then, I demonstrate how educators might apply the AAF to the critical study of a contemporary YA novel featuring a disabled protagonist, *Darius the Great is Not Okay* (Khorram, 2018). I close with implications of the AAF for the analysis of YA and other texts, as well as to posit how the principles of an AAF could be expanded into a full framework with further implications in secondary English instruction and pre-service teacher education programs.

The Anti-Ableist Frame

As I outline below, an AAF does not follow the tenets of any one theoretical framework; however, scholars of critical disability studies (CDS) and disabled advocates of the Disability Justice Movement (DJM) inform its development. Since it is not tied to one theory, an AAF has the potential to weave together various approaches and critical lenses (e.g., feminist, racial, queer) into one analytic approach to uncover and disrupt problematic tropes of disability toward intersectional anti-ableist social justice.

The foundational knowledge detailed below, as well as the current sociopolitical climate, and findings from my own research influenced the creation of an Anti-Ableist Frame (AAF), a

tool for reimagining literary analysis in secondary and higher education literacy and English classrooms. Prior to using the AAF for literary analysis, there are myriad considerations for educators and readers regarding disability and ableism. First, educators must make informed decisions about text selection. Next, educators must grapple with their own ableist biases; then, they must construct their own and their students' foundational knowledge about disability and ableism so they can successfully interrogate them within their literary analyses.

Textual Considerations

When including disabled narratives in the classroom, there are a couple of principles to follow before delving into analyses with students. First, educators must assess texts for how they reify or subjugate disability narratives and ableist perspectives. Teachers might consider Heim's (1994) four criteria to aid their disability text selection: 1) accurate information; 2) absence of stereotypes; 3) rich plot and disabled character development; and 4) sensible disability confrontation "that a child would be likely to experience in real life" (p. 139). Whenever possible, educators should prioritize works by authors who identify as disabled, are about diverse disabilities, and show disabled people engaging in everyday life and complex relationships (Baglieri & Lalvani, 2020). Further, educators should center texts that show the nuance and complexity of disabled experiences, meaning texts not "entirely focused on struggle nor ease, hardship nor joy (Baglieri & Lalvani, 2020, p. 42). We want to center work that "manages the tricky balance of evoking the grind of daily ableism and tokenism without ever essentializing [disabled] characters as victims" (Smith, 2022, para. 22). When selecting texts, educators should also include myriad contemporary and historical stories, encompassing fictional and informational texts. Film, television, and social media can also serve as valuable texts to which

we can analyze the complexity of disabled experiences (Smith, 2022) and consider issues of "inaccurate" portrayals and "not enough representation" (Bahr, 2021, para. 7).

Finally, critiquing disability representation and ableism requires students to draw on complex understandings of how ableism functions in society. Thus, teachers and students need a foundation to develop an anti-ableist literacy in which to build their understanding of a text's depictions of disability and ableism, as well as to consider how those depictions reflect reality. Below, I have listed and defined several key concepts that are important to building that foundational knowledge to assist readers' analysis. An AAF examines how texts represent disability and ableism, especially at the intersection of race, culture, gender, sexuality, economic status, religion, etc. Specifically, an AAF explores how texts reify and/or disrupt stereotypes and oppressions of disability. The following questions are central to an AAF:

- How does the text represent disability, disabled people, and disabling contexts?
- How does the text explore compounding intersectional identities through the representation of disability?
- How does the text reinforce and/or subvert dominant ableist narratives, stereotypes, values, social norms, and assumptions?

With these questions, an AAF provides a tool for identifying representations of disability within a text, questioning how those representations reflect common attitudes, social values, and norms, and considering how those values are rooted in ableist ideology.

Foundational Principles of an AAF

I now turn to an explanation of three foundational understandings about disability and ableism that adults and youths must consider to successfully implement an AAF with texts and

make connections to real-life examples of ableism. These understandings should be introduced to readers in pre-reading instruction and can be further explored during-reading. First, when using an AAF, we must enter the learning situation from a perspective informed by a broad social model of disability. This will help us conceptualize disability and ableism as existing *both* within the body/mind *and* within sociopolitical contexts. Next, we must consider that disability *always* intersects with other identity markers, such as race and gender. Finally, we must understand the function of ableism and its types and levels; further, a study of ableism will help us consider how it informs all systems of oppression. Thus, before using an AAF for literary analysis, the following foundations must be laid: 1) disability is *both* biological *and* a social construct; 2) disability intersects with other identities; and 3) ableist ideology has widespread oppressive effects. These understandings are not meant to be exhaustive as there is much knowledge to gain about disability and ableism; however, it provides an entry-point for scholars, educators, and students wishing to increase their own anti-ableist literacy and broach the topic of ableism in texts and classroom settings.

Disability is *both* Biological *and* a Social Construct

For the purposes of using an AAF, I rely upon the World Health Organization's ([WHO], 2022) definition of disability, in which "disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support" (para. 2). The WHO definition of disability recognizes the importance of context, disability type, individual experiences, accessibility, and oppression as *disabling factors*. This means that while the conditions of the body or mind can be disabling, so too can environments, social expectations, public policies, and nondisabled

attitudes. Readers must also understand that disability is a complex experience that includes myriad conditions. Critical disability studies scholars understand disability is a socially constructed "historical, social, political, and cultural phenomenon" (Bialka, 2015, p. 143) encompassing diverse short- and long-term and invisible or visible traits and conditions (e.g., neurological conditions, sensory functions, psychiatric disorders, limited ability or inability to perform cognitive tasks, chronic illness or disease, absence or loss of limb). In fact, disabled lives and experiences are as varied as nondisabled lives and experiences (Markotić, 2016); disabled people are the largest marginalized group in the world and disability is represented in every other marginalized group (Baglieri & Lalvani, 2020; Bogart & Dunn, 2019; Lewis, 2019; Nario-Redmond, 2020). Further, disability is fluid, unique as one of the only marginalized groups someone can be born into or can join at any stage of their life (Baglieri & Lalvani, 2020; Bogart et al., 2019; Lewis, 2019; Nario-Redmond, 2020). Disability also varies across body, time, place, and culture. For example, in different historical periods and cultures, blindness might be considered a "divine punishment" or a "divine gift" (Baglieri & Lalvani, 2020, p. 13). One's age, gender, physical location, socioeconomic status, access to resources, and disability characteristics also greatly influence their disabled experience (Nario-Redmond, 2020). This perspective of disability also understands that, at times, other conditions and barriers can be *more disabling* than a disability.

Understanding disability as human variation and as context-dependent draws from the social model of disability, recognizing that wide variation in "our bodies, our abilities, and our ways of learning or communication" is natural and inevitable (Baglieri & Lalvani, 2020, p. 16). Thus, lived experiences of disabled people are not solely determined by elements of their individual differences but are also affected by how our social, cultural, and political systems

respond to those differences. In other words, hardships for disabled people are *most often* the result of prejudice, negative attitudes, exclusion, social stigmatization, structural inaccessibility, and institutional or legal barriers rather than as a direct result of their disability; thus, any meaningful improvements to disabling situations must be driven by social change rather than individual perseverance (Barnes et al., 2010; Hahn, 1994; Putnam, 2002). This acknowledgement renders an explicitly Anti-Ableist Frame, which includes intersectional analyses of other disabling factors, not only justified, but incredibly necessary.

