IN THEIR OWN WORDS: THE VOICES OF DISABLED FIRST-PERSON PROTAGONISTS IN CHILDREN'S AND YOUNG ADULT LITERATURE.

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Abstract

Located in the field of education, my dissertation examines the representations of disability in 12 popular children's and young adult novels that are commonly being taught in Ontario schools. Throughout my study, I have used autocritical disability studies, autoethnography, and critical inquiry-based research methods to answer the central research questions of my dissertation within a critical disability studies informed social constructivist theoretical frame. 1. How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? 2. How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner? Based on Bates' (2017) survey of the texts being taught in grades 7-12 in Ontario schools, I initially located 39 disability-themed children's and young adult novels which I reduced to the 12 texts containing 12 disabled first-person protagonists that I have analysed in this study, using a comprehensive inclusion and exclusion criteria. I thereafter applied criteria informed by critical disability studies, education, and English literature scholars to critique disability representation in cultural texts. By deconstructing the portrayals of disability in 12 popular novels through a critical disability studies lens, I have exposed the systemic ableism that is present in many of the stories containing disabled characters which negatively impacts students' beliefs about disability and disabled people. Thus, I have provided examples of disability culturally affirming children's and young adult novels throughout my study for teachers to consider teaching in their language arts classrooms. In response to my second research question, I have developed a new application regarding culturally relevant and responsive pedagogy (CRRP) by demonstrating how CRRP can be used

to teach disability-themed literature in a culturally affirming manner in the language arts classroom by using the middle-grade novel *A Kind of Spark* (McNicoll, 2020) as an illustration. My thesis concludes by making recommendations for teacher preparation programs and in-service teachers for future research in literary disability studies, and disability studies in education regarding the selection, analysis, and teaching of disability-themed children's and young adult literature.

Keywords: critical disability studies, disability representation, language arts education, children's and young adult literature, culturally relevant and responsive pedagogy, disability-themed novels, school literature, children's school reading, young adult school reading

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Epigraphs

Prior knowledge affects comprehension, and comprehension promotes or reinforces attitudes. Mistaken assumptions and urban folktales about disabled persons lead students to read stories containing disabled characters in ways that reinforce negative stereotypes. Teachers find themselves in a self-reinforcing loop that frustrates attitudinal change unless they provide both an appropriate scheme prior to reading and critical thinking activities during reading. Then, and only then, can attitudes concerning persons with disabilities be changed through critical reading and thinking. And tragically, without… intervention by the teacher, language use and social prejudice will provide our students simplistic stereotyped responses to disabled persons as well as ready-made attitudes and prejudices. (Shapiro et al., 1989, p. 91)

"People with disabilities do need heroes, not uncomplaining overcomers, but real disabled heroes who fight bias and battle for control of their lives and insist that they will make their mark in the world" (Longmore, 2003, p. 130).

"Nobody whose life has been touched by both visual impairment and literature can assert wholeheartedly that her or his understanding of the latter has never influenced that of the former" (Bolt, 2005, p. 149).

Contents

Chapter 1: Introduction

As a disabled person,[1] ableism is the central obstacle that I have encountered throughout my life. It impacts everything from the way that literary and filmic representations of disability make me feel about myself, to the interactions that I have had with teachers, professors, and peers throughout my education. Even though disabled people have written for decades about the destructive effects discriminatory depictions of disabled characters in literature and other media have on us (Bolt, 2021; Longmore, 2003), only recently with the rise of social justice education within the language arts curriculum have the perspectives of minority students begun being taught in "culturally authentic" (Brown, 2020, p. 141) ways. Some examples of this scholarship include gender and sexual minority fiction (Helmer, 2015; Malo-Juvera, 2016), Indigenous novels, (Suhr-Sytsma, 2018), and multicultural literature (Bickmore & Clark, 2019, 2022; Ginsberg & Glenn, 2019), with many of these works being written by #Ownvoices authors.[2] Moreover, scholars of disability studies in education such as (Connor & Bejoian, 2007; Dunn, 2013) have suggested numerous approaches for teachers to use when teaching about disability in their language arts classrooms. However, the experiences of disabled students continue to be either absent from classroom discussions regarding the depictions of disability in literary texts or are communicated in problematic ways in the language arts classroom, which negatively impacts the educations of disabled students (Reid, 2010).

[1] Following the suggestion of O'Toole (2013), I have chosen to disclose my identity as a disabled person because it is important for scholars to identify ourselves when our personal experiences are relevant to our scholarship.

[2] The #Ownvoices movement was started by the young adult author Corinne Duyvis to draw attention to the works of writers who self-identify as members of the communities that they write about in their novels. #Ownvoices novels can be written from the perspectives of numerous identities such as those based on race, gender, sexual orientation, disability, and religion.

My Experience with Disability in Language Arts Education

From my earliest memories, my life has been filled with stories about disability and the socially constructed meanings that have been imposed on disabled people. Even though a small number of these texts, such as *Fanny* (Cosgrove, 2013) taught me as a young child to be independent and about the ableism and social stigma that I would encounter, most literary portrayals of disabled characters[3] that I read depicted disabled characters in deficit-based ways such as *Treasure Island* (Stevenson, 2017) in which the disabilities of the pirates were used to physically mark them as evil (Dolmage, 2014, p. 43). More worrisome, however, was that in school I was given problematic texts to read including, *Heidi* (Spyri, 1994), *The Cay* (Taylor, 2011), and *The Giver* (Lowry, 1993). Partly due to reading these narratives, I learned that being a disabled person is a negative societal difference which adversely impacted how I felt about myself as a disabled person.

The Rise of Contemporary Children's and Young Adult Literature in Language Arts Education

For decades canonical literature has been primarily taught in language arts education (Aston, 2020; Hill & Malo-Juvera, 2019). However, more recent scholarship suggests that teachers and teacher educators are beginning to include more contemporary children's and young adult literature in their language arts classrooms as bridges to the classics (Herz & Gallo, 2005), as canonical companions (Malo-Juvera et al., 2021), or as standalone novel studies concerning social justice issues, or to be more inclusive of historically silenced communities (Alsup, 2010;

[3] I have decided to follow the lead of Dunn (2015) in my use of the phrase "disabled characters" which she uses in two senses: first, when referring to characters that challenge ableist representations of disability and second, in reference to characters that reinforce deficit-based portrayals of disabled characters.

Hill & Malo-Juvera, 2019). Many of these contemporary children's and young adult novels incorporate disabled characters or themes related to disability (Dunn, 2015; Richmond, 2019; Wheeler, 2019).

The importance of teaching disability-themed children's and young adult literature in the language arts classroom is presented by Dunn (2015) who argues that:

> I believe that reading high-quality disability-themed fiction can begin to break down the us/them dichotomy so harmful in our society and reduce barriers to full accessibility. Discussions are critical. Done poorly, discussions, too, can reinscribe stereotypes. However, well-placed critical questions about what the text is doing can help readers identify harmful views and to comment on their appropriateness in a just world. (p. 2)

Dunn's (2015) work is critical to the objectives of my dissertation because she documents the necessity of teaching disability-themed children's and young adult texts in the language arts classroom, with the objective of teaching students how to critically examine the representations of disability that are presented in literature and other media. With this in mind, the two objectives of my dissertation are:

1. To identify how disabled first-person protagonists are represented in 12 disability-themed children's and young adult novels that are currently being taught in Ontario schools (Bates, 2017). (Refer to Appendix F).
2. To propose options and alternatives regarding inclusive children's and young adult novels that present disabled characters in a disability "culturally authentic" (Brown, 2020, p. 141) manner for teachers to use in their language arts classrooms as either canonical companions, or as standalone novel studies. (Refer to Appendices G and H).

Research Questions

Based on my previous negative experiences as a disabled student, due to the problematic ways that disability was portrayed throughout my language arts education, my dissertation will examine the following research questions:

- How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools?
- How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner?

In the context of my dissertation, contemporary literature refers to children's and young adult novels set in the present that were written between 1993 and 2015. I have deliberately used the words *contemporary* and *realistic* in my first research question, in order to exclude historical fiction as well as non-realistic genres such as fantasy and science fiction novels from my study, because doing so enables me to focus my analysis on disability-themed children's and young adult novels whose protagonists are portrayed in contemporary real-world settings instead of on characters who have fantastical impairments that do not exist in contemporary real world settings. The answers to my questions will build upon existing scholarship in critical disability studies, education, and English literature by critically examining the diverse ways that disabled first-person protagonists are depicted in the children's and young adult literature currently being taught in grades 7-12 in Ontario schools and by recommending enriched teaching methodologies

that focus on presenting disabled characters in a disability "culturally authentic" (Brown, 2020, p. 141) manner in schools.

Theoretical Perspectives

Historically, disabled people have been stigmatized and excluded from society due to our socially constructed differences from the abled norm. Two examples of early scholarship that have continued to be foundational to society's understanding of disabled people are the work of the sociologist Erving Goffman (2009, 2017) and the philosopher Michel Foucault (1988, 1989, 1990, 2012). Goffman and Foucault's scholarship has been built upon by numerous scholars in the field of critical disability studies including Davis (1995), Garland-Thomson (1997, 2009) and Tremain (2015, 2017), whose work documents the negative ways that disability has been historically socially constructed. The problem with disability having been negatively socially constructed is witnessed in Davis's (1995) work *Enforcing Normalcy*. In his text, Davis (1995) provides a detailed history of the word "normal" and how its antonym "abnormal" began to be applied negatively to disabled people. Davis (1995) argues, "…the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (p. 24). Garland-Thomson builds on Davis's (1995) scholarship when she explains:

> One goal of medical science is to cordon off the pathological from the normal. The pathological shores up the normal, which is 'the centre from which deviation departs,' according to Hacking (1990, 164). People who deviate from formal, functional, or behavioral norms lose the advantages of being normal. In this way, the label *abnormal* reduces people's economic and social status and relegates them to the outer edges of the human community. (2009, 31)

Davis (1995) and Garland-Thomson (2009) have highlighted the impact that socially constructing the normal/abnormal divide has on disabled people. Moreover, Goffman (2009) describes disability as being a socially discrediting trait which he explains as occurring "When there is a discrepancy between an individual's actual social identity and his virtual one" (p. 43). Goffman's definition can be applied to disabled people because our impairments have led us to be socially constructed as having a negative and highly stigmatizing form of physical or mental difference. This has been used to justify denying our normative status within society.

In Foucault's *The Birth of the Clinic* (1989) and *Discipline and Punish: The Birth of the Prison* (2012), he demonstrates how the medical and educational professions have socially constructed normative human health and educational standards based on the pathologizing gaze of medical professionals and teachers. Foucault (1989) shows how doctors used medical knowledge in the 19th century to socially construct normative human bodies that, in turn, pathologized and stigmatized disabled people. In *Discipline and Punish,* Foucault (2012) reveals how the normalizing power of the medical gaze has been applied to education when he writes, "The Normal is established as a principle of coercion in teaching with the introduction of a standardized education and the establishment of the … (teachers' training colleges)" (p. 184).

Foucault's work documents the development of the normalizing gaze along with its associated medical and educational discourses. Moreover, his work reveals the role that testing has played in the subsequent establishment of the normal/abnormal divide, the result of which has been the development of two unequal systems of education, one for abled students and the other for disabled ones. Allan (2015) applies Foucault's scholarship to the socially constructed divide between general and special education teacher preparation. One outcome of not "undertaking the radical reform of pedagogy" (Allan, 2015, p. 287) is the non-critical selection

of novels in language arts classrooms. This can be problematic as it can result in texts being chosen that portray disabled characters in deficit-based ways due to the way teacher preparation programs include content in relation to disability which can be informed by a medical model informed understanding of disability. Smith (2008) defines the medical model of disability as "… a fixed condition related to the severity of a medical impairment. Second, it incorrectly assumes that it is this medical condition, often defined as 'handicapped', which inevitably causes 'dependency' between disabled and non-disabled people" (p. 15). From this perspective, disability is considered to be a physical or cognitive deficit instead of a personal identity. The impact that the medical model of disability has on teacher education is witnessed by Brantlinger (2006) when she reviewed 14 popular special education textbooks and determined that 11 of them were written from a medical model perspective. Brantlinger (2006) concludes "those [textbooks] with categorical chapters [11 of 14] are firmly embedded in medical or deficit models [of disability]" (p. 55). The impact of this approach on teacher preparation regarding disability is described by Allan (2015) when she argues that teachers can "identify students by their deficits, but … [are] unable to recognize the kinds of barriers to the students' participation, which teachers themselves help to create through their own teaching practices" (p. 287). As Allan's (2015) work shows, the medical model informed understanding of disability that underpins many special education textbooks impacts the beliefs and teaching practices of educators. One solution to the pathologization of disability in teacher-education programs is to require faculties of education to include mandatory courses taught deliberately from a disability studies in education (DSE) perspective, in contrast to those which support the traditional deficit-based understanding of disability that have commonly been taught in teacher education programs. Teacher-education courses taught from a DSE standpoint can address the gaps in

teacher candidates' knowledge regarding disability by highlighting how pervasive ableism is in society from a social model perspective while demonstrating that being disabled can be an important aspect of disabled people's identities. For example, faculties of education can include content in teacher education programs on how to identify and challenge problematic representations of disabled characters in the language arts classroom, as part of inclusive pedagogy.

My dissertation will draw on the work of scholars from education (Andrews, 1998; Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001), critical disability studies (Barnes, 1992; Biklen & Bogdan, 1977; Connor, 2017; Dolmage, 2014; Quayson, 2007), and English literature (Monaghan, 2016), each of whom have published criteria for analyzing diverse representations of disability in literature and film.[4] It should be noted, however, that Mitchell and Snyder (2000) have previously critiqued the work of other scholars who have developed categorical criteria regarding the depictions of disability in literature and other media. Mitchell and Snyder describe this form of representational scholarship as belonging to "the negative image school … [because it] [slots] disability types into generic classifications and representational modes" (p. 20). For Mitchell and Snyder (2000), this scholarship is simplistic, in that it focuses solely on locating and identifying typologies of problematic representations of disability. Instead, Mitchell and Snyder argue that in order "to change the negative portrayals, [of disability] a powerful commentary was needed to make authors more self-conscious of the conventions at work in their own media" (p. 20). Mitchell and

[4] For a complete list of scholars who have developed comprehensive criteria for evaluating the depictions of disability in literature and other media see Chapter 3 and Appendix A.

Snyder (2000) suggest that, instead of focusing exclusively on finding and labelling deficit-based depictions of disability, academics could work with authors to change the way that disability is being depicted.

In response to the criticism by Mitchell and Snyder, my dissertation will go beyond locating and critiquing deficit-based portrayals of disabled characters by also examining and recommending disability "culturally authentic" (Brown, 2020, p. 141) depictions of disability in children's and young adult novels in the context of language arts education. Brown (2020) defines cultural accuracy as, "the aspect of culture is described within the realm of what would be realistically experienced" (p. 143). By including both deficit-based as well as disability affirming representations of disabled characters in my study, I will be providing teachers with diverse depictions of the disability experience.

Research Methods

The methodology of my study includes a combination of autoethnography (Lalvani, 2019), autocritical disability studies (Bolt, 2021; Marx, 2023), and critical inquiry based research methods (Charmaz, 2017; Flick, 2015). Autoethnography is described by Lalvani as, "… a qualitative research method in which researchers use their personal stories to explore particular social issues, through a connection of the stories to broader theoretical frameworks or academic literature" (2019, p. 7). The second research method that is vital to my methodology is autocritical disability studies, which Bolt (2021) defines as encouraging scholars to "recognize their experience at the very epistemological level of their methodology, the aim being to herald formal advancement from critical theory and critical disability theory to autocritical disability theory" (p. xviii). Moreover, Bolt (2021) provides a methodological approach that supports

scholars' autoethnographic engagement with literary, filmic, and other forms of cultural texts from an autocritical disability studies perspective when he states:

> Although apparently automatic, the assumed authority is underpinned by a displacement of personal narratives in favour of overarching metanarratives of disability that find currency in a diverse multiplicity of cultural representations – ranging from advertising to comics, drama to film, novels to soap opera, to social media to television, and so on. (p. xvi)

Bolt's (2021) autocritical disability studies scholarship is foundational to the methodology of my dissertation because his work highlights the vital connection between autoethnography and textual analysis from a critical disability studies perspective. For the purposes of my study, Bolt's autocritical disability studies scholarship is central to my analysis of the disability-themed children's and young adult novels that I will be critically examining in my dissertation because my research is located at the intersection of literary disability studies scholarship and my experiential and cultural knowledge of the disability community as a disabled reader of disability-themed texts. My use of an autoethnographic approach to literary disability studies has an extensive history prior to the development of autocritical disability studies (Bolt, 2021). For further examples, refer to Aveling (2009), Bolt (2014) and Keith (2001).

The final research method that underpins my study is critical inquiry, which Charmaz (2017) defines as:

> When I speak of critical inquiry, I include concerns and studies about social justice, although it is an ambiguous and elastic concept. In its various forms, critical inquiry addresses power, inequality, and injustice. … I see critical inquiry as embedded in a

> transformative paradigm that seeks to expose, oppose, and redress forms of oppression, inequality, and injustice. (p. 35)

Based on Charmaz's (2017) definition of critical inquiry, my study is concerned with the power that schools have as social institutions regarding the teaching of disability-themed content within the curriculum, as well as the pedagogies that are used while teaching disability-themed material in the language arts classroom. One example of this considers if the disability-themed content being taught in schools portrays disability in a deficit-based or in a disability affirming manner, as well as the impact that teachers' pedagogical choices have in the teaching of disability centric content in the language arts classroom (Reid, 2010; Ware, 2001, 2002).

In order to conduct my autocritical disability studies informed critical inquiry regarding the representations of the 12 disabled first-person protagonists whose depictions have met the inclusion criteria for my study, I have relied extensively on the diverse categorical scholarship within the fields of critical disability studies, English literature, and education regarding the representations of disabled characters in cultural texts. Some illustrations of these include Andrews (1998), Dolmage (2014), and Monaghan (2016). The publications of the previously cited scholars are essential to the methodology of my study because I have applied their diverse categorical scholarship relating to the representations of disabled characters to the 12 disability-themed children's and young adult novels whose protagonists have met the inclusion criteria of my study. Doing so has enabled me to address the first research question of my dissertation: How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools?

A final scholar whose literary disability studies scholarship informs my methodology is Bérubé (2015). Bérubé's work supports my methodology and text selection process due to his

assertion that literature "can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged with a specific diagnosis" (p. 19). Bérubé's argument is important to my text selection process because his work suggests that characters in literature do not require a medical diagnosis or to self-identify as disabled in order for them to experience social stigma and other forms of ableism. Therefore, I have chosen to include the experiences of characters in my study who have not received a formal diagnosis, such as Ally in *Fish in a Tree* (Hunt, 2015) or Melinda in *Speak* (Anderson, 2019), in addition to the experiences of characters who self-identify as disabled such as Melody in *Out of My Mind* (Draper, 2010) and Craig in *It's Kind of a Funny Story* (Vizzini, 2010).

Text Selection Process

Based on the work of Bates (2017), I began my study by determining which texts are being taught in grades 7-12 in Ontario schools. In her study, Bates identified 695 texts that were being taught in grades 7-12 in Ontario schools. To determine which texts from Bates' study met the inclusion criteria for my dissertation I read online summaries of each text from Amazon.ca and read online book reviews from Amazon.ca, Goodreads, and other websites to discover which narratives contained disabled characters. By analysing the texts in Bates' (2017) study, I initially located 39 children's and young adult novels that include disabled characters, which I reduced to five children's books and seven young adult novels that involve disabled first-person protagonists which were written between 1993 and 2015, based on the text selection procedure that I describe in Chapter 4. By following this procedure, I was left with the 12 children's and young adult novels from Bates' (2017) work that I have analysed throughout my study. The five children's novels that met my inclusion criteria are, *Out of My Mind* (Draper, 2010), *Fish in a Tree* (Hunt, 2015), *Word Nerd* (Nielsen, 2010), *Wonder* (Palacio, 2012), and *Freak the Mighty*

(Philbrick, 1993). The seven young adult novels that met my inclusion criteria include *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007), *Speak* (Anderson, 2019), *The Perks of Being a Wallflower* (Chbosky, 1999), *Fat Kid Rules the World* (Going, 2004), *The Fault in Our Stars* (Green, 2012), *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), and *It's Kind of a Funny Story* (Vizzini, 2010).

Having determined which children's and young adult novels would be included in my study, I needed to locate the criteria that I would use to evaluate the depictions of disability in each narrative. My search led to criteria that have been developed by scholars in education (Andrews, 1998; Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001), critical disability studies (Biklen & Bogdan, 1977; Connor, 2017; Dolmage, 2014; Quayson, 2007), and English literature (Monaghan, 2016).[5] After locating these criteria, I carried out my study by applying them to the representations of disability in the 12 children's and young adult novels that met my inclusion criteria. These results are the focus of Chapters 5 and 6.