This understanding is markedly different from another approach to understanding disability, the medical model of disability, which conceptualizes disability as the antithesis of "normal," wherein a biological difference is viewed as the result of a physical, cognitive, behavioral, psychological, or sensory impairment (Gilson & DePoy, 2002; Barnes et al., 2010). Under this model, disability is understood as an individual problem that must be overcome or cured through pathologized interventions or treatment (Gilson & DePoy, 2002; Olkin, 1999). While support for this conceptualization of disability is less standard in modern practice, the medical model influenced the development of "master narratives on disability" (Baglieri & Lalvani, 2020, p. 2) that undergird assumptions about disability and the ableism embedded within US sociopolitical systems, including Special Education practices. In applying the AAF, we must reject this deficit view of disability. Thus, to build anti-ableist literacy, readers must understand the different approaches to disability and adopt a worldview that is more closely aligned with the social model. Only then will we begin to understand that disability is within our bodies, and is a barrier set in place by sociopolitical attitudes and practices.

Ableist Ideology Has Widespread Oppressive Effects

According to Bamberg (2004), *master narratives* are culturally dependent dominant assumptions about what is considered normal in any given society. The common narrative of disability characterizes disability as "something to be cured, eliminated, fixed, or overcome, and depict life with a disability as tragic, pitiable, and burdensome" (Baglieri & Lalvani, 2020, p. 2). This dominant narrative causes disabled and nondisabled people to view disability as inferior and undesirable. Beliefs of disabled inferiority and undesirability provide the foundation for ableist ideology and oppression (Campbell, 2009).

The term ableism has evolved from the social rights movements within disabled communities of the 1960s and 70s and is historically associated with disability prejudice (Albrecht, 2006). The definition of ableism varies, but is generally understood as the prejudice, stereotyping, discrimination, and oppression of people with disabilities (Bogart & Dunn, 2019; Campbell, 2001; Chouinard, 1997). For the purposes of grounding the AAF, I specifically rely upon, lawyer and disability advocate, Lewis's (2022) updated working definition of ableism:

> A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism. (para. 3)

Regarding the AAF, this definition is important for helping readers conceptualize the link between disability and other identity markers for intersectional analyses, as well as helping them

understand how context can be disabling. Further, I rely upon Nario-Redmond, Kemerling, and Silverman's (2019) conceptualization of ableism as disabled people being "*excluded, ignored, misunderstood, rejected, dismissed, avoided, pitied, envied, objectified, dehumanized, manipulated, shamed, mocked, stereotyped, overprotected, condescended to, and/or provided with unwanted help*" (p. 739, emphasis in original).

Tremain (2017), a disabled feminist philosopher, posited "the artifactual and interactive character of current racist, sexist, ableist, antisemitic, classist, and homophobic practices" are "conjoined" systems of oppression, functioning as "mutually constitutive," always reinforcing one another (p. 68). Lewis (2019, 2022) also outlined that the propagation of ableist assumptions about disability provided the necessary foundation for a widespread system of oppression that is inextricably rooted in and linked to other systems of oppression (e.g., racism, heterosexism, classism), which are grounded in beliefs of inherent superiority and inferiority based on arbitrarily identified traits. Disabled writer, educator, and disability justice trainer, Mia Mingus (2011), outlined numerous examples of ableism's roots in various oppressions, stating:

> Ableism set the stage for queer and trans people to be institutionalized as mentally disabled; for communities of color to be understood as less capable, smart and intelligent, therefore "naturally" fit for slave labor; for women's bodies to be used to produce children, when, where and how men needed them; for people with disabilities to be seen as "disposable" in a capitalist and exploitative culture because we are not seen as "productive;" for immigrants to be thought of as a "disease" that we must "cure" because it is "weakening" our country; for violence, cycles of poverty, lack of resources and war to be used as systematic tools to construct disability in communities and entire countries. (para. 11)

Just like all systems of oppression, ableism is rooted in prejudice and results in discrimination. Nario-Redmond (2020) labeled these prejudices and discriminatory effects as the ABCs of ableism: “affective emotions or attitudinal reactions; behavioral actions/practices; and cognitive beliefs/stereotypes that go beyond general negativity” (p. 6). Like other “isms” in society, oppression from ableism is both covert and overt, and operates at the individual, cultural, and institutional level; disabled people can also internalize effects of ableism. Table 3.1 provides a definition of each level of ableism and provides helpful examples to show readers how each level might appear. Within these three levels, Nario-Redmond, Kemerling, and Silverman (2019) outlined three main types of ableism to which readers should be aware.

- Benevolent Ableism: This type of ableism views disabled people as weak, vulnerable, courageous, deserving of charity, and in need of help. This can often include feelings of “pity, paternalistic protection, and unprovoked praise” for disabled people’s ability to live their daily lives. This form of ableism is often well-meaning, but disabled people can perceive it as “condescending, demeaning, and dismissive” (p. 729).
- Hostile Ableism: This type of ableism is openly negative views of disabled people, which reinforces nondisabled superiority. It often includes using derogatory language, feelings of disgust, bullying, avoidance, violence, and abuse—such as neglect or mistreatment from caregivers and hate crimes—simply *because* someone is disabled.
- Ambivalent Ableism: This type of ableism is a combination of benevolent and hostile ableism, resulting in conflicting positive and negative feelings about disabled people that can vary by situation and context (e.g., expecting elderly adults to use mobility aids, but feeling sad or uncomfortable if a young child were to use the same aid). This form of ableism is complicated and is influenced by whether a disabled person confirms or

contradicts stereotypical expectations (e.g., positive feelings for disabled people who appear friendly, vulnerable, and in need of assistance—which is expected—versus negative feelings if they appear rude, accomplished, and independent—which is unexpected).

Society has devalued disability in its assumption that it is "better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids" (Hehir, 2002, p. 3). Devaluing disability, and privileging ability, is pervasive and situates ableism as a "permissible prejudice" (Chodorow, 1999, para. 2), allowing ableism to operate "below our cultural radar" and remain "socially acceptable" (Derby, 2016, p. 106). Thus, ableism functions to stigmatize disabled experiences and can have detrimental effects. For example, Olkin (1999) found that disabled people are often the only member of their family with a disability; this may cause a sense of isolation from the disabled community and a lack of role models who may offer coping mechanisms to deal with daily forms of ableism. Further, without exposure to positive sentiments toward disability, disabled people may internalize ableist ideas and see their own lives as "tragic," "defective," and "in need of cure" (Nario-Redmond et al., 2019, p. 727). The isolating and oppressive experiences of disabled individuals are further complicated when considering their other identity markers.

Disability and Ableism Intersect with Other Identities and Oppressions

As Crenshaw (1991) established through her concept of intersectionality, individuals are positioned in specific ways to power and privilege based upon the multiple facets of their identity. An individual who identifies as both Black and female, for example, cannot be positioned as *only* Black or *only* female. Therefore, when examining issues of ableism, we must

also consider how disabled individuals cannot separate their disabled identity from their gendered, raced, classed, or sexualized identity (Annamma et al., 2013; Erevelles & Minear, 2010).

Scholars of disability understand that “the apparatus of disability is historically, conceptually, politically, and socially inseparable from the legacies of other apparatuses of force relations” that inform systems of oppression and privilege (Tremain, 2017, p. 71). Thus, disability has always interacted with other identities to be more or less disabling in certain contexts. For example, disability and race have been inherently linked since colonial conquests. Berne (2017) stated, “one cannot look at the history of US slavery, the stealing of indigenous lands, and US imperialism without seeing the way that white supremacy leverages ableism to create a subjugated ‘other’” (p. 149). This link between race and disability was furthered in the nineteenth century when Sir Francis Galton used the concept of normalcy to make meaning of human traits through eugenics, used to justify the exclusion of bodies and minds who deviated from “normal” (Gallagher, 2010; Waldschmidt, 2018). Under this principle, physical features and human skulls were compared to show supposed biological evidence that white people were intellectually superior to People of Color, and this “evidence” was then used to rationalize the widespread enslavement of People of Color (Hayman, 1998). Further, different physical and mental characteristics were marked as more desirable and acceptable for the genetic pool. Fear-mongering propaganda during this time targeted people from Africa, Asia, and parts of Europe, as well as “feeble-mindedness” (Baglieri & Lalvani, 2020, p. 14) and fueled the legal removal and segregation of disabled people, POC, homosexuals, and others with less desirable traits (Carey, 2009; Carlson, 2018). Eugenics turned normality into a biological scientific truth, allowing longstanding social and cultural beliefs to become laws for policing human bodies. We

have seen the enduring effects of eugenics and traits-based laws numerous times throughout history including forced institutionalization, imprisonment, and sterilization, the mass extermination of millions during the Holocaust, and the modern practice of self-contained Special Education classrooms (Baker, 2002; Davis, 2013; Baglieri & Lalvani, 2020; Tremain, 2017).

Further, in January 2022, the CDC director, Dr. Rochelle Walensky, perpetuated concepts of eugenics-based ableism during a *Good Morning America* interview; she stated it was "really encouraging news" that most deaths from the Omicron variant of COVID-19 were those with "at least four comorbidities" and "who were unwell to begin with" (Zaccaro & Schindler, 2022). Put simply, this stance conveys the message that the death of "unwell"—AKA disabled—people is not only acceptable, but "encouraging." As the Disability Rights Education and Defense Fund (DREDF) stated in a Twitter open-letter response, "not only is this message from the head of the CDC abhorrent, but it also perpetuates widely and wrongly held perceptions that disabled people have a worse quality of life than nondisabled people and our lives are more expendable" (Disability Rights Education & Defense Fund, [@DREDF], 2022).

Today, the stigmatization of disability in society is heightened by further oppressions brought on by intersectional marginalized identity markers such as race, gender, or economic status. Considering intersectionality, "ableism helps make racism, christian supremacy, sexism, and queer- and transphobia possible, and that all those systems of oppression are locked up tight" (Piepzna-Samarasinha, 2018, p. 22). That is not to say that all marginalized identities are oppressed in the same way, to the same degree, in the same contexts; simply, systems of oppression intersect and overlap, allowing individuals to be more oppressed or privileged in various settings (Baglieri & Lalvani, 2020; Berne et al., 2018). Thus, belonging to multiple

marginalized groups allows for the cumulative effects of ableism, heterosexism, classism, racism, etcetera to collude with one another for further oppression (Annamma et al., 2013; Berne, 2017; Erevelles & Minear, 2010).

For example, within the American school system, Black, Latinx, and Indigenous males are severely overrepresented in Special Education and often remain segregated from their peers in self-contained classrooms (Ferri & Connor, 2005). Additionally, according to Census data, disabilities tend to affect People of Color more often, with 22.2% of Black, 14.5% of Asian, 17.8% of Hispanic, and 17.6% of white US Americans identifying as disabled (Brault, 2012). Furthermore, the National Health Interview Survey ([NHIS] Center for Disease Control, 2013) reported that people who have a mobility limitation *and* are marginalized racially experienced greater health disparities than those with a mobility limitation *or* a marginalized race alone.

Thus, someone living as a member of the raced and disabled community faces a "double burden" because of compounding sociopolitical challenges (Blick et al., 2015, p. 1); similarly, disabled individuals who are queer are doubly stigmatized because society's obsession with "the normate" (Garland-Thomson, 1997, p. 8) views a heterosexual disabled body as more acceptable (McCruer, 2006; Morgan, 2018). LGBTQ and trans disabled people are also more likely to be socially ostracized and are more often targeted in violent hate crimes (Sherry, 2004), and the likelihood of experiencing violence increases if the individual is also a Person of Color (Chappell, 2015). Further, disabled females are more likely to experience more social disadvantages than disabled males (Priestley, 2001; Thomas 2006); however, both disabled females and males face stigmatization if their disability positions them in opposition to conventional gender norms (Garland-Thomson, 1997; Thomas, 2006). Additionally, disabled—especially invisibly disabled—males of Color are more likely to be killed in interactions with

police (Nario-Redmond, 2020). Attention to the effects of disability at the intersection of other marginalized identities is imperative because, as Erevelles and Minear (2010) stated, the "omission of disability as a critical category in discussions of intersectionality has disastrous and sometimes deadly consequences for disabled People of Color caught at the violent interstices of multiple differences" (p. 128).

Using an AAF for Literary Analysis

For those new to an AAF, I consider an analysis of literary elements as an appropriate entry point for interrogating disability and ableism in texts. Subsequent literary analyses can build upon, complicate, and expand upon this emphasis of literary elements. I chose literary elements as an entry point to using an AAF because they are represented in ELA learning standards, they are familiar to ELA educators, and they are components of literature to which students are repeatedly asked to engage. In outlining the guiding questions for an AAF, I acknowledge that I am not the first scholar to raise questions about analyzing disability in texts. Specifically, I recognize the work of disability studies and YAL scholars who have offered guidance to teachers wishing to include disabled texts within their curriculum (Baglieri & Lalvani, 2020; Dunn, 2015; Garland-Thomson, 1997; Hall, 2016; Nario-Redmond, 2020; Quayson, 2007). While I appreciate the questions that have already been raised within the field, I also position the AAF as a distinct approach to literary analysis as it takes an explicitly anti-ableist stance, and it offers concerns for intersectionality that have largely been missing from analyses of disability.

To offer a concrete example of using the AAF for literary analysis, I created Table 3.2 to provide readers with a tool for examining disabling representations within texts and considering how the representations reflect society at large. While there are numerous literary elements, the

AAF begins with attention to characterization, plot, setting, metaphor, and theme. Once educators and students become more familiar with an AAF, further considerations to other literary elements could, of course, be interrogated. The columns of the chart are meant to move readers from identifying the representation of disability in texts, to interrogating how those representations reflect common attitudes, social values, and norms, to understanding how those values are rooted in ableist ideology. Within the first column of the table, I provide description-based questions that can be answered about the text even if readers lack much of the foundational knowledge on disability and ableism that informs an AAF. Next, the second column provides analytical questions to help readers interrogate representations of disability at a deeper, more critical level. The last column asks readers to consider how each literary element can generate corporeal implications to help them uncover, complicate, and disrupt real-life sociopolitical perspectives on disability. The guiding questions in the final column are meant to help students connect the positioning of disability in fiction and reality to oppression made possible by ableism.

To demonstrate how readers can operationalize the components of this chart, in the next section, I provide an example analysis of Adib Khorram's (2018) YA novel, *Darius the Great is Not Okay*. I selected this novel specifically because of the numerous intersecting identities of the protagonist, Darius; an analysis of those intersections will help readers understand the foundational principles, that our biological differences *and* contextual barriers are disabling, that disability intersects with other identities, and that ableism influences other oppressions. For this sample analysis, I specifically focus on the elements of characterization and setting to show how interlocking social identities and different contexts can be disabling for Darius as a marginalized character.