Research Procedure

To conduct the critical inquiry-based research portion of my study relating to the representations of the 12 disabled first-person protagonists in the disability-themed children's and young adult novels taught in grades 7-12 in Ontario schools, I carried out the following procedure. First, I conducted an individual character study of each text's protagonist to determine how each author represented their disabled protagonist based on the categorical scholarship conducted by Andrews (1998), Biklen and Bogdan (1977), Carroll and Rosenblum

[5] For a complete list of the scholarship regarding the representation of disabled characters in literature and other media refer to Appendix A.

(2000), Connor (2017), Dolmage (2014), Hayden and Prince (2020), Kleekamp and Zapata (2018), Landrum (2001), Monaghan (2016) and Quayson (2007) in respect of the representation of disability in literary and other cultural texts. Second, I identified places within each narrative where the disabled protagonist either conformed to or subverted the categorical depictions of disabled characters, based on the work of the previously cited critical disability studies, English literature, and education scholars. Third, after I had located and evaluated the portrayals of each of the disabled first-person protagonists from a representational perspective, I determined how disability "culturally authentic" (Brown, 2020, p. 141) each character's depiction was from an autocritical disability studies (Bolt, 2021; Marx, 2023) perspective. I conducted an autocritical disability studies informed analysis of the 12 texts that met the inclusion criteria of my study, based on my experiential and academic knowledge of the disability community. Lastly, I concluded my study by identifying numerous common representational themes that were present across the 12 narratives in addition to the various categorical representations of disability within each novel. Some of these factors include the protagonist's race, socio-economic status, family structure, gender, and sexual identity, and whether each protagonist self-identifies as disabled within the narrative. Finally, I concluded my study by suggesting how teachers can apply the results of my analyses to language arts instruction.

Research Ethics

Approval for this study was sought from and granted by York University's Human Participants Review Sub-Committee. The Committee determined that my research contained minimal risk and subsequently approved my research ethics protocol on October 27th, 2022.

Chapter Outline

In Chapter 2, I describe the interdisciplinary theoretical framework I adopted for my study. The first theory that supports my work is the social constructivist approach to critical disability studies, based on the foundational scholarship of Foucault (1988, 1989, 1990, 2012) and Goffman (2009). Critical disability studies scholars whose work has been informed by Foucault and Goffman's scholarship include Allan (2015), Berger (2015), Brantlinger (2006), Davis (1995) and Garland-Thomson (1997). Second, I turn to two literary theories, the transactional theory of literature (Rosenblatt, 1995) and literary disability studies (Bérubé, 2015; Quayson, 2007). By combining critical disability studies informed social constructivist theories, literary theories, and education theories I have developed a strong interdisciplinary theoretical frame that will enable me to answer the question: How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? For the remainder of this chapter, I offer a detailed discussion of each of the previously described theoretical frames under the following headings: ● the binary social construction of ability/disability, ● Foucault's theories of power, normalization, and social control, ● Goffman's stigma theory, ● the application of Goffman's stigma theory by critical disability studies scholars, and ● Rosenblatt's transactional theory of literature, to illustrate how each theoretical frame informs the work that I will undertake in future chapters. In Chapter 3, I set the context for my study by reviewing the literature regarding the representation of disability in the fields of critical disability studies (Biklen & Bogdan, 1977; Connor, 2017; Dolmage, 2014; Quayson, 2007), education (Andrews, 1998; Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001), and English literature

(Monaghan, 2016).[6] My investigation and application of this scholarship have been supported by examples of the disability-themed children's and young adult novels that were taught by my teachers in their language arts classes, such as *Heidi* (Spyri, 1994), *The Cay* (Taylor, 2011) and *The Giver* (Lowry, 1993). This literature is central to the work that I have undertaken in this study because I have used it as the vehicle of analysis when investigating how disabled first-person protagonists are depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools. The literature that I have reviewed in this chapter is organized as follows: representational categories in critical disability studies scholarship (Biklen & Bogdan, 1977; Connor, 2017; Dolmage, 2014; Quayson, 2007), and categorizing depictions of disability in education and literary scholarship (Andrews, 1998; Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001; Monaghan, 2016).

In Chapter 4, I describe my methodology. My interdisciplinary methodology includes autoethnography (Lalvani, 2019), autocritical disability studies (Bolt, 2021; Marx, 2023), and critical inquiry (Charmaz, 2017; Flick, 2015). This chapter also outlines the process used to select the novels included in my study from Bates' (2017) data, the method used to locate the criteria applied to the depictions of disability in each text, and the procedure followed while conducting my study. Lastly, I will conclude this chapter by discussing the ethical implications of my project.

In Chapter 5, I begin to address the first research question of my study: In what ways are disabled first-person protagonists depicted in the contemporary realistic children's and young

[6] For a complete list of the scholarship regarding this criteria refer to Appendix A.

adult literature that is being taught in grades 7 through 12 in Ontario schools? To conduct my analysis, I applied the criteria that I critiqued in Chapter 3 regarding the representations of disabled characters in literature to the five disability-themed children's novels from Bates' (2017) data that met my inclusion criteria. The children's novels whose first-person protagonists have been examined in this chapter are Max in *Freak the Mighty* (Philbrick, 1993), Ambrose in *Word Nerd* (Nielsen, 2010), Melody in *Out of My Mind* (Draper, 2010), August in *Wonder* (Palacio, 2012), and Ally in *Fish in a Tree* (Hunt, 2015). I begin my analysis by considering each text's protagonist as an independent character study based on their depiction as a disabled character. I conclude the chapter by discussing the common representational themes that I have located across the five narratives, together with the protagonist's family demographic and identity information.

In Chapter 6, I continue examining the first research question of my study: In what ways are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? To carry out my analysis, I have applied the criteria that I critiqued in Chapter 3 regarding the depictions of disabled characters in literature to the seven disability-themed young adult novels from Bates' (2017) data that met my inclusion criteria. The young adult novels whose protagonists I have analysed in this chapter are: Melinda in *Speak* (Anderson, 2019), Charlie in *The Perks of Being a Wallflower* (Chbosky, 1999), Troy in *Fat Kid Rules the World* (Going, 2004), Christopher in *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), Craig in *It's Kind of a Funny Story* (Vizzini, 2010), Arnold in *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007), and Hazel in *The Fault in Our Stars* (Green, 2012). When evaluating the depiction of disability in each text, I initially consider each novel's protagonist as an independent character

study based on their portrayal as a disabled character. I conclude the chapter by identifying the common representational themes that were present across the seven narratives, as well as documenting the protagonist's family demographic and identity information.

In Chapter 7, I address the second research question of my study: How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner? In order to examine this question I show how "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) such as those developed by Aronson et al., (2016), Gay, (2018), Ladson-Billings (1995), and Savage et al., (2011) can be applied in the middle-grade language arts classroom while teaching the disability-themed children's novel *A Kind of Spark* (McNicoll, 2020) in a disability affirming manner from a disability studies in education perspective. In addition to the content that I present in this chapter, I have designed a disability studies in education informed unit outline using the middle grade novel *A Kind of Spark* (McNicoll, 2020) as its central text in Appendix I.

In Chapter 8, I present and discuss the findings of my study, and make recommendations regarding teacher preparation as well as future scholarship in literary disability studies and disability studies in education. Lastly, I conclude this chapter by discussing the limitations of my study.

Conclusion

In this chapter, I have introduced the central themes on which I will elaborate in future chapters of my study under the following headings: (a) my experience with disability in language arts education, (b) the rise of contemporary children's and young adult literature in language arts education, (c) research questions, (d) theoretical perspectives, (e) research methods, (f) text

selection process, (g) research ethics, and (h) chapter outline. Each of these is vital to my study as they highlight the theoretical framework, literature reviewed, and research methods that serve as the foundation of my study, as well as introducing the disability-themed children's and young adult novels whose protagonists I will critique in future chapters, in addition to the procedure used to carry out my analysis. In the next chapter, I will describe the theoretical framework that underpins my study.

Chapter 2: Theoretical Framework

In this chapter I present the interdisciplinary theoretical framework that I will use to address the depictions of disability in fiction and education throughout my study. The first theory that underpins my work is the social constructivist approach to critical disability studies scholarship that is based on the foundational work of Foucault (1988, 1989, 1990, 2012) and Goffman (2009). Critical disability studies scholars whose work has been influenced by Foucault and Goffman's scholarship include Allan (2015), Brantlinger (2006), Davis (1995) and Garland-Thomson (1997). Second, I turn to two literary theories: the transactional theory of literature (Rosenblatt, 1995) and literary disability studies (Bérubé, 2015; Quayson, 2007).

The Binary Social Construction of Ability/Disability

Disabled people's lives are more complex and intersectional than the phrase "abled/disabled divide" indicates, which has been demonstrated by scholars working at the intersections of race and disability (Erevelles, 2011; Schalk, 2022), gender and disability (Hall, 2011; Tremain, 2017) and sexuality and disability (Kafer, 2013; McRuer, 2006) whose scholarship present a more nuanced and intersectional perspective regarding the lives of disabled people. I have chosen to discuss ability and disability in binary terms because I will be responding to the socially constructed binary societal perceptions regarding the representations of disability in children's and young adult literature throughout my dissertation. Additionally, I have used the phrase "abled/disabled divide" to differentiate not only between abled and disabled individuals or the fictional characters in my study, but also between fictional characters who consider being disabled to be an important aspect of their identity such as Melody in *Out of My Mind* (Draper, 2010) whose experience and identity as a disabled character can be contrasted with Melinda's representation in *Speak* (Anderson, 2019) who does not self-identify as disabled

even though I argue throughout my dissertation that she is living with an undiagnosed mental health disability. Real-world parallels to this distinction can also be shown between Deaf individuals who participate in the Deaf community and for whom being culturally Deaf is a part of their identity and deaf individuals who do not participate in the Deaf community or consider deafness to be part of their identity (Padden & Humphries, 2005). A similar cultural divide is also present between autistic people for whom being autistic and participating in the neurodiversity movement are central aspects of their identity, in contrast to individuals for whom living with autism is not part of their identity (Kapp, 2020).

Two prominent examples of the binary social construction of disability in cultural texts are the "kill or cure" and the "overcoming or compensation" (Dolmage, 2014, pp. 43-44) depictions of disability. One example of the "kill" representation of disability in literature occurs in John Steinbeck's 1937 novel *Of Mice and Men* in which Lennie Small, who has a developmental disability, is murdered. The "kill" representation of disability has been critiqued by Haller (2010) and Longmore (2003) who have argued that these cultural texts suggest that the lives of disabled people are not worth living. In contrast, the "cure" response to disability suggests society's preference for what McRuer (2006) describes as "compulsory able-bodiedness" (p. 2).[7] This results in disabled characters either receiving miracle or medical cures for their impairments (Dunn, 2015; Keith, 2001) or must engage in "passing" (Goffman, 2009, p. 74) in order to conceal their disabilities. In cure-based narratives, disabled characters receive

[7] Robert McRuer defines "compulsory able-bodiedness" as: I put forward here a theory of what I call "compulsory able-bodiedness" and argue that the system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: that, in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa (McRuer, 2006, p. 2).

either miracle or medical cures, usually at the conclusion of the text such as in *The Secret Garden* (Burnett, 1988) where Collin receives a miracle cure. By doing so, many disabled characters in literature and other media are transformed into stereotypical supercrips or inspirational disabled characters, both of which are problematic portrayals of disability (Grue, 2016; Schalk, 2016: Wheeler, 2019). Wheeler (2019) defines the term supercrip as "a hero with a disability who performs astonishing and admirable feats" (p. 70). One example of this portrayal of disability is the way in which the media depicts Paralympic athletes. Moreover, Grue (2016) defines inspiration porn as "… the representation of disability as a form of disadvantage that can be overcome for the titillation of other people/observers" (p. 838). One example of this occurs in *Wonder* (Palacio, 2012, p. 93) when August receives the Henry Ward Beecher Medal, which I discuss in greater detail in Chapter 5.

In the real world, disabled people's identities and impairments are not necessarily static, for instance, those who experience episodic disabilities (Vick, 2014) or those who live in inclusive communities, for example Martha's Vineyard during the 19th century when hereditary deafness was so common that "*Everyone here spoke sign language*" (Groce, 2003). However, the spectrum of ability is not widely communicated in literary or other cultural representations of disability due to the pervasiveness of the medical model of disability that pathologizes disabled people (Smith, 2008). Consequently, disabled individuals are often viewed by abled people as having a highly stigmatizing master status due to the pathologization of disability (Goffman, 2009, pp. 9-16). This understanding of disability presents individuals' impairments as being not only a negative and socially stigmatizing trait but also the defining characteristics of their identities. This representation of disability is present in literature and film in binary terms where the "kill or cure" trope is used (Dolmage, 2014, p. 43). In these cases, ability and disability are

presented as being polar opposites on the socially constructed spectrum of normalcy, which denies the personal value and complexity of disabled people's lives (Davis, 1995). Thus, throughout my dissertation, I will respond to the binary social construction of ability/disability by demonstrating that the binary portrayals of disability in literary works are oversimplifications that fail to communicate the diversity and complexity of disabled people's experiences.

Foucault's Theories of Power, Normalization, and Social Control

Michel Foucault's scholarship critically examines the historical development of institutions as sources of power and social control. In his genealogical examination of institutions of power, Foucault unearths the historical and philosophical underpinnings of the religious, political, correctional, educational, and medical institutions. The scientific, medical, and academic discourses deployed by these institutions, Foucault claims, are used to construct normativity while serving socially and fictionally as instruments of social control over individuals who are labelled as socially deviant, including disabled people. Foucault's theories of bio-power, normalization, and social control, in particular, support my examination of how disability is socially constructed in the historical context of public Canadian schools as normalizing institutions.

In *The Birth of the Clinic* (1989) and *Discipline and Punish* (2012), Foucault documents the rise of the normalizing gaze within the medical and educational professions which, in turn, led to the socially constructed divide between abled and disabled people. Foucault describes the pathologizing gaze of medical professionals as,

> First, it was no longer the gaze of any observer, but that of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention. Moreover, it was a gaze that was not bound by the narrow grid structure

> (form, arrangement, number, size), but that could and should grasp colours, variations, tiny anomalies, always receptive to the deviant. Finally, it was a gaze that was not content to observe what was self-evident; it must make it possible to outline the chances and risks; it must be calculating. (Foucault, 1989, p. 109)

Foucault (1989) also describes the increased authority given to doctors by the State to determine the statistically average norms regarding human biological functioning and to pathologize individuals whose physical or mental profiles deviated from the socially constructed norms.

The impact of the diagnostic gaze causes individuals whose bodies or minds failed to conform to socially constructed norms to be pathologized and labelled as abnormal. Foucault applies this pathologizing gaze to the field of education in *Discipline and Punish* (2012) where he shows how the development of normative education standards in schools led to students being labelled. He writes,

> the examination combines the techniques of an observing hierarchy and those of normalizing judgment. It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates and judges them. (p. 184)

The normalizing gaze remains a prevalent measure of cognitive and physical ability in the medical and education professions.

In *The Birth of the Clinic* (1989), *Discipline and Punish* (2012), and *The History of Sexuality: An Introduction* (1990), Foucault argues that the rise of socially constructed standards of normalcy was accompanied by the professionalization of medicine, education, and

correctional occupations. Foucault describes the rise in credentialization of these professions as "the era of bio-power" (Foucault, 1990) when he explains:

> During the classical period, there was a rapid development of various disciplines – universities, secondary schools, barracks, workshops; there was also the emergence, in the field of political practices and economic observation, of the problems of birthrate, longevity, public health, housing and migration. Hence there was an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations, marking the beginning of an era of 'bio-power'. (p. 140)

With the rise of bio-power and normalization came the reappropriation of asylums and similar institutions (for example, prisons, hospitals, and schools) as sites of social control. In *Madness and Civilization* (1988) Foucault provides an intellectual and philosophical history of Western society's surprisingly informal and accepting beliefs about, and responses to, mental illness from 1500 to 1900. However, rather than fashioning institutions with this benevolence in mind, Foucault outlines how asylums became institutions for controlling social deviants. He explains:

> John Howard, at the end of the eighteenth century, undertook to investigate … chief centers of confinement 'hospitals, prisons, jails' – and his philanthropy was outraged by the fact that the same walls could contain those condemned by law, young men who disturbed their families' peace or squandered their goods, people without profession, and the insane. (Foucault, 1988, pp. 54-55)

Foucault argues that institutions such as prisons, psychiatric hospitals, and workhouses that were originally designed to serve different purposes became universal establishments for the surveillance, conformance, discipline, punishment, and control of social deviants.

Contemporary sociologists and historians have adapted Foucault's theories of bio-power, normalization, and social control in the context and history of Canadian schooling. McLaren (2014) explains that by developing normative educational standards, teachers were given the authority to determine students' educational standing. When combined with compulsory school attendance laws in the late 19th and early 20th centuries, more Canadian students received disability diagnoses and labels due to the increased surveillance of children in schools. McLaren (2014) writes:

> The shift of attention toward the needs of the retarded (sic) was in part a direct result of their being 'discovered' by teachers as mass education was made compulsory. One of the unexpected consequences of the greater attention given to the care and rearing of children in the early twentieth century was the establishment of arbitrary norms of intellectual achievement. Those who did not meet them were increasingly viewed not simply as unfortunate but as a real "menace" to the normal. (McLaren, 2014, "Public Health and Hereditarian Concerns", para. 30)

To illustrate the role that teachers played in the enforcement of the normal/abnormal divide from the 1920s to the 1980s, teachers in Alberta were required to administer I.Q. tests which resulted in large numbers of students being removed from public schools and placed in institutions (Samson, 2014). Even though parents were told that their child would receive an excellent education, most children who entered institutions received minimal or no schooling. Sociologist Malacrida (2015) explains:

> Although training and education were the given reasons for the existence of PTS (renamed the Michener Centre in 1977), in fact, eugenic concerns played a central role in establishing and sustaining the institution … The lifelong internment of "mental

> defectives" in a virtual fortress set at distance from a small rural town, and the reportedly almost obsessive sex segregation within the institution, functioned as a passive form of eugenics; defective individuals segregated in these ways posed little risk of polluting the social body with their presumed genetic taint. (Malacrida, 2015, p. 4)

Samson (2014) and Malacrida (2015) show how the use of I.Q. testing in schools led to the removal of disabled children from public education (Ellis, 2013). Prior to the enactment of laws such as Ontario's 1980 Education Act, which gave disabled students access to public schools, disabled students were placed in residential schools, disability-specific day schools, or residential institutions (Ellis, 2019; Hodder, 1984). However, in many cases, disabled students were provided with an inadequate education while these placements served as tools of state sanctioned segregation, rampant abuse, and exclusion (Malacrida, 2015; Rossiter & Rinaldi, 2018). Thus, Samson's (2014) and Malacrida's (2015) work demonstrates how Foucault's scholarship regarding the professionalization of medicine, education, and corrections, as well as his theories of bio-power and the normalizing gaze, were applied to disabled people in Canada during the 20th century.

Scholars have also applied Foucault's (1988, 1990, 2012) theories of bio-power, segregation, and social control to the historical education of disabled students, with Berger's (2015) work highlighting the dual roles that 19th-century residential schools for the deaf played as both educational facilities and locations of normalization. Berger (2015) concludes her chapter by providing a Foucauldian analysis of the power and normalizing structures that existed in 19th-century schools for the deaf (and, I would argue, other residential special education schools) when she states:

> Foucault (1977) points out that schools in general perform disciplining functions by preparing pupils for economic utility and political obedience. Institutions for the deaf surpassed these disciplining functions. Institutions taught deaf youth that, although they were deficient, they might escape their stigma if they diligently conformed to mainstream values. (p. 168)

By linking the alleviation of social stigma with correct societal norms, Berger's work demonstrates the normalizing function of schooling as a tool of bio-power whereby deaf students (and, I would suggest, other disabled people) are required to overcome our impairments to participate in society. However, instead of requiring disabled individuals to overcome the social stigma that we experience, schools could serve as inclusive spaces where social stigma is challenged, and disability is presented as a "mere-difference" (Barnes, 2016, p. 7) through the use of inclusive education policies and practices (Valle & Connor, 2019).