Reading *Darius the Great is Not Okay* Through an AAF

Darius is one of only two Persian students attending his Portland, Oregon, high school; to make matters worse, Darius views himself as a “fractional Persian” (Khorram, 2018, p. 32), so he doesn’t fit in well with any of the students at his school. Darius is also clinically depressed; he takes medication to balance his mood but with that comes side effects like weight gain and memory loss. Darius faces intense criticism from his white father to be more “normal” in all aspects of his life, he faces bullies every day at school, and he struggles to connect with his Persian culture and his family in Iran, whom he is about to meet for the first time.

In Iran, Darius meets his extended family and feels more fractionally Persian than ever. He doesn’t speak the language of his family—Farsi—he doesn’t enjoy some classic Persian foods, and he doesn’t understand many of the social cues. His extended family also doesn’t understand his depression as an effect of a chemical imbalance rather than a single event making him “sad” (p. 192). However, as Darius makes his first real friend, Sohrab, and forms bonds with his grandparents, he becomes more attuned to his Persian side, he feels his depression and emotions are more accepted, and he grows to be more confident in his uniqueness.

Examining how Setting and Characterization Disable Darius

Through an AAF, readers can identify elements of Darius’s disability and analyze how it affects his daily life. Readers can also consider how Darius’s disability is influenced by both biological *and* social conditions. Then, readers might grapple with the representation of Darius and how his disability reflects ableist norms and assumptions. Specifically, through a study of characterization and setting using the AAF guiding questions, readers can discern how the interaction between Darius’s multiple identities and his settings contribute to what disables him at any given time.

Characterization

To consider how Darius's settings affect how he is disabled, we must discern how he is characterized, especially in comparison to nondisabled characters. If we refer to the description questions in column one of the AAF literary elements chart, the first step for characterization is examining how Darius identifies himself, how his disability is positioned, and how nondisabled characters are represented. From chapter one, we learn that Darius is "half Persian" (Khorram, 2018, p. 2). Darius describes his looks as "Standard Persian" (p. 13) although he has "pale coloring" (p. 31), which he takes after his mother and Mamou; conversely, his white father is described as having "Aryan looks" (p. 13) and he covets the white characteristics of his sister, especially feeling "jealous" of her large blue eyes (p. 26). Additionally, Darius speaks frequently about his feelings as a "Fractional Persian" (p. 85), a cultural outsider. First, he states he doesn't know Farsi, the home language of his mom and extended Iranian family; he says, "no middle school in Portland has ever offered Farsi as an option. The truth was, my Farsi was abysmal. I never really learned it" (p. 20). He also believes his Iranian relatives are "from some alternate reality" where he is "just a guest" (p. 24). While Darius does not explicitly name his sexuality—but he does in the second book, *Darius the Great Deserves Better* (Khorram, 2020)—readers may recognize that he is questioning. Darius self-discloses his disability early in the novel, explaining that he—and his father—take "medication for depression" (p. 28). From Darius's perspective, his father looks down upon this mental health diagnosis; Darius says, "He was ashamed of me. He was ashamed of us. [We] aren't supposed to need medication" (p. 28). Darius is also honest about the ups and downs of his depression medication journey, explaining how he exhibited large mood swings in the past and how his current medication causes "dull" memory issues (p. 75) and weight gain; Darius's weight is a constant issue in his home where his father

forces him to eat salads "as if salad would counteract the weight gain from [his] meds. As if lack of discipline was the root of all [his] problems. As if all the worry about [his] weight didn't make [him] feel worse than [he] already did" (p. 37). He also speaks comparatively about his dad's experience with medication, stating, "his medication had kept him healthy for years… Stephen Kellner has been managing his depression for so long that he couldn't remember what it was like" (p. 33).

Darius often exhibits negative feelings about his depression. He says "'I'm just messed up. My brain makes the wrong chemicals. Nothing bad has ever happened to me.' I felt terrible saying it out loud" (p. 192). Darius also mentions other manifestations of his depression; for example, while he has never been diagnosed with an anxiety disorder, he frequently experiences anxiety attacks, which his doctor mentioned often go hand-in-hand with depression; he states, "sometimes my heart would pound so fast I thought I was going to die. And then I would start sobbing for no reason" (p. 114).

We also learn early in the novel that Darius has qualities that he hides from others and qualities that he frequently questions as abnormal; we see this especially when qualities are symptoms of his depression or do not seem to align with traditional gender norms. For example, he says:

> I mean, guys are not supposed to love their little sisters. We can look out for them. We can intimidate whatever dates they bring home… We can't admit to having tea parties or playing dolls with them, because that's unmanly. But I did play dolls with Laleh. And I had tea parties with her… And I was not ashamed of it. I just didn't tell anyone about it. That's normal. Right? (p. 16)

When he finally arrives in Iran, he feels anxious and scared to meet his grandfather for the first time face-to-face; again, he wonders, “That’s normal. Right?” (p. 80). We see this again late in the novel when Darius says, “I loved the quiet. Even if it sometimes made me think of sad things. Like whether anyone would miss me if I was dead… if anyone would be sad if I was killed in a car accident or something. That’s normal. Right?” (pp. 223-224).

One character who is presented in direct opposition to Darius is his father, Stephen. We learn early in the novel that Stephen is hard on Darius; he doesn’t believe him about bullying he experiences, he wishes Darius did not express his emotions so intensely, and he thinks Darius would be better off if he tried to “fit in more. If he could just, you know, act a little more normal” (p. 60). Darius’s father also causes Darius to feel symptoms of his depression are abnormal; Darius says, “Stephen Kellner didn’t like it when I got upset. He didn’t like it when I had feelings” (p. 225). This relationship is strained for almost the entirety of the novel, emphasizing Darius’s perspective that his father hates him, doesn’t want him to “feel anything at all” and just wants Darius “to be normal” (p. 283). However, during a heart-to-heart, Stephen expresses that he is scared Darius “‘could be drowning in depression, bad enough to… to do something’” (p. 285). Stephen also shares that this fear is rooted in his own previous suicidal ideation that occurred when Darius was a young child. Stephen finally tells Darius in this discussion that “‘it’s okay not to be okay’” (p. 286).

In Iran, Darius’s grandfather becomes a site of opposition, as well. He regularly doesn’t understand Darius’s depression, which affects Darius’s self-concept; for example, Darius says, “Yesterday I wasn’t Persian enough because I didn’t speak Farsi, because I took medicine for depression, because I brought [Babou] and Mamou fancy tea. [Babou] made me feel small and stupid” (p. 158). We also see the influence of background characters on Darius and his multiple

identities. For example, a school peer calls Darius a terrorist because of his Middle Eastern heritage, even though Darius was born and raised in Portland. Similarly, Darius is "randomly selected" for advanced screening at TSA when he and his family are leaving for Iran (p. 53). Conversely, Darius's Iranian friend, Sohrab, gives him a gift that, two-thirds through the novel, finally "made [Darius] feel like [he] belonged" (p. 181). This is significant because Sohrab is also the first person to allow Darius to openly talk about his depression without judging him or making him feel abnormal. Darius even says, "The thing is, I never had a friend like Sohrab before. One who understood me without even trying. Who knew what it was like to be stuck on the outside because of one little thing that set you apart" (p. 267).

The guiding characterization questions in columns two and three of the AAF chart help readers analyze how Darius's various positions reflect social values and expectations. For example, racial bullying and microaggressions from Darius's Portland classmates are indicative of frequent anti-Iranian sentiments and Islamophobia that exist in the US, especially post-9/11 (Maghbouleh, 2017). The rampant anti-Iranian sentiments may also explain how Darius feels "fractional" and lacks belonging to America and Iran. This may also explain Darius's feelings about his skin tone, especially in relation to that of his father, who is white, and his sister, who has more white characteristics than Persian. Readers might discern how Darius's feelings about his racial appearance reflect a white norm that places more value on white bodies than bodies of Color (Annamma et al., 2013; Kwan, 2010; Maghbouleh, 2017). Further, bullying at school and pressure from his father about Darius's weight directly reflects US values privileging the thin body—which is deemed normal-sized—over the fat body (Kwan, 2010). Through this analysis, readers can see how Darius's identities as disabled *and* biracial, disabled *and* fat, disabled *and* male intersect to disable him because of social values and conceptions of normalcy.

Finally, by analyzing Darius's internal thoughts about his depression, as well as secondary characters' statements about his depression, readers might consider how disability, especially mental illness, is stigmatized in the US (Armstrong, 2019; Richmond, 2018; Solomon, 2012; U.S. Dept. of Health & Human Services, 2020). This stigmatization can also help readers identify how Darius's thoughts reflect internalized ableism (Nario-Redmond, 2020) from his father's and peers' constant beratement. By analyzing these individual social values, readers can then make connections between all of Darius's social identities and begin to ponder how they work together to disable him and reflect ableist ideology. For example, students might connect Darius's experiences with his weight, race, and depression as manifestations of ableist ideology's emphasis on the "normate," white, cisgendered, heterosexual nondisabled body (Garland-Thomson, 1997). Further, students can then reflect that ableism is at the center of "all of our movements because ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (Mingus, 2011, para. 11).

Setting

The intersection of Darius's social identities and his setting greatly affect how he is disabled. For example, in Portland, he is bullied in school more for his cultural background and his weight than he is about his depression. When Darius goes to Iran, however, his mental health is more disabling to him than it was in the US. His immediate family presumes this will be a problem for Darius; on the plane, his mother warns him by saying, "I just want you to be prepared. People in Iran don't think about mental health the way we do back home" (p. 56). She also tells him that if people make negative remarks about his depression, not to "take it

personally" (p. 56). We see the first example of this difference at the airport in Tehran, when Darius has the following exchange with a customs officer:

> …he pulled out my little orange child-proof medicine bottle. "You have prescription?" I nodded. "Yeah. Um. At home. It's written on the bottle." "What is it for?" "Depression." "That's all it's for? What are you depressed about?" … I hated that question: *What are you depressed about?* Because the answer was *nothing*. I had nothing to be depressed about. Nothing really bad had ever happened to me. I felt so inadequate. Dad told me I couldn't help my brain chemistry any more than I could help having brown eyes. Dr. Howell always told me not to be ashamed. But moments like this made it hard not to be. "Nothing," I said. "My brain just makes the wrong chemicals is all." "Probably your diet," Customs Officer II said. He looked me up and down. "Too many sweets." (pp. 68-69).

We see a similar exchange at Darius's grandparents' home in Iran when his grandfather witnesses him taking his medication. Babou asks Darius if he takes medication because he is sick; Darius tells him the pills are for depression and, from Darius's perspective, he can "sense the disappointment radiating" off his grandfather (p. 102). Babou responds by asking what he could possibly have to be depressed about, saying "'you have to think positive, baba. Medicine is for old people. Like me.'" (p. 102).

In the aforementioned scene for characterization, where Darius has a panic attack and worries about crying, we must consider the significance that this happens in public, in Iran. Darius says, "I couldn't let the guys see me do that. That wasn't something True Persians did" (p. 114). This becomes a concern for him when Babou sees Darius growing emotional and tells him that in Iran, boys don't get upset over minor—from Babou's perspective—things. However,

thinking back to Portland, Darius mentions how Dr. Howell told him that "crying is normal" and that it's "a healthy reaction" because it "helps the body excrete stress hormones" (p. 118).

When moving to the analysis and corporeality-based questions of the AAF chart, readers can identify how context influences disability. For Darius, his culture and his physical settings affect the disabling effects of his depression. In Portland, for instance, we see Dr. Howell express that crying is "normal" in moments of stress; in Iran, however, Babou states that Iranian boys don't show emotional distress. Babou's and the customs officer's responses are consistent with views that depression is a "Western" phenomenon, relegating it as a low priority in non-Western countries; there is also a persistent belief that depression does not "directly contribute to morality," which is an important distinction in non-Western cultures (Patel et al., 2004, p. 539). We can also consider how there are social misunderstandings of depression and those can be further disabling. For example, Darius's immediate family understands a chemical imbalance in his brain causes his depression and that it affects numerous elements of his daily life. However, people in Iran see depression as an isolated incidence of sadness that must reflect something bad happening; this inclination is a widespread myth of depression that causes further social stigmatization (Richmond, 2018; UnityPoint Health, 2018). Further, when Babou states medicine is "for old people" (p. 102) he is reinforcing an element of ambivalent ableism, ageism; it is easier for nondisabled people to grasp disability status, symptoms, and treatment in older individuals than younger individuals (Nario-Redmond et al., 2019). Thus, an analysis of Darius's different experiences in Portland and Iran can help readers understand how the social model of disability affects our approaches to understanding disability. It can help readers position disability as within the body *and* within social barriers, understanding how one's age, gender, physical location, socioeconomic status, access to resources, and disability characteristics greatly

influence their disabled experience (Nario-Redmond, 2020). For example, in the characterization section, we highlighted scenes where Darius talks about the importance of his medication as well as the perceptions Iranian's hold about his medication. Here we can see that medication is more normalized in the US than in Iran; hence, not only is the biological condition of his depression disabling, so too is the treatment for his depression.

Implications & Future Considerations of an Anti-Ableist Frame

The purpose of this article was to introduce and describe an Anti-Ableist Frame (AAF) for analyses of disability in myriad texts, such as YAL. As I have outlined throughout this article, we need to expand the work of scholarly and pedagogical attention to disability in texts and educational practices (Baglieri & Lalvani, 2020; Dunn, 2015; Garland-Thomson, 1997; Hall, 2016; Nario-Redmond, 2020; Quayson, 2007). Because of our sociopolitical climate and systemic ableism, because stereotypical representations are still prevalent in contemporary texts centering disability, and because readers' ableist views influence their reading of those representations, I believe an explicitly anti-ableist perspective is necessary for engaging with those texts.

What I have articulated here is that an AAF is a distinct frame to analyze disability representation because it explicitly asks readers to consider intersectional identities, social assumptions of disability, the context-dependency of disability, and effects of ableism. The description, analysis, and reality-based questions allow students to engage with issues of ableism more deeply and allow them to work towards disrupting the widespread roots of ableist oppression. By introducing a new AAF for literary analysis, I aim to influence numerous veins of scholarship and pedagogy. With the establishment of an AAF, I see my work building upon and strengthening the great work of scholars in the fields of YA and other literature (Curwood, 2012;

Garland-Thomson, 1997; Hazlett et al., 2011; Heim, 1994; Markotić, 2016; Mitchell & Snyder, 2000; Prater, 2003; Richmond, 2018), secondary English education (Cameron & Rutland, 2006; Mathis & Vaughan, 2018; Meyer & Wender, 2017; Ware, 2001, 2002), and teacher education (Donovan & Weber, 2021; Olan & Richmond, 2020; Ware, 2006) who are already addressing issues of disability.