Two scholars who have applied Foucault's (1988, 1990, 2012) theories to more recent debates on inclusive education are Brantlinger (2006) and Allan (2015). It is important to discuss how Foucault's work has been applied within the field of inclusive education because his work highlights the forms of institutional power that teachers have in their classrooms regarding the education that their students receive in relation to disability. Brantlinger (2006) examines the deficit-based philosophies regarding the education of disabled students in 14 special education textbooks, which include the authority to identify, label, normalize, or exclude students. She begins her Foucauldian analysis of special education textbooks by revealing how Foucault's concepts of "hierarchical observation, normalizing judgments, and examination" (p. 64) are emphasised. She claims that these methods of research, combined with the assumed state authority granted to special education teachers, gave way to 'expert determinations' that worked

to place students on the continuum that constitutes the normal/abnormal divide. Further, Brantlinger (2006) finds that "the inevitable rationale for surveillance, modification, and exclusion is that it is necessary for the sake of the involved children – for their own good" (p. 65). Brantlinger (2006) does not discuss Foucault's (1990) concept of bio-power; however, she does mention that special education teachers have extraordinary powers to determine the educational lives of disabled students through exclusionary practices, such as denying them access to grade-appropriate curricula, and other deficit-based interventions. Thus, Brantlinger (2006) suggests that,

> … teacher education courses and textbooks are the vehicles that socialize preservice teachers into their roles of recognizing defiance, making expert judgments about normality, conducting examinations, and implementing appropriate instruction. Appropriate, like normality, is a key concept in special education; practitioners and clients do things appropriately – that is, according to the norm. (p. 65)

By preparing preservice educators to make normalizing judgments and to provide educational interventions, traditional special education textbooks such as the ones that Brantlinger examines in her study, reinforce the pathologization of disabled students. These texts train educators to adopt deficit-based mindsets with accompanying normalizing interventions for the purpose of "remediating (fixing) other people's children" (Brantlinger, 2006) without considering the perspectives of the students who are undergoing these interventions. As a result of the deficit-based approaches to disability in their preparation programs, Allan (2015) argues that,

> in many teacher-training establishments, *inclusive education* has provided traditional special educators with a publicly acceptable base from which 'the teacher-training

> imperative' (Slee, 2001, p.173) can be perpetuated. This reconfiguring of teacher training is done without undertaking the radical reform of pedagogy that inclusion requires; furthermore, this form of teacher-training continues to shape the teacher into a 'card carrying designator of disability' (Slee, 2001, p.171) who is able to identify students by their deficits but is unable to recognize the kinds of barriers to students' participation, which teachers themselves helped to create through their own teaching practices. (p. 287)

Along with critiquing the preparation of special education teachers, her chapter demonstrates the impact that the deficit-based discourses of disability in teacher education programs have on teachers' understanding of disability. Her study finds that teachers exit their preparation programs with a detailed knowledge of students' impairments and remedial strategies but have a limited understanding of the impact that these educational practices have on students. Instead, Allan (2015) suggests that inclusion could be considered as an ethical project from a Foucauldian perspective:

> While Foucault's example of ethical practice is directed toward a kind of sexual austerity, the practice itself can be viewed as a means with which to promote inclusion that recognized disabled students' desires, in addition to their needs. This work to recognize students' desires and needs is not only ethical; it is also a political, social, and philosophical endeavor that is put into practice through a kind of 'curiosity'. (p. 285)

By focusing on both the needs and the desires of disabled students, Allan's (2015) ethical engagement with inclusive education from a Foucauldian standpoint offers a critical disability studies approach to education. Critical studies of disability (rather than expert designations) might produce in teachers an informed response to the deficit-based philosophy that underpins special education preparation programs while challenging the expert knowledge that is present in

special education by including the perspectives of disabled students. The impact of using a student-centred approach to teaching disabled students serves as a powerful corrective against the pathologization of disability by providing disabled students with agency regarding the services that we receive, which could lead to necessary reforms in curriculum content.

Goffman's Stigma Theory

Erving Goffman's (2009) publication *Stigma*: *Notes on the Management of Spoiled Identity* is a foundational text in the field of sociology due to its detailed examination of the experiences of stigmatized individuals. For my purposes, Goffman's (2009) text describes the normal/abnormal divide and highlights the negative social impacts encountered by socially stigmatized people on numerous grounds, with my focus being on the exclusion and marginalization of disabled people. Even though Goffman (2009) famously states that,

> … while some of these norms, such as sightedness and literacy, may be commonly sustained with complete adequacy by most persons in the society, there are other such norms, such as those associated with physical comeliness, which take the form of ideals and constitute standards against which almost everyone falls short at some stage in life and even widely attained norms are involved in their multiplicity has the effect of disqualifying many persons. For example, in an important sense there is only one complete unblushing male in America: a young, married, white, urban, northern, heterosexual, Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports. (p. 129)

In his previous statement, Goffman (2009) demonstrates how achieving the socially constructed norms (e.g., statistically average human functioning) is unattainable, while at the same time contradictorily being the minimal societal expectation of normalcy (Davis, 1995).

This results in the social construction of a spectrum of normalcy on which everyone's level of normativity is displayed. The impact of these normalizing judgments is the labelling and stigmatization of individuals and communities based on where each one has been placed on the spectrum between being perceived as having a normal or abnormal identity. Based on our pathologization, disabled people are a highly stigmatized group within society as a result of our physical or cognitive differences from the socially constructed norm. Earlier in his text, Goffman (2009) documents how the social stigma that disabled people experience occurs in public schools, as well as being one of the justifications for special education institutions. He argues:

> Thus, public school entrance is often reported as the occasion of stigma learning, the experience sometimes coming very precipitously on the first day of school, with taunts, teasing, ostracism, and fights. Interestingly, the more the child is "handicapped" the more likely he is to be sent to a special school for persons of his kind, and the more abruptly he will have to face the view which the public at large takes of him. He will be told that he will have an easier time of it among "his own", and thus learn that the own he thought he possessed was the wrong one, and that this lesser own is really his. (p. 33)

Based on my experience as a disabled student I agree with Goffman's (2009) conclusion that public education plays a significant role in constructing, reproducing, and circulating the social stigma experienced by disabled people. In my case, however, it was not the bullying of my classmates that led to my being perceived as different but rather the exclusionary practices of the school which led to my stigmatization. For example, I was not allowed to play on the playground with my classmates during recess because the teachers were afraid that I would get hurt. Thus, I was isolated from my peers who consequently socially constructed me as different, which led to me experiencing social stigma and exclusion. Even though my teachers desired to protect me

from physical injury while playing on the playground, their actions unintentionally taught me that I was physically different from my peers which negatively impacted my ability to form social relationships with my classmates and to being socially stigmatized. This, along with other factors, led my parents to enrol me in a residential special education school.

The Application of Goffman's Stigma Theory by Critical Disability Studies and Literary Scholars

Goffman's stigma theory (first proposed in 1963) has been expanded by critical disability studies scholars to demonstrate that society's understanding of disability has been socially constructed by cultural discourses and representations of disabled people. In *Enforcing Normalcy*, Davis (1995) shows how the normal/abnormal divide has been socially constructed using statistics and eugenics. The major outcome of this led to disabled people being perceived as deviant and pathologized due to our physical and cognitive differences from the socially constructed norm. Davis (1995) describes the impact of society's transition from thinking of human bodies as being ideal to those based on the statistical norm when he writes,

> with the concept of the norm comes the concept of deviations or extremes. When we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants. This, as we have seen, contrasts with societies with the concept of an ideal, in which all people have a non-ideal status. (p. 29)

With the rise of statistics and its subsequent application to human beings, Davis's scholarship communicates how humanity's socially constructed understanding of disability changed from being a common part of the human experience to being a stigmatized and pathologized form of socially constructed otherness. Therefore, disability became a threat to the abled norm or, as Davis explains, "…the problem is the way that normalcy is constructed to

create the 'problem' of the disabled person" (p. 24). Not only was the social threat posed by disabled people socially constructed using statistics and eugenics, but the proponents of human perfectibility used cultural tools such as literature, advertising, and film to stigmatize and pathologize disabled people by presenting disabled characters in deficit-based ways (Longmore, 2003, 2016; Smith, 2011). Further, Davis (1995) argues that literature plays a central role in constructing society's understanding of abled and disabled people when he explains:

> In thinking through the issue of disability, I have come to see that almost any literary work will have some reference to the abnormal, to disability and so on. I would explain this phenomenon as a result of the hegemony of normalcy. This normalcy must constantly be enforced in public venues (like the novel), must always be creating and bolstering its image by processing, comparing, constructing, deconstructing images of normalcy and the abnormal. In fact, once one begins to notice, there really is a rare novel that does not have some characters with disabilities. (pp. 43-44)

By highlighting the role that literature has in the fictional social understanding of and responses to disability and disabled people, Davis's (1995) text illustrates the representational power of fiction when it comes to developing and maintaining the socially constructed divide between abled and disabled people.

A second critical disability studies scholar whose work has built upon Goffman's (2009) stigma theory is Garland-Thomson (1997). In her (1997) text, *Extraordinary Bodies*, Garland-Thomson highlights the impact that stigmatization has on society's beliefs about disabled people when she states:

> Stigma theory is useful, then, because it untangles the processes that construct both the normative as well as the deviant and because it reveals the parallels among all forms of

> cultural oppression while still allowing specific devalued identities to remain in view. It essentially resituates the 'problem' of disability from the body of the disabled person to the social framing of that body. (p. 32)

By demonstrating the negative power that social stigma has on individuals labelled as disabled, Garland-Thomson's (1997) work reveals not only the cause of the societal othering that disabled people experience but also how it can be addressed. One example of this would be to require that teachers critique the messages that abled and disabled students receive about disability in schools. By doing so, teachers are challenging the uncritical use of language arts texts that portray disabled characters in a deficit-based manner, which can negatively impact the interactions between abled and disabled people (Cameron & Rutland, 2006; Connor & Bejoian, 2007).

Garland-Thomson (1997) applies Goffman's (2009) stigma theory in a second way. She argues that the socially constructed representations of disabled characters have real-world consequences regarding the relationships between abled and disabled people. She writes:

> If we accept the convention that fiction has some mimetic relation to life, we grant it power to further shape our perceptions of the world, especially regarding situations about which we have little direct knowledge. Because disability is so strongly stigmatized and is countered by so few mitigating narratives, the literary traffic in metaphors often misrepresents or flattens the experience real people have of their own or others' disabilities. (p. 10)

Here, Garland-Thomson (1997) shows how literary representations of disabled characters impact the assumptions and beliefs that abled people have about disabled people. This has

resulted in the ongoing proliferation of deficit-based beliefs within Western culture relating to disability and disabled people.

To buttress her argument, Garland-Thomson (1997) documents numerous examples of ableism in classic literature that reinforce society's prejudicial beliefs and attitudes regarding disabled people. She writes:

> Most disabled characters are enveloped by the otherness that their disability signals in the text. Take, as a few examples, Dickens's pathetic and romanticized Tiny Tim of *A Christmas Carol*, J. M. Barrie's villainous Captain Hook from *Peter Pan,* Victor Hugo's Gothic Quasimodo in *The Hunchback of Notre Dame,* D. H. Lawrence's impotent Clifford Chatterley in *Lady Chatterley's Lover*, and Tennessee Williams's long-suffering Laura Wingfield from *The Glass Menagerie.* The very act of representing corporeal otherness places them in a frame that highlights their differences from ostensibly normate readers. … Consequently, literary texts necessarily make disabled characters into freaks, stripped of normalizing contexts and engulfed by a single stigmatic trait. (p. 10)

Throughout her previous citation, Garland-Thomson (1997) illustrates not only the prevalence of harmful depictions of disability in canonical literature but also the power that deficit-based literary depictions have on the socially constructed understandings that abled people have regarding disabled people. The impact of this is witnessed when abled people apply the one-dimensional character traits that they read about in fiction to the disabled people that they interact with in the real world. This results in the widespread adoption of myths regarding disabled people by abled individuals which are used to create social, educational, and economic policies that deny instead of protecting the rights of disabled citizens.

Quayson (2007) is a third critical disability studies scholar influenced by Goffman's (2009) work. In Quayson's (2007) text, *Aesthetic Nervousness*, he proposes a theory of aesthetic nervousness which I have interpreted as being the physical, emotional, and social discomfort that abled characters experience when they interact with disabled characters in literary narratives. Quayson's (2007) work demonstrates the vital role that textual interactions have between abled and disabled characters and how these encounters mirror the social engagements between abled and disabled people. By arguing that the literary encounters between abled and disabled characters mirror the social interactions between abled and disabled people in the real world, Quayson's scholarship highlights the important role that imaginative textual encounters have when it comes to establishing and strengthening readers' beliefs about disabled people in society. Moreover, in this study, I consider these essential literary moments between disabled and abled characters, as well as between disabled characters and the implied abled readers, as being representative of what Goffman refers to as "one of the primal scenes of sociology" (2009, p. 13) because these fictional encounters can be representative of the real-world interactions that occur between socially stigmatized and non-stigmatized individuals. When disabled characters are portrayed in a deficit-based manner, abled readers who may unknowingly hold discriminatory beliefs about disability experience a pleasure of recognition that reinforces those beliefs while further alienating and distancing the oppression experienced by disabled people.

Bérubé (2015) is a literary critic who also supports my framings when he argues that characters in literature and other media do not need to self-identify as disabled, or have received a formal medical diagnosis, to experience the social stigma and other barriers that are associated with being disabled. Bérubé's (2015) scholarship also critiques Quayson's (2007) theory of aesthetic nervousness when he argues that fiction can explore themes related to disability without

needing characters to self-identify as disabled in the narrative. Bérubé (2015) explains, "[literature] can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged with a specific diagnosis" (p. 19). Moreover, Bérubé's (2015) work highlights one significant limitation of Quayson's (2007) theory of aesthetic nervousness because his work assumes that a disabled character's impairment is visually apparent which precludes the experiences of characters with invisible disabilities. Thus Bérubé's (2015) scholarship is central to my analysis of the disability-themed children's and young adult literature conducted in Chapters 5 and 6 because his ideas invite me to examine the institutional and stigmatizing responses to sexual violence that Melinda experiences in *Speak* (Anderson, 2019), without her being diagnosed with a mental health disability. Likewise, I am able to study the experiences of disability conveyed by Ally in *Fish in a Tree* (Hunt, 2015) who is suspected of having a learning disability but is not formally diagnosed in the text. Moreover, Bérubé's (2015) work is important for my study because it brings into the conversation how disability discourse is deployed against those who have not been medically diagnosed by refusing to read "a literary text in one hand and the DSM-5 in the other, even when a text explicitly announces that one or more characters is (for example) on the autism spectrum" (Bérubé, 2015, p. 20).

Rosenblatt's Transactional Theory of Literature

Rosenblatt (1995) is a pioneer of literacy and reading practice in the field of Education. Her 1995 transactional theory of literature posits that, "the meaning – [of] the poem – 'happens' during the transaction between the reader and the signs on the page" (p. 1). Rosenblatt's work is vital to the teaching and learning of students in language arts classrooms because her scholarship

demonstrates that every reader's response to literature is individualized based on their identity, lived experience, and the content of the text.

More recently, education scholars have applied Rosenblatt's (1995) transactional theory of literature to language arts education, such as the work of Appleman (2015), and Alsup (2010, 2015). However, to my knowledge, no education scholars have applied Rosenblatt's (1995) transactional theory to teaching disability-themed literature in schools. Even though his work does not address representations of disability in language arts education, Quayson's (2007) literary disability studies scholarship also draws on Rosenblatt's (1995) transactional theory of literature while presenting his theory of aesthetic nervousness which Quayson (2007) defines as,

> aesthetic nervousness is seen when the dominant protocols of representation within the literary text are short circuited in relation to disability. The primary level in which it may be discerned is in the interaction between a disabled and nondisabled character. … The final dimension of aesthetic nervousness is that between the reader and the text. (p. 15)

Using the constructs of affect and anxiety, Quayson's (2007) work builds on Rosenblatt's (1995) transactional theory of literature. To do so, Quayson (2007) describes the literary interactions that occur between abled and disabled characters as well as between abled and disabled readers and the literary work. By revealing the literary transactions between abled and disabled readers and their literary counterparts, Quayson uses literature to make examinable the often silenced or erased daily interactions between abled and disabled people in the real world. By doing so, Quayson's (2007) work gives both abled and disabled readers the opportunity to think about, reflect on, and alter their real-life experiences and views based on interactions taking place between their fictional counterparts. Through reading about the fictional interactions between abled and disabled characters, disabled readers may find a vocabulary to advocate for

their experiences. Abled readers may reconsider their assumptions and attitudes towards disability and disabled people in the real world. Most importantly, literature can support disabled readers to experience recognition when reading fictional mirrors of themselves portrayed as complex persons.

Conclusion

In this chapter, I have addressed how society's understanding of disability has been socially constructed, based on the foundational scholarship of Foucault (1988, 1989, 1990, 2012) and Goffman (2009). Moreover, I have demonstrated that Foucault and Goffman's scholarship has been applied by critical disability studies scholars to literary studies (Bérubé, 2015; Davis, 1995; Garland-Thomson, 1997; Quayson, 2007) and education (Allan, 2015; Berger, 2015: Brantlinger, 2006). This connection is critical to my analysis of the disability-themed children's and young adult novels that are being taught in grades 7-12 in Ontario schools which I examine in Chapters 5 and 6 as my investigation confirms that these narratives largely reinforce society's deficit-based socially constructed assumptions regarding disability. Thus, due to receiving these prejudicial messages uncritically in schools, students are having society's socially constructed beliefs regarding disability and disabled people reinforced, which furthers the marginalization that disabled people experience in society. In the next chapter, I will review the literature regarding the categorical representation of disability in fiction and other media in critical disability studies, education, and English literature scholarship.

Chapter 3: Literature Review

The literature reviewed in this chapter consists of scholarship in the disciplines of critical disability studies (Biklen & Bogdan, 1977; Connor, 2017; Dolmage, 2014; Quayson, 2007), education (Andrews, 1998: Carroll & Rosenblum, 2000; Landrum, 2001), and English literature (Monaghan, 2016)[8] regarding the categorization and representation of disability in fiction and other media. This literature is vital to my study as it establishes the historical and contemporary context for the representations of disability which situates my analysis of the disability-themed children's and young adult novels which are critiqued in Chapters 5 and 6. I have divided the literature reviewed in this chapter as follows: representational categories in critical disability studies (Biklen & Bogdan, 1977; Connor, 2017; Dolmage, 2014; Quayson, 2007), and categorizing depictions of disability in education and literary scholarship (Andrews, 1998; Carroll & Rosenblum 2000; Landrum, 2001; Monaghan, 2016). Throughout my discussion of the education scholarship in this chapter, I have provided additional examples of similar and more recent scholarship. However, due to the largely overlapping nature of their categorizations of disability, I have cited the work of Hayden and Prince, (2020) and Kleekamp and Zapata, (2018) where their work supports my discussion of Andrews (1998), Caroll and Rosenblum (2000), and Landrum (2001). Finally, I have used the disability-themed children's and young adult novels *Heidi* (Spyri, 1994), *The Cay* (Taylor, 2011) and *The Giver* (Lowry, 1993) to illustrate the diverse categorical scholarship reviewed in this chapter.

[8] For a complete list of the scholarship regarding the representation of disabled characters in literature and other media that I located during my literature review refer to Appendix A.

Representational Categories in Critical Disability Studies Scholarship

In their 1977 paper, Biklen and Bogdan[9] describe 10 common deficit-based depictions of disabled characters in literature, television, and film. Even though Biklen and Bogdan's (1977) list of problematic representations of disabled characters is over 40 years old, more recent scholarship regarding the representation of disabled characters has produced similar criteria. Four more recent categorizations of common portrayals of disabled characters include work by Connor (2017), Dolmage (2014), and Quayson, (2007). To provide some literary examples that are representative of common depictions of disability that have been identified by the previously cited scholars, I will use the children's and young adult novels that were taught during my elementary and secondary education as illustrations.

Disability Representation in *Heidi*

The first disability-themed novel that I remember being taught in school was *Heidi* (Spyri, 1994). When readers are first introduced to Clara she is described as "… young and an invalid, who was always obliged to go about in a wheeled chair; she was therefore very much alone and had no one to share her lessons, and so the little girl felt dull" (Spyri, 1994, p. 45). Throughout the narrative, Clara is defined primarily by her impairment even before readers learn her name. Dolmage (2014) refers to this representation of disability as "Disability as Pathology" when he states, "People with disabilities have been historically labelled, sorted, and arrayed on scales according to their deviation from standardized norms. In this way, perhaps the most prominent disability rhetoric is the medical model" (p. 43). A second portrayal that Dolmage

[9] Since Douglas Biklen and Robert Bogdan would become foundational scholars in the fields of critical disability studies and disability studies in education I have placed their scholarship alongside the work of other critical disability studies scholars even though critical disability studies as a discipline did not exist when their article was published.

(2014) has identified that is present in Clara's initial description is "Disability as Isolating and Individuated". Dolmage explains:

> People with disabilities in film and literature most often live in hospitals and institutions, as though these are their natural habitats – they rarely have romantic relationships or enduring friendships and often are left alone at the end of the narrative. (p. 44)[10]

Even though Clara lives at home with her family she is presented as being isolated from society due to her being "very much alone and had no one to share her lessons, and so the little girl felt dull." (Spyri, 1994, p. 45) which suggests that Clara has no friends. From reading and reflecting on the way that Clara's character is introduced in *Heidi* (Spyri, 1994) readers may conclude that they are supposed to pathologize and pity her due to her isolation (Dolmage, 2014).[11] Further, readers learn that Clara is dependent on others to move around her home (Spyri, 1994, p. 50) which suggests that she is a burden on those around her (Biklen & Bogdan, 1977; Connor, 2017).

Later in the text, readers discover that Heidi's grandfather pressures Clara to overcome her disability when the narrator records, "For some days past the grandfather, each morning after carrying her down, had said, 'Won't the little daughter try if she can stand for a minute or two?' And Clara had made the effort in order to please him but had clung to him as soon as her feet touched the ground, exclaiming that it hurt her so. He let her try a little longer, however, each day" (Spyri, 1994, p. 184). By presenting the idea that Clara needs to walk to gain her independence, the novel fails to recognise the fact that wheelchairs often provide their users with autonomy. Instead, the text claims that Clara must overcome her physical impairment which

[10] See also (Barnes, 1992; Biklen & Bogdan, 1977).
[11] See also (Biklen & Bogdan, 1977; Connor, 2017).

Dolmage (2014) refers to as "overcoming or compensation". He writes, "The person with their disability overcomes their impairment through hard work or has some special talent that offsets their deficiencies" (p. 44).[12] In Clara's case, her work to overcome her disability by individual effort is also linked with the "kill or cure" trope which Dolmage (2014) explains as, "Just like a loaded gun shown in the opening scenes of a movie will eventually be fired, a disabled character will either have to be 'killed or cured' by the end of any movie or novel in which they appear" (p. 43).[13] In this case, Clara's rehabilitation is presented in the form of a cure narrative when the narrator explains,

> And Clara went on putting one foot out after another until all at once she called out, and 'I can do it, Heidi! Look! Look! I can make proper steps!' And Heidi cried out with even greater delight, 'Can you really make steps, can you really walk? Really walk by yourself? …You can walk now, Clara, you can walk!' (Spyri, 1994, p. 192).

The cure narrative in *Heidi* has been critiqued by Keith (2001) when she argues:

> When Clara learns to walk again, we are asked to believe that this is the result of two apparently contradictory factors: that God has judged the time to be right for the healing to take place and that Clara, deciding that she no longer wants to be dependent on others, has found the energy to take matters into her own hands. (p. 96)

In a second quotation, Keith (2001) continues:

> For critics and commentators, the issue of walking/not walking in these novels is most often understood as merely a symbolic representation of the psychological or spiritual

[12] Other scholars such as Barnes, (1992), Biklen, and Bogdan (1977), Connor, (2017) and Schalk (2016) refer to this portrayal of disability using varying renditions of the term supercrip.
[13] See also (Connor, 2017).

> healing of unhappy children… In such a reading, illness and the eventual cure of the disabled child are not recognised as significant issues in themselves but as the metaphorical equivalent of sadness, powerlessness and dependency. (pp. 96-97)

The use of overcoming and cure-based narratives uncritically in classroom literature is highly problematic because they reinforce society's deficit-based beliefs and attitudes regarding disabled people in schools.

Disability Representation in *The Cay*

The second disability-themed novel that I read in school was *The Cay* (Taylor, 2011). In the novel, Phillip acquires a visual disability which is used metaphorically to teach him a lesson about race, which Quayson (2007) refers to as "*disability as the interface with otherness (race, class, sexuality, and social identity*)" (p. 39).[14] Phillip describes his initial reaction to acquiring a visual disability when he explains, "I'll never forget that first hour of knowing I was blind. I was so frightened that it was hard for me to breathe" (Taylor, 2011, p. 33). Even though fear is an understandable response to acquiring a disability the narrative purpose for Phillip's impairment is portrayed in a manner that reinforces deficit-based assumptions regarding disability throughout the text. Two additional myths that occur in the novel are Phillip's belief that his other senses have increased to compensate for his visual disability (Taylor, 2011, p. 92), and the medical cure that Phillip receives at the conclusion of the novel (Taylor, 2011, pp. 100-101). In the first example, Phillip is disseminating the overcoming myth that visually disabled people's other senses compensate for our visual impairment (Biklen & Bogdan, 1977).[15] Instead, I would suggest that Phillip gradually develops an increased familiarity with the physical and sensory

[14] The italics are in the original.
[15] See also (Connor, 2017; Dolmage, 2014).

environment of the island. Lastly, *The Cay* propagates the "cure" (Dolmage, 2014, p. 43) myth that visual disabilities can be easily treated, as a requirement to live a fulfilling life (Biklen & Bogdan, 1977, p. 9). Phillip briefly relates the medical treatment that he receives at the conclusion of the novel when he narrates:

> Four months later, in a hospital in New York, after many X-rays and tests, I had the first of three operations. The piece of timber that had hit me the night the Hato went down had damaged some nerves. But after the third operation, when the bandages came off, I could see again. I would always have to wear glasses, but I could see. That was the important thing. (Taylor, 2011, pp. 100-101)

The medical cure that Phillip receives at the end of the novel is highly problematic because most visual disabilities are permanent (Carroll & Rosenblum, 2000). Moreover, the moralizing use of Phillip's visual disability is highly objectionable from a critical disability studies perspective because Taylor (2011), through his authorial choices, is suggesting that acquiring a visual disability is an appropriate punishment for the social evil of Phillip's racist beliefs (Quayson, 2007, pp. 38-39). Likewise, *The Cay* does not show readers how disability can be a meaningful part of visually disabled people's identities (Quayson, 2007, p. 52).[16] By presenting cure-based conclusions in their novels, the authors argue that disabled people need to be cured in order to participate meaningfully in society. Otherwise, disabled people are assumed to be "incapable of fully participating in everyday life" (Biklen & Bogdan, 1977, p. 9).

In her chapter regarding *The Cay* Dunn (2015) documents the numerous problematic discourses in relation to disability that are present in the novel when she writes:

[16] See also (Biklen & Bogdan, 1977; Connor, 2017).

> In *The Cay,* Phillip's temporary blindness is a metaphor for his moral blindness and prejudice concerning race. ... the disability is a plot device, not a serious consideration of realistic views of disability in society. … After say a week-long lesson plan on the vocabulary, themes, and symbols in texts like these, students might come away from class discussions with the notion that people with disabilities just simply die, get cured and/or function simply as metaphors. To counter that myth, teachers should also pose other questions. (p. 79)

In her criticisms of *The Cay* Dunn's (2015) work demonstrates the numerous deficit-based perspectives that are present in the narrative that can reinforce the prejudicial beliefs that students may hold, while internalizing the ableism that disabled students may be experiencing.

In their analysis of *The Cay* (Taylor, 2011) Caroll and Rosenblum (2000) also address the issue of cure-based narratives when they warn:

> This back-to-normal theme may communicate to adolescents with visual impairments that a story can have a happy ending only when the blindness is removed. It may also give adolescents and their peers a false hope that blindness or low vision is cured. (p. 625)

By considering how a character's visual disability is presented in the narrative, teachers are better equipped to help their students identify and critique the representation of disability in the text.

Disability Representation in *The Giver*.

The final text that I will be discussing in this section is *The Giver* (Lowry, 1993) which I read in secondary school. My analysis of *The Giver*, from a disability perspective, differs from my previous discussions of *Heidi* (Spyri, 1994) and *The Cay* (Taylor, 2011) because the novel

does not contain any overtly disabled characters. Thus, *The Giver* is an example of Bérubé's (2015) argument that characters in fiction can experience ableism without requiring them to be formally identified as disabled. Instead, *The Giver* (Lowry, 1993) depicts a society where McRuer's theory of "compulsory able-bodiedness" (2006, p. 2)[17] is witnessed through their adoption of the philosophy of "sameness" (Lowry, 1993, p. 91). In this case, Lowry's (1993) text examines a society in which eugenics is used to justify killing infants who do not meet their developmental milestones, or when twins are born because only one child is permitted to be born at a time (pp. 16, 118, 140, 148-152). Moreover, the philosophy of "sameness" also requires that elderly people be institutionalized and later killed during "The Ceremony of Release" (Lowry, 1993, pp. 16, 28, 36-41). The permissive attitude towards death in this society is also demonstrated through the absence of mental health professionals. For example, instead of providing Rosemary (The Giver's previous apprentice) with mental healthcare for the trauma that she was experiencing due to her training, she was enabled by her society to commit suicide (Lowry, 1993, pp. 144-153). In response to Rosemary's failure Jonas, her replacement, is prohibited from discussing his training with others, requesting medication to help him deal with the trauma that is associated with his training, or from applying for release (Lowry, 1993, p. 74). As a result of these restrictions, Jonas is required to endure the physical and emotional anguish that is related to his training without being able to seek any form of relief.

By using widespread social control measures such as eugenics, infanticide, the institutionalization of elderly people, and euthanasia programs, *The Giver* (Lowry, 1993) depicts

[17] Robert McRuer defines "compulsory able-bodiedness" as: I put forward here a theory of what I call "compulsory able-bodiedness" and argue that the system of compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness: that, in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa (2006, p. 2).

a world in which normalcy is rigidly enforced by pathologizing, socially excluding and, in most cases, killing disabled individuals (Dolmage, 2014; Davis, 1995). As such, *The Giver* (Lowry, 1993) is a powerful example of what can occur when deficit-based ideological understandings of disability are taken to their extreme but logical conclusions, resulting in a society where being disabled is grounds for immediate termination by the State.

Categorizing Depictions of Disability in Education and Literary Scholarship

To support teachers when they are selecting and teaching disability-themed content in their language arts classrooms, the education scholars Andrews (1998), Carroll and Rosenblum (2000), and Landrum (2001)[18] have developed lists of categorical criteria regarding the representation of disabled characters in literature. In this section, I discuss some of the criteria developed by these scholars, both positively and negatively, based on my experiences as a disabled academic reader of disability-themed texts. However, my review of this literature will focus on the lists of criteria developed by Andrews (1998), Carroll and Rosenblum (2000), and Landrum (2001), even though more recent categorizations of disability in education scholarship have been developed by Hayden and Prince (2020) and Kleekamp and Zapata, (2018). I have done so for three reasons. First, the scholarship completed by the above scholars contains a greater number of criteria regarding the representation of disability in literature, second, these scholars tend to provide more detailed explanations for each criterion, and third, considerable overlap exists within this body of scholarship, making detailed discussions of each scholar's criteria regarding the portrayal of disabled characters in literature unnecessary. Thus, I have cited

[18] See also (Hayden & Prince, 2020; Kleekamp & Zapata, 2018).

the similarities that exist within this scholarship where appropriate, but I have only discussed the work of Andrews (1998), Carroll and Rosenblum (2000), and Landrum (2001) in detail.

As part of her analysis of inclusive literature in the classroom, Andrews (1998) suggests 10 criteria to help teachers determine if a literary work is an appropriate choice for an inclusive disability-themed language arts unit. As I read Andrews' (1998) criteria, I found many valuable suggestions for teacher educators and classroom teachers. For example, Andrews highlights the importance of selecting disability-themed texts that accurately represent the character's disability (p. 422)[19] in addition to portraying them as having similar life experiences as their abled peers (Andrews, 1998, p. 423).[20] Second, Andrews discusses the role that language plays in the representation of disability and suggests that teachers choose novels that use disability-specific language correctly (Andrews, 1998, p. 423).[21] This criterion is significant because it provides a vital corrective against ableism by introducing students to the terminology considered to be appropriate, as well as explaining why other language is offensive. However, I disagree with her suggestion that texts should only use person-first language (p. 423) as opposed to identity-first language because the preferred language varies (Andrews et al., 2022).[22] Even though person-first language was more prominently used during the 1980s and 1990s (Blaska, 1993) and continues to be the preferred terminology within the developmental disability community (Foreman, 2005; Pelka, 2012),[23] language preferences have changed to support the use of identity-first terminology (Andrews et al., 2022; Botha et al., 2023). A third point that Andrews

[19] See also (Carroll & Rosenblum, 2000; Landrum, 2001).
[20] See also (Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001).
[21] See also (Hayden & Prince, 2020).
[22] See also (Best et al., 2022; Botha et al., 2023; Linton, 1998)
[23] For a detailed history of the People First organization refer to Pelka (2012).

(1998) prioritizes is challenging deficit-based interpretations of disability (p. 423),[24] which is essential when the purpose of inclusive education is to create a more just world for disabled people. A final important suggestion that Andrews makes is that there continues to be an appropriate place for problematic portrayals of disability in the language arts classroom (p. 424). However, when using texts that depict disabled characters in deficit-based ways, teachers need to discuss with their students why the representations of disability that are being disseminated in a literary work are problematic. For example, these discussions could include the language used regarding disability and disabled characters in the novel, the ways that the novel reflects the historical setting or the time in which the author was writing, and how these ideas have changed over time.

Landrum (2001) has also developed general criteria regarding the depiction of disability in language arts texts. Landrum's work differs from that of Andrews (1998) because she has subdivided her criteria into three categories: "plot", "character development", and "tone".

Under her first category, "plot" Landrum (2001, p. 254) suggests that teachers choose texts that realistically represent disabled characters who participate meaningfully alongside their abled peers.[25] This is an important consideration because it serves to challenge several deficit-based representations of disability that present disabled characters as different from their abled peers. I also concur with Landrum (2001, p. 254) that it is vital for the information regarding the impairments that disabled characters have to be depicted realistically within the narrative (Andrews, 1998). There are, however, several of Landrum's (2001) criteria that I find problematic. First, I disagree with Landrum when she recommends that "A superhero theme does

[24] See also (Hayden & Prince, 2020).
[25] See also (Andrews, 1998: Hayden & Prince, 2020).

not appear in the story" (p. 254) because when effectively portrayed, superhero-themed literature can be used to discuss disability (Bérubé, 2015).

Second, I find Landrum's (2001) suggestion that "Although both the climax and the ending may include the disability of one of the characters, they do not focus on it" (p. 254) to be problematic from a critical disability studies informed perspective because novels in which a character acquires a disability and then over time incorporates becoming disabled into his or her identity, are vital disability-themed narratives that should be taught in schools (Hayden & Prince, 2020). By recommending that narratives of adjustment not be used in schools, Landrum's (2001, p. 254) work fails to consider the vital role that narratives of adjustment have in the lives of disabled people. When an individual experiences a significant life-changing event, one of the things that we often do is seek out people who have had similar experiences in order to learn from others. Part of this educational process can also involve reading novels and watching films about the fictional experiences of disabled characters. Therefore, teachers should include numerous textual examples of disabled characters with diverse impairments as well as characters with both acquired and congenital disabilities in the texts that they teach (Menchetti et al., 2011).

In her second subcategory, "Character Development", Landrum (2001, p. 254) focuses on selecting narratives that challenge numerous deficit-based depictions of disability such as disabled characters who are dependent, overly emotional, are portrayed as loners, as well as characters who are assumed to be asexual because of their impairments (Hayden & Prince, 2020). Instead, Landrum (2001) suggests that teachers use texts in their classrooms that portray disabled characters as equal participants in all aspects of the narrative (Andrews, 1998).[26] Each

[26] See also (Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018).

of these criteria is important because they challenge problematic depictions of disability that are commonly present in literature, while providing literary role models for disabled readers.

In Landrum's (2001, p. 254) subsection, "tone", she suggests that inappropriate language should be discussed when it occurs in classroom literature, but I do not think that it is practical to expect teachers to use only texts that do not include any deficit-based language. For example, even though Draper (2010) described Melody's experience as a disabled character, as well as the social stigma and attitudinal barriers that she experiences at school, *Out of My Mind* uses deficit-based language relating to disability (pp. 18, 22, 38, 94, 177). Second, Landrum (2001) recommends that texts which lead readers to pity disabled characters or present the lives of disabled characters as being tragic should be avoided because these portrayals of the disability experience communicate harmful messages to readers about the lives of disabled people, such as the depiction of Tiny Tim in *A Christmas Carol* (Dickens, 2004).

Carroll and Rosenblum's (2000) work provides teachers with seven criteria to consider when selecting novels that contain visually disabled characters. First, I appreciate the fact that Carroll and Rosenblum draw attention to the fact that visual disabilities are a spectrum, thus making every visually disabled person's experience unique (p. 626). This is particularly so because people who acquire visual disabilities do so at different times in their lives and therefore have different experiences as a result. Second, Carroll and Rosenblum argue that visually disabled readers should have fictional role models whose experiences are representative of their lived experiences because this challenges myths about visually disabled people (p. 626). Carroll and Rosenblum also note the importance of participation in community life, having friends, and other common experiences while describing the realities of living with a visual disability in the

21st century (p. 626).[27] Carroll and Rosenblum's (2000) work has provided excellent criteria that teachers should consider when they are planning to teach a novel that contains visually disabled characters.

Monaghan (2016) has identified four criteria for evaluating the representation of characters with mental health disabilities. These include:

> The protagonist/narrator accurately reflects the knowledge of someone his age under the circumstances in which he finds himself. The protagonist's/narrator's illness experiences allow the reader to draw parallels between her life and experiences and those represented in the narrative. The protagonist's/narrator's story rings true: if Point A is connected to Point B, it does so according to the logic of the narrative. Somewhere in the narrative, the illness or condition is explicitly articulated. (p. 39)

Monaghan's (2016) criteria regarding the importance of having characters with mental health disabilities that realistically reflect the knowledge and experiences of adolescents who live with mental illnesses, such as Craig's representation in *It's Kind of a Funny Story* (Vizzini, 2010), is vital because it is a clear acknowledgement that adolescents do live with mental health disabilities as part of their identities while also showing how the characters' experiences are similar to those of adolescents who live with mental health disabilities. However, I believe Monaghan's (2016) criterion that, "Somewhere in the narrative, the illness or condition is explicitly articulated" (p. 39) to be problematic because as Bérubé's (2015) work demonstrates, literature "… can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged with a specific diagnosis."

[27] In the context of the representation of developmentally disabled characters Dyches et al., (2009) also argue that disabled characters should be shown as meaningful participants within their wider communities.

(Bérubé, 2015, p. 19). This representation is also important because a disabled character may not have been formally diagnosed with a mental health disability before or during the narrative.

Conclusion

In this chapter, I have reviewed the literature that supports my study regarding the representations of disability in literature in the disciplines of critical disability studies, (Biklen & Bogdan, 1977; Dolmage, 2014; Connor, 2017; Quayson, 2007), education, (Andrews, 1998: Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001), and English literature (Monaghan, 2016). The literature reviewed in this chapter provides a representational history of the categorical scholarship regarding the depiction of disability within the disciplines of critical disability studies, education, and English literature. My work in this chapter reveals the overlapping categorisations of disability that exist across this scholarship together with how these can be applied to the portrayals of disability in literature. The importance of this literature to my study is based on the fact that I have drawn on this representational scholarship when conducting my analysis of the representations of the 12 disabled first-person protagonists in the 12 disability-themed children's and young adult novels that have met the inclusion criteria for my study based on the work of Bates (2017). I presented this material as follows: representational categories in critical disability studies scholarship, and categorizing depictions of disability in education and literary scholarship. In the next chapter, I will provide a detailed discussion of the research methods, text selection process, the criteria that I have used to evaluate the representation of disability in each novel, the procedure used while conducting my study, and the research ethics that are associated with this project.

Chapter 4: Research Methods

Introduction

In this chapter, I will describe my use of autoethnography (Lalvani, 2019), autocritical disability studies (Bolt, 2021; Marx, 2023), and critical inquiry (Charmaz, 2017; Flick, 2015) as the central components of my methodology. Moreover, I will document how my use of critical inquiry has been guided by the theoretical work of critical disability studies, education, and English literature scholars who have developed criteria regarding the representations of disabled characters in literature and other cultural texts such as Andrews (1998); Dolmage (2014); and Monaghan (2016).[28] The publications of the scholars cited above are foundational to my methodology because throughout my dissertation I have applied their numerous categorical understandings of disability to answer the first research question of my study: How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? Additionally, this chapter includes a detailed description of the text selection process that I used to determine which novels would be included in my study, the research procedures I followed while completing this study, and the ethical considerations related to my dissertation.

Autoethnography

Autoethnography is a research method which Lalvani describes thus: "Autoethnography is a qualitative research method in which researchers use their personal stories to explore particular social issues, through a connection of the stories to broader theoretical frameworks or academic literature" (2019, p. 7). In my study autoethnography is a central research method

[28] For a complete list of this scholarship refer to Appendix A.

because I will be using my lived experience as a disabled person to critique the depictions of disabled characters in disability-themed children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools (Bates, 2017). To my knowledge, autoethnographic research has never previously been used to examine the representations of disabled characters in classroom literature based on the experience of a disabled academic reader. Despite disabled scholars having critiqued the representations of disabled characters in fiction (Aveling, 2009; Bolt, 2014; Keith, 2001), they only briefly discuss their experiences as disabled readers in their publications.

Autocritical Disability Studies

Importantly, autoethnographic research has recently begun to emerge within the field of critical disability studies which Bolt (2021) has described as autocritical disability studies (Bolt, 2021; Marx, 2023). Bolt (2021) defines autocritical disability studies as inviting scholars to "recognize their experience at the very epistemological level of their methodology, the aim being to herald formal advancement from critical theory and critical disability theory to autocritical disability theory" (xviii). My work in this dissertation merges Bolt's (2021) autocritical disability studies with other critical disability studies informed scholarship, English literature, and education research to conduct a critical inquiry (Charmaz, 2017; Flick, 2015) regarding the depictions of the 12 disabled first-person protagonists in the disability-themed children's and young adult literature being taught in grades 7-12 in Ontario schools (Bates, 2017). My autocritical disability studies informed approach to critical inquiry has been guided by the first question of my study: How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? My investigation of each of the disabled protagonist's characterizations has

been informed by my lived experience as a disabled academic reader of disability-themed literature, as well as the diverse scholarship regarding the representation of disability in literature and other media within the fields of critical disability studies, education, and English literature, including research conducted by Connor (2017); Dolmage (2014); and Monaghan (2016) whose publications have underpinned my analysis of the disabled first-person protagonists whose depictions I have critiqued throughout my study.