Further, I envision this frame of literary analysis naturally leading to an expanded anti-ableist framework for English language arts instruction. For example, a framework would expand upon the literary elements chart to include considerations such as author's purpose, asking readers to grapple with questions such as: *What does the creator want you to know or understand about disability? What underlying messages about disability does the author deliver through their plot, characterization, and lexicon choices? How might the representation of disability reflect about the assumed reader? How are readers expected to react to the representation of disability?* Additionally, a full framework would allow us to critique and disrupt ableism as it infiltrates elements of our everyday life, such as the reliance on disability metaphors and euphemisms in our daily lexicon. Through a framework, I would also include considerations for in-depth analyses of ableist language, writing practices, media literacy, and educational traditions. Thus, this framework would provide pedagogical suggestions for educators to dismantle ableism from several directions in the ELA classroom.

Conclusion

In creating an explicitly anti-ableist frame, I hope to establish a space within literary analysis and education to purposefully explore the context-dependent disabling effects of various identity categories. The establishment of an AAF acknowledges that disability has been historically ignored in the realm of education, especially as it pertains to diversity and social

justice (Buffington-Adams & Vaughan, 2019; Gibson, 2015; Liasidou, 2014), and that now is the time to correct that error. It also recognizes that ableism is at the root of "all of our movements because ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (Mingus, 2011, para. 11), and that "ableism helps make racism, christian supremacy, sexism, and queer- and transphobia possible, and that all those systems of oppression are locked up tight" (Piepzna-Samarasinha, 2018, p. 22).

I understand that centering disability perspectives and critiquing ableism is necessary to challenge the normative status quo and to dismantle the social injustices faced by people whose multiple identities are marginalized because disabled people are hindered by ableism as it frequently intersects with racism, sexism, classism, and other oppressive and exclusionary practices (Alim et al., 2017; Annamma et al., 2013; Gabel & Connor, 2014). Hence, by using an Anti-Ableist Frame for instruction, educators can naturally analyze the intersection of ableism and other prejudicial systems.

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Appendix

Table 3.1: *Levels of Ableism*[1]

Level	Definition	Examples
Systemic or Institutional	Ableism at the structural or institutional level combines individual biases and cultural values to create disability discrimination at a systemic level. This discrimination includes systems of built environments, as well as social, economic, and political policies (Baglieri & Lalvani, 2020).	• Homes are constructed with stairs instead of ramps • Businesses are not typically able to accommodate mobility, hearing, and visual disabilities • Most restaurants do not offer Braille menus • Success and productivity are regimented; those who cannot meet expectations are less than able and/or excluded • The existence of self-contained special education classrooms to segregate disabled students
Cultural	At the cultural level, ableism functions through our social values, norms, and expected behaviors. Examining social norms and intended behaviors can reveal "values surrounding speed, communication and language, and social behavior that can position a person with a disability as an outsider, interloper, misfit, or obstructionist" (Baglieri & Lalvani, 2020, p. 72).	• Cultural definitions of "normal" determine what people should be able to do and how they should do it; stigmatizes people who cannot meet this standard • Social settings have expected behaviors (e.g., speaking quietly in a library, sitting still in chair, walking quickly on a sidewalk); individuals who do not follow these behaviors are viewed as abnormal • Cultural norms establish standards of beauty and desired bodies; these norms are represented in media; those who do not meet these standards are less desirable and under- or misrepresented in media • Many cultures (e.g., the US) value independence and individuality; interdependence and mutual care is not desirable • Cultural metaphors, euphemisms, and slurs have negative connotations of disability (e.g., retarded, special needs, wheelchair-bound, lame, "blinded by hatred," "paralyzed with fear")

[1] Sources: (Baglieri & Lalvani, 2020; Baglieri & Shapiro, 2012; Nario-Redmond, 2020; Nario-Redmond et al., 2019)

Table 3.1 Continued

Individual	Individual ableism is the manifestation of us vs. them mentality (Nario-Redmond, 2020). It may present as patronizing behaviors, making jokes, using disability slurs, believing stereotypes, holding negative assumptions, teasing, or avoiding people based on the assumption that disabled people are “deserving of or unaware of taunts, or is so different that they are not interested or able to interact” (Baglieri & Lalvani, 2020, p. 72).	• Beliefs that disabled people are:
		  ○ inspirational for completing daily tasks
		  ○ deserving of pity for the state of their lives
		  ○ tragic – “I’d rather be dead than disabled”
		• Use of microaggressions (e.g., “What’s wrong with you?” “What’s it like to be Deaf?” “You look so normal, are you sure you’re not faking it?” “You’re so lucky you can bring your dog to work.” “I could never live your life.”)
		• Questions of the validity or seriousness of a disability, especially if it is invisible

Internalized	Internalized ableism outlines how disability prejudice—or the assumption of prejudice—can lead to physical and mental stress for the disabled person experiencing that prejudice, such as “depression, anxiety, paranoia, and suicidal ideation, negative moods, and lower overall well-being” (Nario-Redmond, 2020, p. 223). Taking in negative messages of disability can make disabled people believe those messages about themselves and other disabled individuals. This can include feelings of invalidation, feelings of shame and self-blame, questioning the validity of their disability, and questioning the need for access or accommodations (Nario-Redmond et al., 2019).	• A disabled person feeling:
		  ○ shame, or not identifying as disabled because you’ve been taught that is inherently bad or tragic
		  ○ embarrassed to ask for and/or rejecting accommodations or refusing to use non-typical aids (e.g., a cane)
		  ○ pressured to “overcome” elements of your disability
		  ○ they must minimize or downplay how disability affects their life
		  ○ self-questioning; believing they’re making up symptoms
		  ○ it’s better to “pass” as nondisabled to avoid tokenism and stigmatization

Table 3.2: *Using an AAF for Analyzing Literary Elements*

Literary Element	**Description Questions**	**Analytical Questions**	**Real-World Questions**
Plot	What conflicts do the disabled characters face in the text? How is disability positioned in relation to these conflicts? What is the cause of these conflicts? What are the consequences of these conflicts? How are the consequences resolved?	What meanings can be derived from the types of conflict the disabled characters experience? How do disabled and nondisabled characters interpret the conflict and the resolution?	What do these conflicts imply about sociopolitical assumptions about and expectations of disabled people?
Characterization	What social markers do disabled characters use to identify themselves (i.e., Does the character refer to themselves as disabled? Does the character express their race, gender, sexual orientation, etc.?)? Do characters reinforce or reimagine ableist stereotypes? What capabilities, interests, actions, desires, and thoughts do the disabled characters have? How are nondisabled characters represented and how do they feel about, act around, and treat disabled characters?	How are disabled characters positioned in relation to nondisabled characters in the text? What binaries are used within the text to position disabled and nondisabled characters (e.g., abnormal/normal, sick/healthy, helpless/independent, incapable/capable, insane/sane)? What meanings can be derived from these various positions?	In what ways do numerous social identities affect disabled people? How might the positioning of disabled and nondisabled characters reflect common views of disabled people? In what ways does the characterization perpetuate or disrupt dominant views and stereotypes about disabled people?
Theme	What are the themes of the text? Are dominant themes and/or tropes of disability (e.g., overcoming, cure, child-like, villain) evident in the text?	How do the themes in the text reflect common ideas, social values, beliefs, and norms about disability?	How do the themes normalize, complicate, or disrupt notions of disability and ableist systems?