Critical Inquiry

The final research method that underpins my study is critical inquiry which Charmaz (2017) defines as:

> When I speak of critical inquiry, I include concerns and studies about social justice, although it is an ambiguous and elastic concept. In its various forms, critical inquiry addresses power, inequality, and injustice. … I see critical inquiry as embedded in a transformative paradigm that seeks to expose, oppose, and redress forms of oppression, inequality, and injustice. (p. 35)

In keeping with Charmaz's (2017) definition of critical inquiry my methodology considers the power that schools, as social institutions, have regarding the socially just or unjust teaching of disability-themed content in the language arts classroom. This phenomenon is witnessed most commonly in the language arts classroom when disability-themed literature is being taught (Reid, 2010; Ware 2001, 2002) due to the impact that the representations of disability within literature can have on readers' beliefs about disability and those who have them (Cameron & Rutland, 2006; Casalme, 2016). Further, my use of critical inquiry is supported by Flick (2015) whose work provides a detailed procedure to guide users of critical inquiry. Flick outlines the central aspects that underpin critical inquiry methodologically when he writes:

> (1) Identify vulnerable groups in society; (2) Identify social problems these groups are confronted with; …(3) Analyze how the institutions deal with these problems; (4) Use(fulness) of research; (5) Relevance and implementation.[29] (p. 600)

My application of Flick's (2015) outline in relation to critical inquiry includes, (1) I have identified disabled people as a "vulnerable" cultural community within society, (2) I consider the frequently deficit-based representations of disabled characters in the children's and young adult literature that is being taught in Ontario schools to be an urgent social problem that is being experienced by students in the language arts classroom. (3) Before conducting my study, I located numerous academic publications that have identified various cultural depictions of disabled characters that document the largely negative representations of disabled characters in literature and other media such as Connor, (2017), Dolmage, (2014), and Monaghan, (2016). This scholarship demonstrates how scholars within post-secondary institutions have attempted to address the issue of the representation of disabled characters in cultural texts in the fields of critical disability studies, English literature, and education. (4) My dissertation is a new and useful application of the existing scholarship regarding the academic criticism of disability-themed literature because I have suggested new alternatives with regard to the problem of the often deficit-based portrayals of disabled characters in the children's and young adult literature being taught in grades 7-12 in Ontario schools. One example of this is the suggestion that teachers consider using "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) when teaching disability-themed content in the language arts classroom. (5) The results of my dissertation are relevant because, based on the findings of my study, I have made

[29] For ease of reading, I have added numbers to Flick's (2015) procedure.

recommendations regarding teacher preparation in respect of the teaching of disability-themed children's and young adult literature in the language arts classroom as well as regarding future scholarship within the fields of critical disability studies and education.

Experiential Readings of Socially Constructed Systems of Power

Throughout my dissertation, I have used my experience as a disabled reader of disability-themed texts to critically examine the ways that disabled first-person protagonists are portrayed by the authors of the twelve disability-themed children's and young adult novels that are being taught in grades 7-12 in Ontario schools. As such, my experiential readings are consistent with an autocritical disability studies informed methodology (Bolt, 2021; Marx, 2023). My experiential readings of the twelve narratives that have met the inclusion criteria for my study are supported by the diverse categorical scholarship concerning the representation of disability in literature and other media, including the work of Andrews, (1998), Connor (2017), and Dolmage (2014). The philosophical and sociological work of the previously cited scholars has been underpinned by the social constructivist scholarship of Foucault (1989, 1990, 2012) and Goffman (2009). Chapter 2 provides a more detailed explanation of how Foucault's and Goffman's scholarship underpin the theoretical framework of my study. As such, my interdisciplinary methodology enables me to identify how socially constructed systems of power (Foucault, 1989, 1990, 2012) have been used to stigmatize and socially exclude (Goffman, 2009) disabled people through the use of cultural texts (Davis, 1995). Thus, my critical and experiential reading of the texts being considered in my study permit me to conduct a critical inquiry (Charmaz, 2017; Flick, 2015) into the socially constructed and categorical discourses of disability that are being communicated to readers, with a particular emphasis on social stigmatization and other forms of "bio-power" (Foucault, 1990, p. 140) that are enacted upon,

and resisted by, the 12 protagonists whose experiences as disabled characters I have investigated throughout this study.

Text Selection Process

Before undertaking this study, I needed to determine which literary works were being taught in grades 7-12 in Ontario schools. Based on the work of Bates (2017) I discovered that 695 texts were being used in grades 7-12 in Ontario classrooms. I began my analysis by identifying how many children's and young adult novels in Bates' (2017) data contained disabled characters. I made this determination by reading the summaries of each novel on GoodReads, Amazon.ca, or other websites to confirm that each text contained disabled characters. This procedure decreased the number of books from 695 to 39.[30] I then purchased the Kindle editions of 38 of the remaining 39 novels. Due to its unavailability in Kindle format, I had to exclude *Cut* (McCormick, 2011) from my study because of my accessibility requirements. Lastly, I excluded *Thirteen Reasons Why* (Asher, 2007) because Hannah Baker (the text's first-person protagonist who may have had an undiagnosed mental health disability) died before the beginning of the novel. Due to Hannah's narration occurring posthumously throughout the text, this excludes her character from my study because it can be argued that deceased individuals are no longer disabled. This reduced the number of texts being considered for inclusion to 37. The next phase of my text selection process involved reading each of the remaining books twice. To further reduce this number, I excluded the children's and young adult novels that were written before 1993. I chose 1993 as the starting point for my study because I wanted the books in my dissertation to coincide with my experience as a disabled reader of disability-themed literature.

[30] For a complete list of the 39 novels with which I began my analysis refer to Appendix C.

Next, I excluded the novels that were not written in the genre of contemporary realistic fiction. Lastly, I excluded the texts that did not contain a disabled first-person protagonist. As a result of this inclusion/exclusion process, I will examine the representations of 12 disabled first-person protagonists in contemporary realistic fiction that were published between 1993 and 2015 that were being taught in grades 7-12 in Ontario schools (Bates, 2017).[31]

After reducing the number of texts in my study to 12, it was still necessary to make several decisions regarding my inclusion/exclusion criteria. For example, would I only include protagonists who self-identify as disabled? Or would I include characters whose impairments have not been diagnosed, such as Troy in *Fat Kid Rules the World* (Going, 2004) or Ally in *Fish in a Tree* (Hunt, 2015)? To address this issue, I have adopted the perspective of the literary disability studies scholar Bérubé (2015) who argues that texts "can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged with a specific diagnosis" (p. 19). As a result, characters whose impairments have not been formally diagnosed or who do not self-identify as being disabled will be included in my study.

A second question that I needed to address during my text selection process was how I would define disability. For example, are life-threatening allergies such as Ambrose's in *Word Nerd* (Nielsen, 2010) considered to be a disability? To resolve this question, I chose to use the definition of disability developed by the critical disability studies scholar Garland-Thomson (1997). She defines disability as,

[31] For a list of these texts refer to Appendix F.

> … an overarching and in some ways artificial category that encompasses congenital and acquired physical differences, mental illness and retardation, chronic and acute illnesses, fatal and progressive diseases, temporary and permanent injuries, and a wide range of bodily characteristics considered disfiguring, such as scars, birthmarks, unusual proportions, or obesity. (p. 13)

Based on the above definition of disability, I have decided to include novels that have first-person protagonists with terminal illnesses such as Hazel in *The Fault in Our Stars* (Green, 2012) and texts that have obese first-person protagonists such as Troy in *Fat Kid Rules the World* (Going, 2004).

A third question that I needed to answer regarding my text selection process was: Will I include novels with more than one first-person protagonist, provided that one of them is a disabled character? I chose to include *Wonder* (Palacio, 2012) in my study because even though there are six first-person narrators in the text August, who has physical disabilities, narrates 55% of the text which makes him the primary narrator of the book. Once my exclusion and inclusion criteria were developed, I was left with the remaining 12 novels that I analysed in my study. The 12 texts are further divided into five children's books and seven young adult texts that were written between 1993 and 2015. The five children's books that I examine in Chapter 5 of my study are, *Out of My Mind* (Draper, 2010), *Fish in a Tree* (Hunt, 2015), *Word Nerd* (Nielsen, 2010), *Wonder* (Palacio, 2012), and *Freak the Mighty* (Philbrick, 1993). The seven young adult novels evaluated in Chapter 6 include, *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007), *Speak* (Anderson, 2019), *The Perks of Being a Wallflower* (Chbosky, 1999), *Fat Kid Rules the World* (Going, 2004), *The Fault in Our Stars* (Green, 2012), *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), and *It's Kind of a Funny Story* (Vizzini, 2010).

Research Procedure

To conduct the critical inquiry-based research portion of my study regarding the representations of the 12 disabled first-person protagonists in the disability-themed children's and young adult novels that were being taught in grades 7-12 in Ontario schools, I carried out the following procedure. First, I conducted an individual character study of each text's protagonist to determine how each author represented their disabled protagonist based on the categorical scholarship conducted by Andrews (1998), Biklen and Bogdan (1977), Carroll and Rosenblum (2000), Connor (2017), Dolmage (2014), Landrum (2001), Monaghan (2016), and Quayson (2007) regarding the representation of disability in literary and other cultural texts. Second, I identified situations within each narrative where the disabled protagonist either conformed to or subverted the categorical depictions of disabled characters based on the work of the previously cited critical disability studies, English literature, and education scholars. Third, after I had located and evaluated the portrayals of each of the disabled first-person protagonists from a representational perspective, I determined how disability "culturally authentic" (Brown, 2020, p. 141) each character's depiction was from an autocritical disability studies (Bolt, 2021; Marx, 2023) perspective. I conducted an autocritical disability studies informed analysis of the 12 texts that met the inclusion criteria of my study based on my experiential and academic knowledge of the disability community. Lastly, I concluded my study by identifying numerous common representational themes that were present across the 12 narratives in addition to the various categorical representations of disability within each novel. Some of these factors include the protagonist's race, socio-economic status, family structure, gender, sexual identity, and whether each protagonist self-identifies as disabled within the narrative.

Categorical Representations of Disability in Critical Disability Studies Scholarship

To carry out my analysis, I began by locating published critical disability studies scholarship regarding the representation of disability in literature and other media.[32] Through this critical inquiry I located criteria developed by Barnes (1992), Biklen & Bogdan (1977), Connor (2017), Dolmage (2014), and Quayson (2007). Due to the numerous similarities that exist within the categorical scholarship regarding the representation of disability in critical disability studies scholarship, I have defined the representational criteria that I have used throughout my study while evaluating the representation of each of the disabled protagonists. Moreover, I have identified the scholars whose publications address each criterion. These representations of disability include: disabled characters as burdens (Barnes, 1992),[33] kill or cure (Dolmage, 2014, p. 43), the overcoming representation of disability (Dolmage, 2014, p. 44),[34] disability as a justification for offensive humour (Barnes, 1992; Biklen & Bogdan, 1977), disability as a socially isolating experience (Biklen & Bogdan, 1977; Dolmage, 2014), the pitied disabled character (Connor, 2017),[35] the sexually incapable or sexually deviant disabled character (Barnes, 1992; Biklen & Bogdan, 1977), the feared or evil disabled character (Connor, 2017; Quayson, 2007, pp. 38-39),[36] the medicalized disabled character (Dolmage, 2014), the victimized disabled character (particularly relating to violence) (Connor, 2017),[37] disability as a normative aspect of human life (Barnes, 1992; Connor, 2017),[38] "*disability as epiphany*" (Quayson, 2007,

[32] Due to there being numerous lists of criteria that have been developed by scholars and many overlapping categorizations of disability depictions within these lists, I have only provided a representative sample of this scholarship based on the scholars whose publications I have used throughout my analysis.
[33] See also (Biklen & Bogdan, 1977; Connor, 2017).
[34] See also (Barnes, 1992; Biklen & Bogdan, 1977; Connor, 2017).
[35] See also (Barnes, 1992; Biklen & Bogdan, 1977; Dolmage, 2014).
[36] See also (Barnes, 1992; Biklen & Bogdan, 1977; Quayson, 2007).
[37] See also (Barnes, 1992; Biklen & Bogdan, 1977).
[38] See also (Barnes, 1992; Quayson, 2007).

p. 45), disability as a justification for social othering (Quayson, 2007, p. 39), "disability drop" (which occurs when a character's impairment is introduced at the beginning of the narrative but is not mentioned again within the text) (Dolmage, 2014, p. 45),[39] "disability drift" (Dolmage, 2014, p. 45) which occurs when a character with a physical disability is also considered to have a cognitive disability, and vice versa. Each of these categorical representations of disability is present to varying degrees across the characterizations of the 12 disabled first-person protagonists whose portrayals I have evaluated throughout this study, and which will be discussed in relation to each novel's protagonist where appropriate.

Depictions of Disability in Education Scholarship

Across the education scholarship that examines the depictions of disabled characters in literature (Andrews, 1998; Dyches et al., 2009; Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001; Menchetti et al., 2011) each of whom include recommendations regarding the selection and teaching of disability-themed content in the language arts classroom. Examples include the medical accuracy of information about the character's disability (Andrews, 1998),[40] in that disabled characters should be depicted as having similar life experiences, desires, goals, and dreams as abled characters (Landrum, 2001),[41] that the disabled character should be shown as having similar family, peer, and romantic relationships as abled characters (Andrews, 1998)[42] and that being disabled is only one aspect of the disabled character's identity (Andrews, 1998).[43] Each of the recommendations made by Andrews (1998),

[39] For additional categorical representations of disability in literature and other cultural texts refer to Appendix A.
[40] See also, (Carroll & Rosenblum, 2000; Landrum, 2001).
[41] See also (Andrews, 1998: Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018).
[42] See also (Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001).
[43] See also (Carroll & Rosenblum, 2000; Hayden & Prince, 2020; Kleekamp & Zapata, 2018; Landrum, 2001).

Carroll and Rosenblum (2000), Dyches et al., (2009), Hayden and Prince (2020), Kleekamp and Zapata (2018), Landrum (2001), and Menchetti et al., (2011) have been examined in my study in relation to the portrayals of the disabled first-person protagonists in the children's and young adult literature being taught in grades 7-12 in Ontario schools, based on the work of Bates (2017).[44]

Research Ethics

Because my dissertation research encompasses an autoethnographic component, approval was sought and received from York University's Human Participants Review Sub-Committee. The Committee determined that my research contained minimal risk and subsequently approved my research ethics protocol on October 27th, 2022.

Conclusion

In this chapter, I have described the research methods that I have used to answer the first research question of my study, including the following components: autoethnography, autocritical disability studies, and critical inquiry. Each of these is vital to my analysis of the 12 disability-themed children's and young adult novels whose protagonists I have evaluated in Chapters 5 and 6. First, autoethnography and autocritical disability studies are important to my study's methodology because they enable me to use my experience as a disabled academic reader of disability-themed texts to critique the representations of disability in each narrative, both academically and experientially. Second, critical inquiry permits me to examine the depictions of disability in each novel from a social justice perspective regarding the ethical portrayal of disabled characters whose experiences are depicted in the literature being taught in grades 7-12

[44] For additional categorical representations regarding selecting and teaching disability-themed texts within education scholarship refer to Appendix A.

in Ontario classrooms (Bates, 2017). This chapter also includes my text selection process, the criteria used to evaluate each novel, the procedure used to analyse the representation of each novel's protagonist, and the research ethics that are associated with my study. In the next chapter, I critically examine the representations of five disabled first-person protagonists in five children's novels that were being taught in grades 7-12 in Ontario schools that met the inclusion criteria for my study based on Bates' (2017) data.

Chapter 5: In What Ways are Disabled First-Person Protagonists Being Depicted in the Children's Literature Being Taught in Grades 7-12 in Ontario Schools?

Introduction

In this chapter, I describe the representations of disability in the children's novels whose disabled first-person protagonists have met the inclusion criteria for my study. Initially, I investigate each novel's protagonist as an individual character study, after which I will conclude this chapter by discussing the common representational themes that I have located across the five narratives, and the protagonist's family demographic and identity information. The children's novels whose protagonists will be examined in this chapter are, Max in Freak the *Mighty* (Philbrick, 1993), Ambrose in *Word Nerd* (Nielsen, 2010), Melody from *Out of My Mind* (Draper, 2010), August in *Wonder* (Palacio, 2012), and Ally in *Fish in a Tree* (Hunt, 2015). Due to each of the disabled characters whose experiences I am examining in this chapter being the text's only or primary first-person protagonist, each novel has met the requirements to be included in my study. Moreover, each narrative has met the criteria recommended by Menchetti et al., (2011) when they suggest that the novel be "written from the perspective of the character with a disability" (p. 61). By identifying and demonstrating that each of the five texts has met this criterion, I will exclude this content from my analysis of each individual novel.

Disability Representation in *Freak the Mighty*

The first children's novel that I will be critically examining is *Freak the Mighty* (Philbrick, 1993).[45] In this novel, readers are introduced to Maxwell (Max) Kane, the novel's first-person protagonist who has been placed in a special education classroom for learning

[45] Philbrick's (1993) novel was being taught in 14 Ontario schools in grades 7-12 and is the 30th most commonly taught text according to Bates (2017).

disabled students (p. 3). From the opening sentence, Max identifies himself as having a developmental disability when he states, “I never really had a brain until Freak came along and let me borrow his for a while” (Philbrick, 1993, p. 1). In her analysis of the text, Meyer (2013) describes Max’s social and educational location at the beginning of the novel when she writes:

> Indeed, the novel begins with Max explaining to his reader that he is ‘a butthead,’ that he spends his school days in ‘L.D.’ classes – classes for students with learning disabilities – and that his ‘brain is vacant’ (4, 6). Because his educators have placed him in L.D. classes and his peers call him ‘the giant retard,’ readers must assume, at least in the first part of the novel, that he does in fact have some kind of disability; though his diagnosis is never given, he is treated as though he has an intellectual disability (35). (p. 281)

Meyer’s (2013) perspective regarding the identification of Max’s disability is contrasted by the work of Carico and Stanley, (1999) who describe Max as having “a learning disability” (“Freak the Mighty” para. 6). The description of Max’s placement in a class for learning disabled students, while characterizing him as being developmentally disabled, is a categorical error because learning disabilities and developmental disabilities are different; thus, disabled students who have learning disabilities and developmental disabilities receive different accommodations and other special education services. Even though Max may possibly have both learning and developmental disabilities, I suspect that what has occurred in this case is what Dolmage (2014) describes as “disability drift” in which “physical disabilities are equated with mental disabilities and vice versa” (p. 45).

In his self-introduction on the novel’s opening page Max describes himself as violent, “I had a way of saying things with my fists and feet” (Philbrick, 1993, p. 1). Throughout the text, Max’s violent behaviour and physical resemblance to his father cause Max to be feared

(Philbrick, 1993, pp. 4, 25-26, 40) because his father is in prison for murdering Max's mother (Philbrick, 1993, p. 26). As a result of his father's actions Max receives a "courtesy stigma" (Goffman, 2009, p. 31). Moreover, Max's characterization can be viewed from a eugenics-based standpoint, due to having the presumed identity of potential criminal thrust upon him, which implies that Max's behaviour is biologically linked to his father's criminality (McLaren, 2014). Quayson (2007) describes this representation of disability as "Disability as bearer of moral deficit/evil" (p. 42). By describing Max's conduct in moral and biological terms, *Freak the Mighty* (Philbrick, 1993) uses eugenics-based arguments to explain Max's behaviour which socially constructs him as a feared and pathologized potential criminal, thus combining the "villain" and "monster" representations of disability (Connor, 2017, p. 205).

Before Kevin moves in next door (Philbrick, 1993, p. 7), Max experiences bullying at school (Philbrick, 1993, p. 3), a form of violence that he experiences as a disabled character (Biklen & Bogdan, 1977). He appears not to have any friends and spends most of his time in his room in the basement of his grandparents' house, which he refers to as "down under" (Philbrick, 1993, p. 5) and which Dolmage (2014) describes as "Disability as Isolating and Individuated" (p. 44). Due to his friendship with Kevin, Max begins to go on adventures outside his home (Philbrick, 1993, pp. 28-40, 57-62). This leads to a moment of "aesthetic nervousness" (Quayson, 2007, p. 15) when Max and Kevin meet Tony D., who draws attention to their physical differences from society's socially constructed norm. Tony D. states, "Yeah, Andre the Giant and the dwarf, hold on a sec, I want a word with you" (Philbrick, 1993, p. 30). At this moment readers discover how Max and Kevin, as disabled characters, are perceived in public spaces when we are shown the ableism and social stigma that they experience due to their "stareable bodies" (Garland-Thomson, 2009, p. 8). Max and Kevin's physical otherness is a

recurring theme throughout the novel (Quayson, 2007). One demonstration of this is that Kevin is given the nickname "Freak" due to his physical disabilities (Philbrick, 1993, p. 2). Thus, Kevin's depiction as a disabled character is historically linked to the Freak Shows of the 19th and early 20th centuries where disabled people and other marginalized individuals were publicly displayed for the entertainment of abled people (Bogdan, 1990; Garland-Thomson 1997). One example of this in *Freak the Mighty* (Philbrick, 1993) occurs when Kevin and Max become a spectacle at school. Max narrates:

> But Freak was riding me like he's the jockey and I'm the horse, he's steering me around the classroom showing off. He's raising his fist and punching it in the air and going 'Freak the Mighty! Freak the Mighty! Freak the Mighty!' And pretty soon he's got all the other kids chanting, 'Freak the Mighty'! (p. 78)

In this example, Max and Kevin are using their combined supercrip (Schalk, 2016) identity to challenge the authority of their teacher by putting themselves on display for the entertainment of their classmates. Moreover, this moment is a textual illustration of the "Overcoming or Compensation" (Dolmage, 2014, p. 44) portrayal of disability because, together, Max and Kevin collectively overcome their impairments (Philbrick, 1993, p. 40).

In the course of the novel, Max transfers from a special education class to a general education classroom (Philbrick, 1993, p. 75), and learns to read (p. 81) which leads one of his teachers to suggest that Max does not have a disability (p. 81). Max documents this discussion as follows:

> My reading skills tutor, Mr. Meehan, he says stuff like, 'Max, the tests have always shown that you're not dyslexic or disabled, and this proves it. As you know, heh heh, my personal opinion has always been that you're lazy and stubborn and you didn't *want* to

> learn. So if hanging out with Kevin somehow improves your attitude and your skills, that's great. Keep up the good work.' (p. 81)

Under Kevin's tutelage, Max learns to read and causes his tutor to question if Max has a learning disability. By doing so, Mr. Meehan's comments raise questions about Max's identification and subsequent labelling as a disabled student while demonstrating the role that Foucault's concepts of "bio-power" (Foucault, 1990, p. 140) and "the normalizing gaze" (2012, p. 184) have regarding the education of disabled students. Based on his school's "normalizing gaze" (Foucault, 2012, p. 184), along with the power granted to schools over the education that their students receive, Mr. Meehan has socially constructed Max as having been inappropriately placed in special education due to his lack of motivation (Philbrick, 1993, p. 81). However, this perspective problematically denies the impact that Max's impairment has had on him both socially and academically.

In either case, when Max and Kevin unite to create their combined identity as Freak the Mighty the novel suggests that together they are overcoming or compensating (Dolmage, 2014, p. 44) for their impairments. Max discusses the new combined identity that he and Kevin have created for themselves when he recalls Kevin's statement that, "'We're Freak the Mighty that's who we are. Nine feet tall, in case you haven't noticed.' [Max narrates] 'That's how it started, really, how we got to be Freak the Mighty, slaying dragons and fools and walking high above the world'" (Philbrick, 1993, p. 40). By creating a new identity for themselves Max and Kevin have developed the means through which they can collectively address the social stigma and other forms of ableism that they experience because of their impairments. However, by doing so, Philbrick's (1993) text propagates the discourse that disabled characters need to overcome their impairments by becoming supercrips (Schalk, 2016) instead of using Max and Kevin's

experience to argue for societal change which more closely reflects a social model understanding of disability.

At the conclusion of the narrative Kevin dies in hospital. This places Kevin in a long line of inspirational disabled child characters in literature that have succumbed to the "kill or cure" (Dolmage, 2014, p. 43) depiction of disability. In kill or cure representations of disability, the disabled character dies after fulfilling their inspirational role in the development of the usually abled character's life, who has subsequently become a better person because of their relationship with the disabled character (Keith, 2001). In Kevin's case, he died because, as Dr. Spivak explains to Max, "his heart just got too big for his body" (Philbrick, 1993, p. 157) which is also an example of what Dolmage (2014) refers to as "disability as pathology" (p. 43). Dolmage (2014) elaborates on the "disability as pathology" trope in literature and film when he explains:

> There is almost always a moment in a narrative in which the disabled character is 'explained' by a doctor or nurse, who provides a sort of WebMD overview of their pathology. Disability rarely circulates in popular culture without a medicalized explanation and definition. (p. 43)

Moreover, this moment in the narrative is also revelatory or, in Quayson's (2007) words, "*disability as epiphany*" (p. 45). In this case, the epiphany is not that Kevin has a disability but rather that he has a terminal illness which explains his fantasy of getting a robot body (Philbrick, 1993, p. 52) as a coping mechanism in preparation for his early death. Furthermore, Kevin's deathbed scene is also presented in a moralizing way when he tells Max "Don't get me upset, … I won't have time, so you'll have to do it. Just write it down like you're talking. Put in all the fun we had, the cool things we did. Our adventures" (Philbrick, 1993, p. 151). The disability community describes this depiction of disability as the "inspirational" (Connor, 2017, p. 205)

disabled character. By the end of the text, Max has returned to his isolated existence after the death of his only friend. However, readers discover that Max has written the novel we have been reading (Philbrick, 1993, p. 160).

From an education perspective, Carico and Stanley (1999) recommend *Freak the Mighty* (Philbrick, 1993) to classroom teachers and school therapists as a "great read-aloud" (Carico & Stanley, 1999, "Literary Merit" para. 1). Moreover, Carico and Stanley (1999), suggest that teachers can conduct day-long disability simulation activities as part of a unit based on *Freak the Mighty* (Philbrick, 1993), (Carico & Stanley, 1999, "Follow-up Activities" para. 7) even though many disabled people (me included) consider disability simulation activities to be extremely offensive (Lalvani & Broderick, 2013). Finally, Carico and Stanley, (1999) encourage teachers to ask their students questions such as, "Do I treat disabled persons differently from nondisabled persons? If so, how? Do I believe that physical disabilities would keep me from being friends with a person? Why or why not?" (Carico & Stanley, 1999, "School-Wide Interventions" para. 9). Carico and Stanley's questions are problematic because they reinforce the socially constructed divide between abled and disabled people by permitting abled students to justify their prejudicial beliefs regarding disabled people. Instead, teachers can challenge the social exclusion and other barriers that disabled people experience in social settings by showing students that living with a disability is a normative part of the human experience (Quayson, 2007, p. 52) by challenging the social stigma that disabled people encounter through the use of inclusive pedagogy. Landrum (2001) suggests that teachers select disability-themed narratives in which "The events are realistic and reasonable, rather than unrealistic and contrived. …A superhero theme does not appear in the story. ...[and] even though the book is fiction, all the data pertaining to the disability are accurate" (p. 254). Based on Landrum's (2001) criteria, *Freak the*

Mighty (Philbrick, 1993) is not an appropriate choice for a disability-themed language arts unit due to its superhero-based response to disability, the inaccurate medical information communicated throughout the narrative, and the text's unrealistic plot. Three alternative novels that examine similar themes to *Freak the Mighty* which challenge deficit-based understandings of disability and also focus on the protagonist's intersectional gender and sexual identities are: *The Trouble with Robots* (Mohrweis, 2022),[46] *Thanks a Lot, Universe* (Lucas, 2021),[47] and *Jude Saves the World* (Riley, 2023).

Disability Representation in *Word Nerd*

In *Word Nerd* (Nielsen, 2010) readers meet Ambrose Bukowski, the 12-year-old only child of a single parent family. Ambrose's mother works as a sessional professor who moves the family every few years in search of a tenure track position (Nielsen, 2010, pp. 18, 86).[48] At the beginning of the text, readers learn that Ambrose is lonely, poor, experiences bullying on a regular basis, and that he has a life-threatening peanut allergy (Nielsen, 2010, pp. 1-4, 73-74). Ambrose describes the social isolation that he experiences at school and his family's economic circumstances when he states:

> Sometimes a guy could feel lonelier surrounded by people than he could when he was alone. …Mom could never afford Nikes, but when she'd taken me to Chinatown on the weekend, I'd spotted a knockoff brand that was practically identical and a quarter of the price. (pp. 1-2)

Ambrose also explains why he does not have any friends at school when he narrates:

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[46] This novel has a sequel *The Problem with Gravity* (Mohrweis, 2023).
[47] This novel has a sequel *You Owe Me One, Universe* (Lucas, 2023).
[48] *Word Nerd* (Nielsen, 2010) is the 162nd most taught book in Ontario schools in grades 7-12 according to Bates (2017).

> On the field, Troy, Mike, and Josh were kicking a soccer ball around. For a moment I thought about asking if I could join them, but the last time I tried that they made me the goalie, then kicked the ball at my head over and over again until I got a headache. So I decided to stay put. (p. 2)

Later Ambrose elaborates on his history of friendlessness when he tells his mother, "I told her that I had friends, and their names are Troy, Mike, and Josh. I can see how happy it makes her, because in Edmonton, Regina, and Kelowna, I never really had friends" (Nielsen, 2010, p. 9). In opening the novel by describing Ambrose's loneliness, the bullying that he experiences, and his family's economic status, Nielsen has established three of the four most important aspects of Ambrose's identity, the fourth being Ambrose's life-threatening peanut allergy. Due to the episodic nature of Ambrose's impairment (Vick, 2014) his disability is not as prominent as those of the other four protagonists whose representations I will critique in this chapter. This enables Ambrose to "pass" (Goffman, 2009, p. 74) as an abled person who does not self-identify as disabled.

In response to Ambrose's allergy, his school has instituted a new 'no peanuts' policy to accommodate him (Nielsen, 2010, p. 4). However, Troy blames Ambrose for the school's new 'no peanuts' policy when he states, "I've been going to this school for, like, six years. For six years, I've eaten peanut butter and jam sandwiches for lunch. Then you show up, and suddenly our school's declared a peanut free zone" (Nielsen, 2010, p. 3). In retaliation for Ambrose's allergy causing the school to implement a 'no peanuts' policy, Troy hides a peanut in Ambrose's sandwich, resulting in an allergic reaction (Nielsen, 2010, pp. 5-7), which is a form of violence that Ambrose experiences as a result of his disability (Biklen & Bogdan, 1977). Ambrose describes what experiencing an allergic reaction is like when he explains, "I was going into

anaphylactic shock. All the mucous membranes in my throat were swelling up and I could hardly breathe" (Nielsen, 2010, p. 6). Ambrose's description of his allergic reaction is important because the realistic representation of a disabled character's impairment is an essential part of inclusive disability-themed literature as Andrews (1998) explains, "The most important and most often cited criterion when selecting inclusion literature is accuracy of information (related to the character's disability)" (p. 422). By portraying Ambrose's allergic reaction in a realistic manner, readers can learn what it is like to have an allergic reaction.

When asked why they placed the peanut in Ambrose's lunch Troy, Josh, and Mike explain:

> [Josh] 'We thought he was exaggerating'…[Mike] 'Yeah how could we know he was serious. …See? He's [Ambrose] a big fat liar…' [Ambrose lied about going to Troy's birthday party to hide from his mother the fact that he does not have any friends (p. 10)]. [Troy] 'He [Ambrose] told us his family was loaded and the only reason he went to public school was because his parents wanted him to mix with regular kids.' …[Josh] 'He told us you spent your weekends up at Whistler, in your chalet.' (Nielsen, 2010, pp. 23-24)

In their defence, Troy, Mike, and Josh use Ambrose's history of lying to justify their actions, thereby blaming Ambrose's past behaviour for their skepticism when he disclosed that he has a life-threatening allergy. Ambrose's mother responds by threatening to have the boys charged when she states:

> You three deliberately put a peanut in my son's sandwich, knowing that he had a deadly peanut allergy. What kind of heartless half-wits …And calm down? My son was almost

> killed and you're asking me to f-ing calm down? …I could file criminal charges against these three punks: assault causing bodily harm, willful malice. (Nielsen, 2010, pp. 22-23)

Mrs. Bukowski's threat to have Troy, Mike, and Josh charged for placing a peanut in Ambrose's lunch demonstrates how serious the incident was as well as how protective she is of Ambrose. Since her husband died before Ambrose was born, his mother has been protective of him due to the grief that she still experiences, even though her husband died over 12 years ago (Nielsen, 2010, p. 17). Because of her fear that Ambrose will also die, Mrs. Bukowski has become extremely protective of Ambrose. For example, she does not have the internet at home because she is afraid of "pornographers" and "pedophiles" (Nielsen, 2010, p. 40). In a second example, she was livid when she learned that Ambrose ate supper with their landlords, because their son had just been released from jail (Nielsen, 2010, pp. 51-52). Lastly, Ambrose has to sneak out when his mother is at work to join the Scrabble Club and later to go to the competition because Mrs. Bukowski would not sign the permission form (Nielsen, 2010, pp. 80-85, 157, 177). Then, after Ambrose gets caught, she becomes even more controlling (Nielsen, 2010, pp. 206, 210-214, 218-219). Each of these incidents highlights the power that Mrs. Bukowski has over her son's life which requires Ambrose to lie repeatedly in order to escape from her control, including running away from home (Nielsen, 2010, pp. 223-230). By governing almost every aspect of her son's life Mrs. Bukowski denies Ambrose's autonomy and prevents him from participating in activities that are common for children his age. Andrews (1998) highlights the importance of portraying disabled characters as having similar life experiences to their abled peers when she states:

> Teachers should also look for books that point out that characters with disabilities share the same kinds of life experiences, dreams, successes, and failures that the readers do – to

> do otherwise is to select works that portray characters with disabilities as one sided, as only disabled. (p. 423)

Unlike other characters whose disabilities are used to justify their social exclusion, in *Word Nerd* it is the limits that Ambrose's mother puts on his social activities that prohibit him from having the experiences that he desires, resulting in the numerous acts of rebellion that Ambrose engages in throughout the narrative.

Principal Acheson discourages Mrs. Bukowski from pressing charges when he informs her, "If you're going to make threats like that, I'll have to call the boys' parents as well as the school board superintendent" (Nielsen, 2010, p. 23). As a result of their actions Troy, Josh, and Mike received only "a severe reprimand … their parents have been informed. They're also on lunchroom cleanup for a month (Nielsen, 2010, p. 25).

By failing within the text to appropriately address the bullying that Ambrose experiences, Nielsen is showing readers how schools, as social institutions, often fail to respond appropriately to bullying, as witnessed by the light punishment that Troy, Mike, and Josh receive (Nielsen, 2010, p. 25). Instead, Principal Acheson recommends that Ambrose receive his education through "correspondence schooling" (Nielsen, 2010, p. 39) which further isolates the already friendless Ambrose by removing him from the school. In this scene, Principal Acheson is asserting his educational authority over Ambrose by examining and pathologizing him using his "normalizing gaze" (Foucault, 2012, p. 184) through which he determines that Ambrose should be removed from the school. This point in the novel demonstrates the institutional power that principals have over the education of vulnerable students who are subjected to their authority and control within schools. As Foucault (2012) explains:

> The examination combines the techniques of an observing hierarchy and those of normalizing judgment. It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates and judges them. (p. 184)

By excluding and marginalizing Ambrose, Principal Acheson illustrates the power that the pathologizing administrative gaze has within education. In this case, Principal Acheson's authority is also a form of "bio-power" (Foucault, 1990, p. 140) due to the impact that his decision to recommend that Ambrose receive his education through "correspondence schooling" (Nielsen, 2010, p. 39) has on Ambrose's social and academic life. In responding to Ambrose's allergic reaction by suggesting that he receive his education through home schooling, Principal Acheson has socially constructed Ambrose as having an individual medical problem which requires an individualized medical solution which is to remove Ambrose from school (Nielsen, 2010, p. 39), which Dolmage (2014) describes as "disability as pathology" (p. 43). The social isolation and educational segregation that Ambrose experiences throughout the novel is an example of the social exclusion that disabled characters commonly encounter in literature (Dolmage, 2014). Even though Ambrose develops friendships with Cosmo and the other adult members of the Scrabble Club (Nielsen, 2010, p. 194) he remains segregated from children his own age due to having been removed from school.

While reading *Word Nerd*, I located only a limited number of occurrences of problematic language in the text, and there are only a small number of deficit-based depictions of Ambrose as a disabled character in the novel. Moreover, *Word Nerd* is thematically rich due to the text's exploration of family relationships, social stigma, bullying, friendships, single parent families, poverty, and the importance of language. Additionally, the text is artfully narrated from the first-

person perspective of a protagonist who is living with an invisible episodic disability. Thus, *Word Nerd* could be an excellent choice for classroom teachers to use in their language arts classrooms. However, if teachers are looking for more recently published disability-themed children's novels that explore similar themes, *Honestly Elliott* (McDunn, 2022), *Rain Rising* (Comrie, 2022), and *No Matter the Distance* (Baldwin, 2023) are good options.

Disability Representation in *Out of My Mind*

In *Out of My Mind* (Draper, 2010)[49] readers are introduced to Melody Brooks, an 11-year-old girl who has cerebral palsy, synesthesia,[50] and is non-verbal.[51] Throughout the narrative, Melody is viewed by other characters through their deficit-based understanding of disability which Quayson (2007) refers to as "*disability as the interface with otherness* (*race, class, sexuality, and social identity*)" (p. 39),[52] and Dolmage (2014) describes as "disability as pathology" (p. 43). Moreover, Foucault's concepts of "the normalizing gaze" (2012, p. 184) and "bio-power" (1990, p. 140) are demonstrated throughout the novel. One example occurs when Melody is diagnosed by Dr. Hugely, as he states, "It is my opinion that Melody is severely brain damaged and profoundly retarded" (Draper, 2010, p. 22). By misdiagnosing Melody with a developmental disability Dr. Hugely has propagated the myth that Dolmage (2014) describes as "disability drift" which occurs when "physical disabilities are equated with mental disabilities and vice versa" (p. 45). Moreover, Dr. Hugely's diagnosis has "create[d] the 'problem' of the disabled person" (Davis, 1995, p. 24) through his pathologization of Melody (Dolmage, 2014).

[49] This novel has a sequel *Out of My Heart* (Draper, 2021).
[50] Throughout the novel, Melody describes her multi-sensory experiences such as when she tells the reader that she "can almost hear colors and smell images when music is playing" (Draper, 2010, p. 5). Melody later learns that what she is experiencing is called synesthesia (Draper, 2010, p. 220). However, due to space constraints, I will not discuss this aspect of Melody`s impairments.
[51] According to Bates (2017), *Out of My Mind* (Draper, 2010) was only being taught in 2 Ontario schools.
[52] The italics are in the original.

However, when Mrs. Brooks argues that "a person is so much more than a name of a diagnosis on a chart" (Draper, 2010, p. 23) and gives evidence supporting Melody's intelligence, Dr. Hugely uses his medical power to dismiss her evidence and reminds Mrs. Brooks of all of Melody's deficits. By doing so, Dr. Hugely has socially constructed Melody as a "burden" on her parents which Biklen and Bogdan (1977, p. 8) have documented as one of the most prominent deficit-based responses to disability.

Later in his discussion with Mrs. Brooks, Dr. Hugely proposes three solutions to solve – in his view – the medical problem of Melody's education when he recommends that Melody's parents can either "keep her at home … send her to a special school ... [or] put Melody in a residential facility where she can be cared for and comfortable" (Draper, 2010, p. 24). Dr. Hugely's perspective appears to be a consequence of the medical model of disability which portrays disability as an individual medical pathology that requires an individualized medical response (Dolmage, 2014). However, in Melody's case, readers witness not only the impact of Dr. Hugely's diagnostic gaze on her education but also the importance of parental activism regarding inclusive education (Carey et al., 2020). This is witnessed in the narrative when, instead of placing Melody in one of the restrictive educational options suggested by Dr Hugely (Draper, 2010, p. 24), Mrs. Brooks enrolls her daughter in her community's local elementary school (Draper, 2010, pp. 26-27).

When Melody enters school, she describes the social exclusion that she experiences from the abled students when she narrates, "They [the abled students] look like they're having so much fun. They ask one another to play, but no one's ever asked any of us" (Draper, 2010, p. 28). Goffman (2009) suggests that behaving as though the stigmatized person is "not present at all" (p. 18) or as Melody explains, "we get treated like we're invisible" (Draper, 2010, p. 29) is

one technique that non-stigmatized people use to avoid having to interact with stigmatized individuals.