Table 3.2 Continued

Setting	What are the various settings (e.g., physical, social, cultural) disabled characters moves through? How do different settings affect characters?	How is disability positioned in relation to each setting in the text (i.e., Do characters face more freedom or challenges in certain settings? Is disability more accepted or stigmatized in certain settings)? How do expectations in different settings function to disable characters?	What role does context play in understanding disability and/or being disabled? How do attitudes, values, norms, and sociopolitical barriers in different contexts disable people?
Metaphor	What metaphors are used to describe disability? What disability euphemisms are used in the text?	How does the text use metaphors of disability to provide commentary on other things?	How do metaphors of disability and disability euphemisms within the text reflect an unsaid message about disability?

Chapter 5: Conclusion

The purpose of this dissertation was to highlight an area of young adult literature and social justice education that often does not get a seat at the table: disability. Historically, examining disability in literature highlighted negative depictions (Markotić, 2016; Mitchell & Snyder, 2000); emphasizing negative attributes of disability was standard because, often, disabled characters served as narrative props meant to illicit reader sentimentality, to teach an important life lesson, or to help other characters with a moral dilemma (Dyches & Prater, 2000; Meyer & Wender, 2017). Similarly, cultural hegemony and deficit views in society and education have relegated disability to the outer fringes of social justice and diversity endeavors (Connor & Gabel, 2010; Erevelles, 2000; Goodley, 2007; Nario-Redmond, 2020). This dissertation attempted to remedy the systemic exclusion of disability, centering it as a valuable topic for exploration and discussion in the classroom.

Thus, the purpose of my work was three-fold: 1) to critically analyze the representation of disability in young adult (YA) novels written by disabled and nondisabled authors, 2) to explore readers' responses to the representation of disability in YA novels, and 3) to develop an anti-ableist frame to which English and literacy educators can employ for analyses of disability in classroom texts, highlighting this element of diversity and dismantling effects of ableism.

This three-article dissertation was informed by Critical Disability Studies (CDS) and guided by the following research questions: 1) How is disability represented in contemporary young adult literature? and 2) How do readers respond to the representations of disability in YAL and what are the effects of those responses? In the following chapter, I will summarize the findings of those two questions and discuss the larger implications for the three congruent articles presented in this dissertation.

A Call for Counter-Stories of Disability in YAL

Within article one, I explored four contemporary YA novels to examine the portrayal of disability. I conducted a critical content analysis, adopting CDS as a theoretical lens for reading *A Time to Dance* (Venkatraman, 2014), *Marcelo in the Real World* (Stork, 2009), *Sick Kids in Love* (Moskowitz, 2019), and *This is Not a Love Scene* (Megale, 2019). Two novels (*Sick Kids in Love* and *This is Not a Love Scene*) were written by disabled authors—meaning the authors have the same or similar disabilities to the characters in their novels—and two novels (*A Time to Dance* and *Marcelo in the Real World*) were written by nondisabled authors—meaning the authors do not share the same disability experiences as their character(s). I explored the findings of my first research question—how is disability represented in YAL?—in article one; however, the short answer is that it depends. My findings indicate the representation of disability may be largely influenced by an author's positionality as disabled or nondisabled.

I found that the two disabled authors wrote more authentic and nuanced depictions of disability whereas the nondisabled authors included stereotypical portrayals of disability, aligning with the same historical tropes used since 430 AD (Bowman & Jaeger, 2004). These findings are problematic because nondisabled people may internalize disability stereotypes when engaging with texts that do not work to dispel them (Nario-Redmond, 2020). Further, disabled people can also internalize these depictions, which may have detrimental effects to their self-concept (Baglieri & Lalvani, 2020; Nario-Redmond et al., 2019). Thus, if people's frame for understanding disability is built on stereotypical portrayals, there are possible negative effects on their beliefs and attitudes towards disabled people they encounter in the real world.

Thus, there is an immediate need for centering disabled authors who write about disabled experiences to which they can relate. These narratives can serve as counter-stories (Solórzano &

Yosso, 2002) to the problematic narratives that are circulated in literature, the media, and engrained in our ableist institutional policies.

Readers' Responses to Disability in YAL

Grounded in Rosenblatt's (1938/1968) transactional reader response theory (RRT), in article two I sought to answer my second research question: how do readers respond to the representations of disability in YAL and what are the effects of those responses? Within this article, I explored how readers in a college-level YAL course reacted to disabled characters and examples of ableism in three YA novels written by disabled authors: *Sick Kids in Love* (Moskowitz, 2019), *The Silence Between Us* (Gervais, 2019), and *This is Not a Love Scene* (Megale, 2019). Again, the short answer to the research question is that it depends.

Readers identified blatant examples of ableism and were quick to reject this frame of thought; however, they also overlooked subtle examples of ableism. Further, they relied upon ableist language and failed to make connections to real sociopolitical levels of ableism. Thus, readers' own ableist views influenced their reading of disability and their exploration of ableism in the novels. Those ableist views may have prevented them from considering how authentic disabled characters and problematic ableist characters influence their understanding of and engagement with corporeal disabled individuals. Therefore, readers may not fully grasp how ableism functions at a cultural and structural level in society, rendering it difficult to dismantle those systems. To help toward that goal, readers must develop deeper understandings of existing ableist systems of oppression and have a pedagogical tool to assist in their ability to make connections between fictional texts and the real world.

The Need for an Anti-Ableist Lens

The findings of articles one and two directly influenced the development of a new theoretical perspective in which to approach literary analysis and pedagogy. Because I found that disability representation in YAL is still problematic and I found that readers may hold ableist views that influence their reading of disability, I determined it necessary to develop an Anti-Ableist Frame (AAF) for analyzing examples of disability and ableism within texts. While the AAF is not tied to one theoretical lens, I grounded it in CDS and the disability justice movement (DJM). When considering an anti-ableist frame, I also adopted the stance that ableism is at the root of every oppressive system and allows for the systemic policing of normal/abnormal bodies and minds (Mingus, 2011; Lewis, 2019; Tremain, 2017). As Mingus (2011) stated, "ableism dictates how bodies should function against a mythical norm—an able-bodied standard of white supremacy, heterosexism, sexism, economic exploitation, moral/religious beliefs, age and ability," (para. 11). Thus, an anti-ableist frame also considers how ableism functions to oppress characters at the intersection of their other identity markers (Crenshaw, 1991).

To begin, I outlined foundational knowledge inspired by CDS and the DJM, informing the creation and use of an AAF. I then introduced a table outlining descriptive, analytical, and implication-based questions to guide an analysis of ableism through a study of literary elements. Then, I provided an example to demonstrate how educators might apply the AAF to the critical study of a contemporary YA novel featuring a disabled protagonist, *Darius the Great is Not Okay* (Khorram, 2018). I specifically focused on elements of characterization and setting to demonstrate how Darius was *more* disabled at times by the location-based social barriers of his culture, gender, and sexuality than his clinical depression. I closed the article with implications of the AAF for analyzing YA and other texts, as well as positing how the principles of an AAF

could be expanded into a full framework with further implications in secondary English instruction and pre-service teacher education programs.