Moreover, Melody's social exclusion and placement in segregated special education classrooms are also examples of Dolmage`s (2014) argument that disabled characters are often portrayed as being isolated from society due to their impairments (p. 44). Melody's social marginalization continues when she is placed in an integrated classroom, which I will illustrate by describing Melody's social relationship with Rose. Melody meets Rose when she starts attending Mr. Dimming's class (Draper, 2010, p. 99). Initially, Melody looks forward to seeing Rose during class on Wednesdays, but Melody discovers that their friendship is conditional because Rose is only willing to spend time with her during class or on the weekend (Draper, 2010, p. 100). This is demonstrated when Melody's family invites Rose to the Aquarium. When they are at the Aquarium Rose is approached by Molly and Claire who ask her "You here with your mom? …Your dad?" (Draper, 2010, p. 119). Rose tells them "I'm here with Melody and her family" (Draper, 2010, p. 119), leading Claire to ask, "On purpose?" (Draper, 2010, p. 119), to which Rose replies, "It's not so bad" (Draper, 2010, p. 119). In other social situations Melody confides that she is never invited by Rose or other students to sit with them at lunch, attend their birthday parties, or participate in other social activities after school (Draper, 2010, p. 146). In a third example, Rose questions why Melody has come to Mr. Dimming's classroom when she knows that this is where students are meeting to try out for the Whiz Kids team (Draper, 2010, p. 177). In this instance, Rose's question assumes that Melody is either not interested in, or not capable of, being a contributing member of the Whiz Kids team. By doing so, Rose is questioning Melody's competence, also witnessed in the limited and situational nature of her relationship with Melody. In a final example, Rose confesses to not calling Melody to let her

know about the change to their flight time, a decision she made in solidarity with the other members of the Whiz Kids team (Draper, 2010, p. 291). Rose explains her actions when she states, “We looked at each other. Everyone made just a tiny head shake no. … So I closed the phone and we got on the plane. I … never made the call” (Draper, 2010, p. 291). As an apology for deliberately excluding her, the members of the Whiz Kids team give Melody their Ninth-Place trophy (Draper, 2010, p. 292). In response Melody breaks it before stating “I don’t want it! … You deserve it!” (Draper, 2010, p. 292) and quickly leaves the room. Each of these moments of provisional friendship and social exclusion are representative of the social difficulties that disabled people experience due to the “courtesy stigma” (Goffman, 2009, p. 31) that others fear acquiring by interacting with disabled people (Shakespeare, 2014). Thus, Melody ends the novel where she begins the narrative, being socially excluded and having to continuously demonstrate her academic competence.

A second common response utilized by non-stigmatized individuals is to stare at individuals whose stigmas are visually apparent (Goffman 2009, p. 16). Garland-Thomson, (2009) describes not only why abled people stare at disabled individuals but also the impact that doing so has on disabled people when she writes:

> When we do see the usually concealed sight of disability writ boldly on others, we stare in fascinated disbelief and uneasy identification. …The visibly disabled body intrudes on our routine visual landscape and compels our attention, often obscuring the personhood of its bearer. (p. 20)

Melody and the other students from her segregated special education class experience social stigma as they are stared at by the abled students when they are integrated into Mrs. Lovelace’s music class. Melody documents this encounter when she states:

> All of the 'normal' children in the music class – I guess about thirty of them turned to stare. Some laughed. Others looked away. …Two girls Molly and Claire … mimicked Willy. They made sure they stayed just out of the teacher's line of sight. But I saw it. So did Willy. (Draper, 2010, pp. 93-94)

In this example, Melody describes the diverse responses that the students in Mrs. Lovelace's music class have to the integration of Melody and her classmates, which Goffman (2009) refers to as "mixed contacts" (p. 12) as well as being a demonstration of Quayson's (2007) theory of "aesthetic nervousness" (p. 15) due to the social discomfort that occurs during the literary interactions between abled and disabled students in Mrs. Lovelace's music class. Unlike other teachers, Mrs. Lovelace responds to the ableism that the disabled students experience by disciplining Molly and Claire for their behaviour (Draper, 2010, p. 95). However, her actions are questionable because she describes the disabled students as "guests" (Draper, 2010, p. 95) which socially constructs them as different from the presumed abled students who have the right to be in her classroom. Even though Mrs. Lovelace is supportive of the integration of disabled students, other teachers that Melody has have differing philosophies regarding the education of disabled students. For example, Melody's second-grade teacher Mrs. Tracy "presumed (Melody's) competence" (Biklen & Burke, 2006) by giving her access to age- and grade-appropriate language arts content. Melody writes:

> She (Mrs. Tracy) figured out I liked books, so she got some earphones and hooked me up with audiobooks on CD. She started out with baby stuff like Dr. Seuss … [but] she figured out I needed something better. I listened to all of the Baby-Sitters Club books and those goofy Goosebumps books. She asked me questions after each book, and I got every single question right. (Draper, 2010, p. 52)

Miss Gordon is another teacher who also "presumes [Melody's] competence" (Biklen & Burke, 2006) and for whom Melody has written an autobiography assignment which readers discover at the conclusion of the text is the novel that we have been reading. (Draper, 2010, p. 294)

The perspectives of Mrs. Tracy and Miss. Gordon regarding Melody's education are contrasted by her third-grade teacher Mrs. Billups who has a deficit-based medical model informed philosophy of special education which informs her beliefs and attitudes regarding her disabled students. Melody narrates the deficit-based age- and grade-inappropriate curriculum that she and her classmates endure in Mrs. Billups' class. Melody records:

> Mrs. Billups started every morning by playing her favorite CD. I hated it. 'Old Macdonald Had a Farm,' 'Twinkle, Twinkle, Little Star' … Mrs. Billups put it on – at full volume every morning. … Once she had the tin-pan band on, Mrs. Billups went over the alphabet. Every single day. With *third* graders. (Draper, 2010, p. 53)

In this example, Melody describes the fact that curriculum content and expectations are often below grade level for students in self-contained special education classrooms, in keeping with the deficit-based medical model informed nature of special education, which academic research regarding student placement and curricular access confirms (Agran et al., 2020; Kurth & Mastergeorge, 2012). In response to the age and grade-inappropriate curriculum that Melody and her classmates are receiving, Mrs. Brooks confronts Mrs. Billups, who argues "These children need constant review because they don't retain information like the rest of us" (Draper, 2010, p. 56). Mrs. Brooks replies "I dare anything for my daughter, ... and the rest of these children" (Draper, 2010, p. 57) and advocates for Melody to be placed in general education classes while receiving support from an educational assistant (Draper, 2010, pp. 90, 104). When

Melody is placed in general education classes, she is able to demonstrate her academic skills (Draper, 2010, pp. 107, 110), but it is not until Melody receives an assistive communication device that she is able to participate in school and communicate independently (Draper, 2010, p. 132). However, Melody is still not presumed to be competent by Mr. Dimming when he tells Catherine that "I don't think that it's appropriate for Melody to be here. This is not a recreational activity just for fun. The purpose of this meeting is to choose our official [Whiz Kids] team" (Draper, 2010, p. 178). Despite Melody having previously demonstrated her academic knowledge in his class (Draper, 2010, pp. 110, 151), Catherine (Melody's educational assistant) has to argue for Melody's right to try out for the team (Draper, 2010, p. 179).

When Melody does well academically, she is either accused of cheating (Draper, 2010, p. 151), or congratulated and portrayed as an inspirational disabled character (Draper, 2010, p. 152; Connor, 2017). For instance, when she is permitted to join her school's Whiz Kids team and the team win their local tournament Melody is socially constructed as an inspirational disabled character just for being on the team (Draper, 2010, pp. 225-227). This representation of Melody as a disabled character also occurs during the television news broadcast and the newspaper coverage of the tournament (Draper, 2010, pp. 240-241). By portraying Melody as an inspirational disabled character, Mr. Dimming and the media are reinforcing the myth that disabled people deserve exceptional praise for doing ordinary life tasks such as being a good student or being a member of a winning team, in keeping with the overcoming discourse regarding disability (Dolmage, 2014). Linton (1998) elaborates on how the overcoming narrative applies to the lives of disabled people when she writes:

> Because it is physically impossible to *overcome* a disability, it seems that what is *overcome* is the social stigma of having a disability. This idea is reinforced by the equally

> confounding statement 'I never think of you as disabled.' An implication of these statements is that other members of the group from which the individual has supposedly moved beyond are not as brave, strong, or extraordinary as the person who has *overcome* that designation. (p. 31)

The news media's focus on Melody during the post-tournament interview highlights the problematic cultural discourse that disability needs to be overcome. By doing so the media is communicating the message that ordinary activities become exceptional feats when they are completed by a disabled individual. This results in unreasonably high expectations being set for other disabled people and presents them as failures for not meeting or exceeding these socially constructed and often unattainable requirements to participate in education and recreational activities.

Even more problematic, however, is that Melody`s characterization utilizes the non-verbal genius rendition of the supercrip trope (Dolmage, 2014). Melody describes herself as "having a photographic memory" (Draper, 2010, p. 13) then for the remainder of the text Melody is required to continuously demonstrate her intelligence, which I discussed in Melody's interactions with Mr. Dimming and the Whiz Kids team. Thus, in *Out of My Mind*, Draper (2010) contends that disabled students need to continually demonstrate their intelligence in order to remain in general education classrooms, instead of arguing for them to receive inclusive education placements. Moreover, the narrative documents how the ideology of overcoming requires disabled students to continuously prove that they belong in general education and punishes those who are unable to meet this exceptionally high standard of academic attainment.

From my perspective as a disabled academic reader, Melody's portrayal as a supercrip is the most problematic aspect of her character because, otherwise, many of her experiences in the

novel are similar to ones that I have experienced throughout my education. For example, shortly after I was born prematurely, a doctor gave my parents a similar negative prognosis based on his deficit-based medical model understanding of disability. Second, I had a teacher who refused to teach me, so I was sent to a residential special education school which, as I discussed above, was one of the options that Dr. Hugely suggested to Mrs. Brooks regarding Melody`s education. Third, my mother was a strong advocate for my educational rights, as is Mrs. Brooks for Melody. Fourth, when teachers questioned my ability to understand the advanced language that I was using my mother convinced the school to get me tested, which showed that I understood the advanced terminology that I was using at a young age. Fifth, when I returned to the regular education system I was provided with assistive technology and the support of educational assistants and inclusive teachers, which enabled me to be included in general education classrooms because they presumed my competence (Biklen & Burke, 2006), which Melody also eventually receives. Sixth, I also experienced bullying, fake friendships, and social exclusion which Melody describes throughout the novel. Last, similarly to Melody, it was my intellect that enabled me to be included in age- and grade-appropriate academic content which permitted me to graduate secondary school and earn a bachelor's degree and two graduate degrees. However, without the parental advocacy of my mother and the support of inclusive teachers and educational assistants that I received in secondary school, my life would have been completely different, but do my achievements make me a supercrip? (Schalk, 2016). From an outsider's perspective, one may consider me to be a supercrip based on my academic qualifications, but I do not view myself this way. Instead, due to the internalized ableism that I regularly experience, I often consider myself to be a failure due to my inability to meet society's socially constructed and unrealistic expectations regarding the participation of disabled people.

Out of My Mind (Draper, 2010) has been the most challenging of the novels that I have discussed in this study because of the numerous similarities that exist between Melody's fictional experiences and my real-life experiences as a disabled person. Rosenblatt (1995) describes the similarities between fictional characters' experiences and the lives of readers when she writes,

> the literary experience has been phrased as a *transaction* between the reader and the author's text. … there will be selective factors moulding the reader's response. He comes to the book from life. He turns for a moment from his direct concern with the various problems and satisfactions of his own life. He will resume his concern with them when the book is closed. Even while he is reading, these things are present as probably the most important guiding factors in his experience. (p. 34)

Due to how strongly Melody's fictional experiences "mirror" (Bishop, 1990, p. 4) my own experience as a disabled person, *Out of My Mind* (Draper, 2010) evoked a powerful literary and personal response to the narrative. Even though I have now read this novel at least four times, it has only been with some deep reflection on Melody's experiences and the book's themes that I have fully appreciated the richness of *Out of My Mind*. As a disabled scholar, I have a deep appreciation for the level of disability "cultural authenticity" (Brown, 2020, p. 143) that Draper brought to Melody's characterization and experiences, such as the level of detail that she provides regarding Melody's impairment, her daily activities, experiences with ableism, and her developing identity as a disabled person. Draper was able to depict Melody's character and experiences with a high degree of realism because Melody's character in *Out of My Mind* was based on her daughter's experience as a disabled person (Brown, 2020). If the text had been published a decade earlier and had been made available to me while I was attending a residential

special education school, it may have produced a life-changing literary encounter based on the novel's subject matter and themes.

Now that I have discussed my literary interactions with the text, in this section I will examine the merits of *Out of My Mind* (Draper, 2010) as an inclusive language arts novel. I will begin my examination of the narrative by using the criteria developed by Hayden and Prince, (2020) which I have divided into two sets of criteria: "strength-based" and "Narrative Appeal, Effectiveness, Flow". When I applied Hayden and Prince's (2020) first set of criteria to *Out of My Mind* I discovered that Melody meets many of their criteria such as, "accepts his/her disability", … "character with a disability grows and changes throughout the story", [and has] … "similar life experiences as peers without disabilities" (p. 12), thus demonstrating that Melody is a fully developed character. However, *Out of My Mind* (Draper, 2010) illustrates numerous examples of physical, attitudinal, and educational obstacles that impede Melody's social and educational inclusion. Therefore, Melody must continuously fight for her right to be included due to the medical model informed worldview of her teachers, classmates, and medical professionals. Consequently, *Out of My Mind* reinforces numerous deficit-based understandings of disability such as the social exclusion, pathologization, and overcoming/inspirational discourses of disability (Connor, 2017; Dolmage, 2014) each of which socially constructs disabled individuals as having a negative and highly stigmatized form of societal difference from the assumed abled norm. Moreover, *Out of My Mind* (Draper, 2010) does not meet Hayden and Prince's (2020) criteria that the "Setting allows [the] character with a disability to be included in society (school, work, recreation) [and] Theme rectifies a stereotype/myth about people with disabilities" (Hayden & Prince, 2020, p. 12). This is because the text requires that Melody earn the right to be included within her school's educational and social environs without questioning

the impact that doing so has on her. In relation to Hayden and Prince's (2020) second set of criteria "Narrative Appeal, Effectiveness, Flow" (p. 12) *Out of My Mind* (Draper, 2010) addresses all eight of their criteria, making *Out of My Mind* a linguistically appropriate, engaging, and thematically rich reading experience for middle grade students. Three examples of this include, "Language/vocabulary is appropriate for children/clear style/appropriate vocabulary. Narrative and dialogue portraying characters with disabilities is appropriate for age of reader. [and] … Theme is familiar and appealing to children (making friends, sibling conflicts, school issues)" (Hayden & Prince, 2020, p. 12).

After conducting my analysis of *Out of My Mind* (Draper, 2010), I would caution teachers about the deficit-based depictions of disability and discriminatory language that are present throughout the narrative. Before teaching *Out of My Mind* I suggest that teachers prepare students for its content by introducing them to key critical disability studies concepts such as ableism, ableist language, the social and medical models of disability, common deficit and disability-affirming representations of disability, and the historical and contemporary experiences of disabled people in society (Baglieri & Lalvani, 2019; Connor & Bejoian, 2007). If teachers and school librarians are looking for newer disability-themed children's novels that are similar to *Out of My Mind* (Draper, 2010), *Real* (Cujec & Goddard, 2020), and *Air* (Roe, 2022) could be good alternatives.

Disability Representation in *Wonder*

In *Wonder* (Palacio, 2012) readers are introduced to August (Auggie) Pullman who is mixed-race Brazilian American, has a facial deformity and is hard of hearing (Palacio, 2012, pp.

1, 26, 32, 65).[53] Until recently August has been home-schooled due to his numerous surgeries (Palacio, 2012, pp. 1, 3).[54] August's otherness (Connor, 2017; Quayson, 2007) is communicated by the novel's title and epigraph which states, "fate smiled and destiny laughed as she came to my cradle" which is a quotation from Natalie Merchant's (1995) song *Wonder* (quoted in Palacio, 2012, unpaginated). The song on which the novel's title is based tells the story of a physically disabled child which foreshadows the ableism that August experiences by socially constructing him as "a literary freak" (Meyer, 2022, p. 62). Meyer defines the term "literary freak" when she writes:

> In literary narratives, freak characters – especially children and adolescents – sacrifice dignity and humanity in order to advance plotlines, catalyze growth, and inspire others. They serve to help other characters, along with readers, appreciate what they have, put their problems in perspective, and never give up – because if a freak keeps trying so can anyone. (p. 62)

Meyer's (2022) phrase "literary freak" harkens back to the historical spectacle of Freak Shows in which disabled people, racialized individuals, and members of other diverse minority communities were publicly displayed in often ableist, racist, and other demeaning ways as a form of popular entertainment during the 19th and early 20th centuries (Bogdan, 1990). Likewise, Wheeler (2013) describes the fear that August's appearance causes other characters as the "monster model" (p. 345). This idea is communicated throughout the narrative when literary and

[53] Even though August's sister Via describes their mother as being Brazilian American (Palacio, 2012, pp. 26, 32) these are the only references regarding August and Via's ethnicities in the novel. Moreover, August does not participate in Brazilian culture or experience racism because of his mixed-race identity in the text.
[54] According to Bates (2017), *Wonder* (Palacio, 2012) is the 41st most commonly taught text in grades 7-12 in Ontario schools.

film characters that are feared, such as serial killers, aliens, and orcs (Wheeler, 2013, p. 345) are used to describe August's appearance, which socially stigmatizes him by questioning his humanity (Palacio, 2012, pp. 25, 81). The fear that August's appearance causes other characters is also present in their belief that if they come into contact with him, they will contract "the plague" (Palacio, 2012, p. 37) which reflects the disability as contagion myth (Park et al., 2003).

In the opening paragraph of the novel August describes the fear that his facial difference causes others, as well as his beliefs about himself when he states:

> I feel ordinary. Inside. But I know ordinary kids don't make other ordinary kids run away screaming in playgrounds. I know that ordinary kids don't get stared at wherever they go. If I found a magic lamp and I could have one wish, I would wish that I had a normal face that no one ever noticed at all. (Palacio, 2012, p. 1)

From his opening statements, August has been positioned to reflect numerous deficit-based understandings of disability. These include the physical otherness, pathologization, and fear that society associates with disability and those who have them (Dolmage, 2014; Quayson, 2007). Each of these deficit-based social constructions of disability exemplify Quayson's (2007) theory of "aesthetic nervousness" (p. 15) by highlighting the apprehension that the abled characters experience when they meet August who has "a stareable body" (Garland-Thomson, 2009, p. 58) which emulates the "encounter between a starer and a staree" (Garland-Thomson, 2009, p. 3) in the real world. Moments of "aesthetic nervousness" (Quayson, 2007, p. 15) occur in *Wonder* (Palacio, 2012) when Jack recounts seeing August for the first time. He narrates:

> He was sitting right next to me. I know it wasn't cool, but I kind of went 'Uhh!' when I saw him because I honestly got scared. I thought he was wearing a zombie mask or

> something. It was the kind of 'uhh' you say when you're watching a scary movie and the bad guy like jumps out of the bushes. (Palacio, 2012, pp. 42-43)

In this example, Jack describes the fear that he experienced when he saw August for the first time which conveys not only his response to August's appearance but also Jack's understanding that his initial response was inappropriate. At other times throughout the text readers witness the characters' moments of "aesthetic nervousness" (Quayson, 2007, p. 15) such as when August is introduced to Julian and Charlotte (Palacio, 2012, p. 7) and he meets students from a different school during a field trip (Palacio, 2012, p. 81). Each of these has a different response to August's appearance, from Julian who looks away (Palacio, 2012, p. 7) and Charlotte who "waves" at him nervously (Palacio, 2012, p. 7), while other students respond by "screaming", "covering their eyes", "pointing", and "cursing loudly" (Palacio, 2012, p. 81). Each of these initial social interactions between August, who has "a stareable body" (Garland-Thomson, 2009, p. 58), and non-stigmatized characters is also an "encounter between a starer and a staree" (Garland-Thomson, 2009, p. 3) as well as an example of Quayson's (2007) theory of "aesthetic nervousness" (p. 15). These literary interactions reveal the range of responses that abled characters may experience when they are introduced to a disabled character. Moreover, these portrayals often communicate problematic messages to readers about disability, as the four examples that I have cited from the novel thus far have shown.

In contrast, Summer sits with August during lunch and acts in a friendly manner towards him, which suggests that she is not nervous about being seen socially interacting with him (Palacio, 2012, p. 17). Later in the novel, Summer describes the first time she ate lunch with August from her perspective when she writes, "So I just went over and sat with him. Not a biggie. I wish people would stop trying to turn it into something major. He's just a kid. The

weirdest-looking kid I've ever seen, yes. But just a kid" (Palacio, 2012, p. 37). Even though Summer acknowledges August's facial difference, her beliefs about him as a person are not impacted by August's disability which Connor (2017) describes as "The Everyday and Therefore No Big Deal Portrayal of Disability" (p. 205).

Additionally, August's opening statement expresses his desire to be perceived as normal by others, thus articulating his longing to be cured of his impairment (Palacio, 2012, p. 1). Dolmage (2014, p. 43) refers to this depiction of disability as the "kill or cure" myth which communicates to readers the negative impact that August's impairment has on his identity, including the social isolation that he experienced (Palacio, 2012, p. 1). August's isolation is another of Dolmage's (2014) disability myths (p. 43) that stems from the medicalized approach taken to surgically address August's physical appearance (Palacio, 2012, pp. 17, 21). The use of medical interventions to normalize August's appearance serves as a form of "stigma management" (Goffman, 2009, p. 53) in response to the pathologizing gaze of abled individuals. This is evidenced when Jack asks August "Are you always going to look this way? I mean, can't you get plastic surgery or something?" (Palacio, 2012, p. 21). To which August replies, "Hello? This *is* after plastic surgery!" (Palacio, 2012, p. 21) showing how medical interventions to normalize disabled people often fail to alleviate the social stigma that they encounter in public spaces. This quotation also serves as a form of self-deprecating humour and is an additional deficit-based depiction of disability that is commonly portrayed in literature and film which Barnes (1992) describes as "the disabled person as an object of ridicule" (p. 13). Meyer (2022) discusses the problematic use of humour in the context of *Wonder* (Palacio, 2012) when she writes:

> Humor in *Wonder* is a bit less dark, but Auggie – like Freak – uses demeaning and self-deprecating jokes as social lubricant throughout the novel. Even though he knows the names that people call him …While Auggie's jokes may indeed dispel tension in social settings, they also position Auggie as someone at whom it is acceptable to laugh. (p. 69)

By using derogatory humour in the narrative, Palacio is furthering the myth that offensive jokes are appropriate, instead of viewing them as being demeaning to disabled people, in addition to being a form of verbal violence that is commonly portrayed in disability-themed literature and other media (Barnes, 1992). Thus, readers learn that it is acceptable to insult disabled people while the novel furthers the social othering that disabled readers experience by being subjected to demeaning content.