Why this Matters

According to the National Alliance on Mental Illness (NAMI) (2019), 1 in 5 adults *and* 1 in 5 youth experience a mental illness, with the onset of about 50% of all mental illnesses occurring before age 14. In 2020, the Center for Disease Control and Prevention (CDC) reported that 61 million adults—26% of the overall population—in the US live with a disability and about 1.3 million young people in the US live with a disability or chronic illness (Erickson et al., 2016). Additionally, approximately 6.7 million US students in K-12 settings received special education services in the 2015-16 school year (National Center for Educational Statistics [NCES], 2018). Further, in December 2021, the US Surgeon General released an advisory to highlight a youth mental health crisis as an effect of the COVID-19 pandemic (US Dept. of Health and Human Services, 2021). Thus, we can assume our schools include many youths and adults living with diverse disabilities; despite this, disability remains stigmatized in school settings and is often a taboo topic of discussion and analysis outside of special education environments (Baglieri & Lalvani, 2020).

Disability is both biological and a social construct. It has also been historically excluded from equity and diversity efforts. Despite these facts, disabled people remain largely stigmatized and oppressed; this has wide-reaching effects for other forms of oppression. Thus, it is time that disability and disabled voices be offered a seat at the table. Only then can we address the very real and systemic effects of ableist prejudice and work to dismantle ableism and other oppressive systems.

Although this dissertation is not representative of all YAL featuring disabled characters, nor is it representative of all readers' responses to those characters, we can draw important conclusions for education and society. First, before educators use novels with disabled characters in their classrooms, we must address our own biases about disability and disabled people. Only by interrogating our own ableist views can we begin to understand how our perceptions and approaches toward disability are shaped by those beliefs. Then, once we have questioned our ableist views, we can work to unlearn them and ultimately dismantle ableism in our classrooms and society. Because our society is built on ableism, we must also be weary of how the literature we read can reinforce or disrupt ableist systems.

Hall (2016) explained why quality representations of disability are important when she stated literature "has the potential to reach large and diverse populations; it serves a pedagogic function in the sense that it not only documents but also shapes attitudes toward disability" (p. 4). As a result, educators must strive to include authentic disability representation within classrooms and adopt an anti-ableist lens when engaging with those representations. We must also conduct in-depth analyses of stereotypes that remain in texts we choose to center in our classrooms. The disability stereotypes explored in the YA novels within this dissertation support current ableist systems that continue to place value in nondisabled lives. Carlson (2016) stated:

> The oppression of bodies directly links with the way perceptions of bodies create identities, and these identities shape lived realities. Thus, if a woman is perceived to be passive, child-like, asexual, and "special need," then society treats her as such. Representation not only structures, but also creates realities; it is both informed by and responsible for the creation of the kinds of binaries that systems of oppression require. (p. 141)

By exploring disability representation in literature, asking readers to interrogate ableism within texts, and asking educators to adopt an anti-ableist stance, we can finally move the conversation forward. We can reject problematic tropes, dispel the use of ableist metaphors, and demand authentic portrayals highlighting disabled narratives. Then, we can work to dismantle ableism and its widespread roots across all systems of oppression for a more equitable and just society.

Moving Forward: Implications for Future Research

Limitations of this dissertation lend themselves to several avenues for future research which might include textual and content analyses, reader response studies, and pedagogical explorations. First, only four novels were included in article one; to support my findings, a larger-scaled study of YAL is necessary. Similarly, a replicable study could be conducted with picturebooks, middle grade novels, and adult fiction to cast a wider net for analysis of disability representation.

Further, although intersectionality is explored in article three's analysis of *Darius the Great is Not Okay*, several of the novels included in the first two articles included problematic portrayals at the intersections of disability and other identity markers that were outside the scope of those studies, including disability and: gender (*Sick Kids in Love*, *The Silence Between Us*, and *This is Not a Love Scene*), race and gender (*Marcelo in the Real World*), culture and gender (*A Time to Dance* and Sick *Kids in Love*), and sexuality (*Sick Kids in Love*). Examining the intersectionality of disabled characters is a critical area of future research to show that disability is not a monolithic experience (Baglieri & Lalvani, 2020; Nario-Redmond, 2020); further, a study of intersectionality would help readers understand how context influences how we are disabled (Baglieri & Lalvani, 2020; Berne et al., 2018; Nario-Redmond, 2020).

Readers' responses to disabled characters would also need to be explored in other contexts. The study explored in article two featured adult readers in a YA college-level course. Thus, I—and other future researchers—must consider the importance of age when studying what effects reading YAL featuring characters with disabilities may have on readers. It would be important to replicate the study with young adult readers and children in K-12 settings and pre-service educators, as well. Further investigations are also necessary to determine if there is a difference in responses from readers in school—who are asked to complete class assignments—and out of school—who read YAL for pleasure—since this case was bound by the course design. As RRT demonstrates the importance of context in the reading relationship, it is necessary to discern how different reading contexts influence readers' responses to disability narratives (Rosenblatt, 1994).

Finally, much more research is needed to support the integration of my Anti-Ableist Frame (AAF) for literary analysis and considerations in English education. While the foundation knowledge and rationale of this frame were outlined in article three, only one element was explored in-depth, an anti-ableist analysis of literary elements within one YA novel. The frame would need to be applied to numerous other texts to show its validity as a tool for analysis. Further, more scholarly articles—or an academic book—are needed to provide in-depth examples of how to expand the frame to other pedagogical practices. These future explorations would include using the AAF to interrogate ableist language, ableist imagery, ableist writing and rhetorical expectations, ableist media depictions, ableist educational practices, and ableist pedagogical design and implementation. Additionally, studies would need to be conducted with K-12 teachers and students, as well as preservice educators, to demonstrate its implementation and effects for learning to adopt an anti-ableist stance in the world.

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Vita

Caitlin Metheny was born in North Charleston, South Carolina and lived the life of a military child, attending school in South Carolina, Virginia, and Ohio. In 2010, Caitlin earned a Bachelor of Science degree in Integrated Language Arts Education (7-12) from Ohio University. Following the completion of her degree, Caitlin taught sixth and seventh grade language arts for four years in rural North Carolina. She then taught seventh grade gifted and talented language arts in an urban district in South Carolina. In these two school districts, Caitlin fell in love with diverse children's and young adult literature and saw, firsthand, the power these books hold for young readers. After her tenure as a middle school teacher, she returned to graduate school, earning a Master of Arts degree in English Composition and Rhetoric in 2018. While completing her Masters, Caitlin served as a Positive Behavior Interventions and Supports (PBIS) coach in northeastern Ohio, offering professional development to large districts on trauma informed teaching, adverse childhood experiences, restorative justice practices, and mental health first aid in education. There, she became interested in the representation of mental health, trauma, and illness in young adult literature; this interest inspired her to enroll in a doctoral program. In 2018, she started coursework toward a Doctor of Philosophy in Education, with a concentration in Literacy Studies and a specialization in Children's and Young Adult Literature from the University of Tennessee, Knoxville (UTK). While at UTK, Caitlin served in a variety of roles including a research assistant for The Center for Children's and Young Adult Literature, a course instructor for English Education and Special Education, and the creator of a graduate certificate in Gifted and Talented Education. Caitlin's research interests were inspired by her role as a teacher and PBIS coach, her life experiences as a cancer survivor, and as a disabled woman. She has a particular passion for the representation of disability in fiction and the effects those representations have on readers. Her goal is to center diverse experiences in children's and young adult literature and to explore the transformative power of literacy to promote equity and shift our understanding of diverse experiences.