A second problematic representation of disability that is present throughout the narrative is the absence of any discussion regarding the academic accommodations that August, as a disabled student, could receive at school. Instead, when Julian's mother questions whether August should have been permitted to enrol at Beecher Prep Mr. Tushman informs her:

> As for your other concerns regarding our new student August, please note that he does not have any special needs. He is neither disabled, handicapped, nor developmentally delayed in any way, so there was no reason to assume anyone would take issue with his admittance to Beecher Prep – whether it is an inclusion school or not. (Palacio, 2012, p. 51)

Mr. Tushman's statement serves as a literary example of Foucault's concepts of "the normalizing gaze" (2012, p. 184) and "bio-power" (1990, p. 140) in the context of education. This is because Mr. Tushman's "examination, [whose purpose is the] perpetual comparison of each … (student) that made it possible both to measure and to judge" (Foucault, 2012, p. 186), is

a form of educational "bio-power" (1990, p. 140) through which Mr. Tushman determines if a student meets the school's requirements for admission through his "normalizing gaze" (2012, p. 184). However, even though Beecher Prep is a private school it is still required to provide limited special education services to disabled students (Eigenbrood, 2004), which contradicts Mr. Tushman's statement regarding "whether it is an inclusion school or not" (Palacio, 2012, p. 51). Moreover, Mr. Tushman's statement is deeply problematic because it denies the physical, social, and academic realities of August's impairments. Wheeler (2013) elaborates on this point when she argues:

> Palacio represents August as having no impairments, even though sometimes he wakes up choking on his own saliva and he gets hearing aids in the course of the novel (Palacio, 2012, pp. 31, 65). Nor does August suffer any enduring pain or complications from his long surgical history. When August starts [attending] Beecher Prep his mother only needs to get over her own nervousness; she doesn't have to teach the school nurse how to tube-feed him or suction excess saliva out of his lungs. (p. 340)

Furthermore, readers do not learn that August is hard of hearing until nearly a third of the way through the novel and this information is provided by August's sister Via instead of by August himself (Palacio, 2012, p. 28). August does not discuss his hearing loss until two-thirds of the way through the narrative when he states, "Also, people have been really nice about the hearing aids I started wearing" (Palacio, 2012, p. 65). August has not, until now, discussed having an audiological difference or the impact that it has had on his interactions with his peers, teachers, or his family. August describes his hearing disability briefly when he informs the reader:

> My hearing was getting worse, but I hadn't told anyone about it. The ocean sound that was always in my head had been getting louder. It was drowning out people's voices, like I was underwater. I couldn't hear teachers if I sat in the back of the class. But I know if I told Mom and Dad about it I'd end up with hearing aids – and I was hoping I could make it through fifth grade without having that happen. (Palacio, 2012, p. 65)

Until this moment readers are unaware of August's hearing disability or how it has impacted him which I, as a disabled academic reader, consider to be problematic. This is because Palacio does not permit August to share this important aspect of his identity with readers or show us how being hard-of-hearing impacts him socially and academically. Instead, shortly after disclosing his hearing impairment to readers, August informs readers that he has received hearing aids which enable him to hear "brightly" (Palacio, 2012, p. 66). Revealing August's hearing disability and then immediately resolving it serves as a further example of the pathologization of disability in *Wonder*. This is because the novel continues to describe disability as an individual medical concern that requires an individualized medical response, instead of viewing disability from a social model perspective (Dolmage, 2014). Thus, August's being hard of hearing is presented by Palacio as yet another obstacle that he needs to overcome (Dolmage, 2014, p. 43) instead of showing readers the accommodations that schools provide for hard-of-hearing students. Moreover, August propagates the myth that his hearing aids "made me hear better than most people" (Palacio, 2012, p. 78) which does not accurately describe the experience of acquiring hearing aids. Furthermore, only once are readers shown how August's hearing disability impacts him when his hearing aids are stolen. August writes, "I touched my ears. The hearing aid band was definitely gone. That's why I felt like I was underwater" (Palacio, 2012, p. 83). Thus, Palacio uses August's hearing loss throughout the narrative as yet another obstacle

that he needed to overcome. This, however, not only removes August's hearing loss from serious textual consideration but also communicates the myth that hearing disabilities can easily be cured (Dolmage, 2014, p. 43), which denies the complexity of hearing disabilities.

In her discussion of education in *Wonder,* Wheeler (2013) documents the unrealistic representation of August's school experience from an inclusive education perspective when she writes:

> Disability inclusion at school usually requires adaptations of curriculum or physical space, and additional help from staff. In a purely social model, all people have to change is their attitudes. The school doesn't have to spring for expensive equipment. The students don't have to learn a new way of communicating. The teachers don't have to modify their instruction. They don't even have to rearrange the furniture. R. J. Palacio's model for understanding disability relies on kindness, not civil rights. Beecher Prep is a private school with no inclusion mandate. It doesn't have to guarantee August services in an Individualized Education Plan, so it's a good thing he doesn't seem to need them. (p. 340)

Wheeler (2013) further describes August's attendance at Beecher Prep as:

> … a carefully controlled lab experiment. From this experiment we learn what happens when a child with a disability singlehandedly desegregates a school. We see able-bodied people gather a community around the child and come into a disability identity of their own. (p. 341).

By portraying August's first year at Beecher Prep as an "experiment" in inclusion, Wheeler (2013) shows how emphasising the responsibility of the disabled character to demonstrate their individual effort to earn the right to be included diminishes the reality of

disabled people's experiences in school. By doing so, Palacio's (2012) narrative erases the impact that academic, social, and other educational barriers have on the education of disabled students. Therefore, August, like Melody in *Out of My Mind* (Draper, 2010), has to earn the right to be included through his academic attainment, which transforms the everyday experience of attending middle school into an inspirational overcoming narrative (Connor, 2017; Dolmage, 2014). August's academic attainment is described in an e-mail by Mr. Tushman as the result of being "an extremely good student" (Palacio, 2012, p. 51). This discourse continues the argument that I made regarding *Out of My Mind* (Draper, 2010), which suggests that only disabled students who do well academically can receive an inclusive education. This justification is then used to argue that developmentally disabled students should not be given access to inclusive school placements, which is reinforced by the different classroom assignments (based on the student's assumed level of intelligence) that are given to physically and developmentally disabled characters in disability-themed children's and young adult literature (Meyer, 2013).

Moreover, *Wonder* (Palacio, 2012) like *Out of My Mind* (Draper, 2010) fails to address the underlying problematic educational structures and attitudinal barriers that turn the normative experience of attending school into a morality tale in which disabled characters are depicted as "uncomplaining overcomers, … [instead of] real disabled heroes who fight bias and battle for control of their lives and insist that they will make their mark in the world" (Longmore, 2003, p. 130). *Wonder* fails to address the problematic spectacle that August becomes because he is put on display during his school's graduation ceremony, when he is given the Henry Ward Beecher Medal which is usually given for "volunteerism or service to the school" (Palacio, 2012, p. 93). Instead, August receives the award because, as Mr. Tushman explains, it has been presented "to the student whose quiet strength has carried up the most hearts" (Palacio, 2012, p. 93). By

presenting August with the Henry Ward Beecher Medal, this further portrays him as an inspirational "supercrip" (Shalk, 2016) or as an example of "inspiration porn" (Grue, 2016). This is because August's "volunteerism or service to the school" (Palacio, 2012, p. 93) has been in tolerating the social stigma and other forms of ableism that he has experienced at school. However, it is also at this moment when August begins to realize the deficit-based role that he has played throughout the narrative when he states:

> I wasn't even sure why I was getting this medal really. No, that's not true. I know why. It's like people you see sometimes, and you can't imagine what it would be like to be that person, whether it's somebody in a wheelchair or somebody who can't talk. Only, I know that I'm that person to other people, maybe to every single person in that whole auditorium. (Palacio, 2012, p. 94)

As a disabled academic reader, I believe that Palacio's chapter "Floating", from which the previous two quotations have been excerpted, is one of the most offensive representations of disability in recent memory. Not only because August is characterized as an inspirational supercrip (Connor, 2017; Wheeler, 2019), but because *Wonder* (Palacio, 2012) circles back to the disability as public spectacle depiction of disability, as witnessed in 19th and early 20th century Freak Shows and more recently in Telethons (Bogdan, 1990; Longmore, 2016). This not only erases the systemic barriers that disabled people experience in school but also socially constructs unattainably high standards that disabled students need to meet to be included. Furthermore, the argument that abled people need only to "be kind" (Palacio, 2012, p. 92) to disabled people denies the legal rights and autonomy of disabled individuals while also reinforcing the problematic discourse that perceives disabled people as being pitiable and deserving recipients of charity (Dolmage, 2014; Longmore, 2016). This representation of

disability is most prominently portrayed in *A Christmas Carol* (Dickens, 2004) when Bob Cratchit describes the moralizing work of Tiny Tim when he states:

> He told me, coming home, that he hoped the people saw him in the church, because he was a cripple, and it might be pleasant to them to remember upon Christmas Day, who made lame beggars walk, and blind men see. (Dickens, 2004, p. 39)

Throughout *Wonder* (Palacio, 2012), August is portrayed as a public spectacle whose character, like Tiny Tim's, is intended to teach moralizing messages to abled people about disability while denying his rights and agency in the narrative. Mr. Tushman's speech at the graduation ceremony focuses on kindness, including religious moralizing statements such as, "And if you do this, if you act just a little kinder than is necessary, someone else, somewhere, someday, may recognize in you, in every single one of you, the face of God" (Palacio, 2012, p. 92). By placing Mr. Tushman's speech just before the award ceremony where August receives an award for just being himself (or for inspiring people) communicates the moralizing special child circular message of the text's epigraph that opens the novel. Hence, the text begins with August being represented as a feared and socially excluded child and ends with him being presented with an award for tolerating the ableism that he encounters daily. Moreover, Wheeler (2013) reminds readers that August's attendance at Beecher Prep has been an "experiment" (p. 341) to determine if he can inspire the other characters and readers by overcoming the social stigma associated with his disability by reminding them to be kind? Yes! But by doing so, August's characterization reinforces many offensive messages about disability which place the onus on him to overcome his disabilities, instead of on the school to remove the social and structural obstacles that deny his rights by failing to provide August with the educational accommodations to which he is legally entitled (Eigenbrood, 2004).

Finally, if the "inspirational" (Connor, 2017) disabled character trope has not been hammered home sufficiently, the text concludes by reminding readers that August is a wonder, which I discussed in my analysis of the novel's epigraph. This time, however, it is August's mother when she says, "Thank *you* Auggie. … For everything you've given us, … for coming into our lives. For being you. … You really are a wonder, Auggie. You really are a wonder" (Palacio, 2012, p. 95). This final statement at the conclusion of the narrative could be interpreted as a mother bonding with her son and thanking him for all of the joy that he has brought into her life, but in the context of the novel's theme of disability as spectacle, I do not believe that this is the case. Instead, I would suggest that Palacio uses this final moment between August and his mother to create a circular narrative by reminding readers of the novel's title and epigraph. By doing so, Palacio is reminding readers that disability is a socially stigmatizing form of visible difference while inviting readers to stare at August in an act of literary voyeurism.

From a language arts education perspective, scholars have mixed responses to *Wonder* (Palacio, 2012), with Jocius and Shealy (2018) suggesting that the novel is an excellent choice for teachers to use as part of critical book clubs using reader response theories. By using *Wonder* and other disability-themed novels, Jocius and Shealy (2018) concluded that "students developed essential skills in textual interpretation, they also became more empathetic readers and responders who interrogated stereotypes and representations of disability and difference" (p. 700). In a second study, Meyer and Wender (2016) discuss both the positive and problematic aspects of R. J. Palacio's text when they state, "we argue that middle, high school, and even college students will be challenged by these novels [*Wonder* (Palacio, 2012) and *Marcelo in the Real World* (Stork, 2010)] if teachers push them to read both with and against their various and sometimes contradictory message about disability" (p. 73).

Lastly, Casalme (2016) documents the problematic messages that uncritical readers of the text could receive about disability while highlighting the role that critical classroom discussion can have as a means of critiquing disability representation in literature. Casalme (2016) writes:

> This study showed that students will not necessarily be engaged with reading or discussing *Wonder* and can, without discussion, be prone to feelings of pity rather than empathy, shallow understandings of *Wonder's* themes, as well as the stereotyping and generalizing of people with disfigurement and disabilities. Why then bring *Wonder* into the classroom? This study demonstrated the capability of children to go beyond the passive admiration of the emotional and inspirational nature of *Wonder* and its charming characters to the active critique of the novel and collaborative discussion of the complicated social issues that it touches upon. (p. 41)

I agree with the warnings given by Meyer and Wender (2016), and Casalme (2016) regarding the problematic representations of disability that are communicated to readers in the novel, as well as the vital role that teachers play in teaching students to become critical readers of disability-themed texts. However, this requires that teachers be aware of the numerous deficit-based messages that are conveyed to readers throughout *Wonder* (Palacio, 2012) as well as teaching the novel from a critical disability studies informed perspective. Two disability-themed children's novels that teachers could use as alternatives to *Wonder* that examine similar themes are *A Kind of Spark* (McNicoll, 2020), and *Aniana Del Mal Jumps In* (Mendez, 2023).

Disability Representation in *Fish in a Tree*

In *Fish in a Tree* (Hunt, 2015) readers meet Ally Nickerson, who is in the sixth grade and is attending her seventh school in seven years because her father is in the military (Hunt, 2015, p.

2).[55] Ally begins the novel without any friends which socially isolates her until a third of the way through the book when she starts eating lunch with Keisha and Albert (Hunt, 2015, p. 91; Dolmage, 2014). Throughout the novel, Ally's friendships with Keisha and Albert are shown to be important to her, one example of which occurs when she confides in them that "I have a lot of trouble in school. With reading and writing and well, everything but math and art" (Hunt, 2015, p. 182). To Ally's surprise, however, Albert and Keisha already know about her academic difficulties and offer her support (Hunt, 2015, p. 182). Then, in a second example, Albert and Keisha help Ally when she experiences bullying at school (Hunt, 2015, pp. 246-247) which is a common form of violence that disabled characters encounter in literature and other media (Barnes, 1992). By the end of the novel, Ally has gotten enough support from her classmates to win the class presidency (Hunt, 2015, p. 208) which demonstrates how important friendship and community are for disabled students when it comes to social and educational inclusion.

Unlike the other novels that I have discussed in this chapter, readers are not told that Ally has a disability. Instead, Ally is not suspected of being dyslexic by her teacher Mr. Daniels until more than halfway through the narrative (Hunt, 2015, p. 157). Thus, *Fish in a Tree* is representative of Bérubé's (2015) argument that characters in fiction can experience ableism without being formally diagnosed or considering themselves to be disabled. In Ally's case, prior to being suspected of having dyslexia, she engages in "passing" by using "techniques of information control" (Goffman, 2009, pp. 74, 93) to conceal from her teachers and classmates the fact that she has difficulty reading. Two examples include being sent to the principal's office (Hunt, 2015, pp. 11-15) and lying about having understood something that she has been asked to

[55] *Fish in a Tree* (Hunt, 2015) was being taught in 5 Ontario schools in grades 7-12 (Bates, 2017).

read (Hunt, 2015, p. 14). Prater (2003) and Altieri (2006) discuss in their reviews of learning-disabled characters in children's and young adult fiction that these characters often deliberately get into trouble as a strategy to avoid having to read or complete other school tasks. Moreover, Ally uses humour to make her classmates think that she is purposefully misreading things (Hunt, 2015, p. 22). A fourth technique that Ally uses is memorization when she memorizes her poetry assignment so that she does not need to read it aloud (Hunt, 2015, p. 135). In each case Ally "passes" by using "techniques of information control" (Goffman, 2009, pp. 74, 93) to hide from her teachers and classmates the fact that she cannot read.

Near the end of the novel, Mr. Daniel's comments on how effective Ally has become at passing when he states "I've really gotten a sense lately of how hard you've had to work to learn what you have. And … you've fooled a lot of smart people. So, how smart does that make *you*?" (Hunt, 2015, p. 242). In his above statement Mr. Daniels is suggesting that Ally's ability to pass is directly related to her intelligence, which implies that intellectual ability is correlated with school placement. Moreover, Hunt's narrative suggests that learning disabilities need to be overcome or compensated for through individual effort or technological means, in keeping with an individualized deficit-based understanding and response to disability (Dolmage, 2014). Furthermore, by linking Ally's ability to pass with her intelligence Hunt's (2015) novel continues the recent trend in contemporary disability-themed children's and young adult literature that disabled protagonists need to be "witty, articulate, quick with a comeback and utterly charming. Above all, you have to be really smart: genius, an intellectual Supercrip, or at least an academic overachiever" (Wheeler, 2019, p. 109). Earlier in this chapter, I discussed how Melody's intelligence in *Out of My Mind* and August's intelligence in *Wonder* were used to justify their inclusion in general education classes based on their academic abilities. This

argument also applies to Ally in *Fish in a Tree* because it is due to her ability to pass that she has been placed in general education. When authors link general education placements with the intellectual ability of their disabled characters, they are suggesting that only academically strong disabled students should be placed in general education classes (Meyer, 2013).

One negative consequence of Ally's use of "techniques of information control" (Goffman, 2009, p. 93) is that she has been socially constructed as a troublemaker by her teacher Mrs. Hall and the Principal Mrs. Silver. From a Foucauldian standpoint, Mrs. Hall and Mrs. Silver have used their "normalizing gaze, … to classify and to punish" (Foucault, 2012, p. 184) Ally in response to her misbehaviour which she has, in turn, used to avoid having to read or write in the classroom (Hunt, 2015, pp. 3-5, 11-15). Prater (2003) notes in her review of learning-disabled characters in children's and young adult fiction that, "The manner in which teachers are portrayed varies greatly" (p. 58) from being supportive of learning-disabled students to holding prejudicial views. Prater's (2003) finding is witnessed in *Fish in a Tree* through the different approaches taken by Mrs. Hall and Mr. Daniels regarding Ally's behaviour throughout the narrative (Hunt, 2015, pp. 3-5, 39-42). During her brief interactions with Ally, Mrs. Hall appears to believe that Ally is a troublemaker who continually misbehaves and needs to be punished. In contrast, Mr. Daniels takes the time to get to know Ally, which enables him to uncover the reasons for her behaviour. As a result, Mr. Daniels is able to provide Ally with the additional educational support she needs prior to her being formally diagnosed with a learning disability (Hunt, 2015, pp. 146-149, 165-167). By getting to know Ally's academic strengths, in addition to his developing knowledge of special education through his course work (Hunt, 2015, pp. 165-167), Mr. Daniels has become what Goffman (2009) describes as 'The Wise':

> 'The Wise' namely, persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance. … Wise persons are marginal men before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other. (p. 28)

By becoming 'The Wise' in relation to disability and special education Mr. Daniels has positioned himself to accommodate Ally who is in the process of being diagnosed with a learning disability. However, I disagree with how Hunt has portrayed Ally's work with Mr. Daniels because she has done so in a way that reinforces a deficit-based understanding of disability. This occurs when Mr. Daniels describes Ally as "brave" when he states, "You're brave. … Coming to school every day, knowing what you're in for. Knowing school will be hard. And other kids are going to razz you. And you still come every day and decide that you're going to try again" (Hunt, 2015, p. 157). By describing Ally's educational attainment as an act of bravery Mr. Daniels is communicating the problematic discourse that disabled characters in fiction and disabled people in the real world exist to inspire people by simply living their lives (Grue, 2016). In this context, being a good student and being disabled are assumed to be mutually exclusive traits. Thus, when a disabled person or character does well academically or in other areas they are portrayed as "inspirational" (Connor, 2017, p. 205) instead of showing readers "The Everyday and Therefore No Big Deal Portrayal of Disability" (Connor, 2017, p. 205).[56] This problematic idea is further presented in *Fish in a Tree* when Mr. Daniels teaches a social studies lesson about famous historical individuals who have been posthumously diagnosed

[56] Capitals appear in the original.

with learning disabilities (Hunt, 2015, pp. 236-241). Prater (2003) considers the practice of posthumously diagnosing people with disability labels to be problematic for three reasons. Prater (2003) explains:

> Baskin and Harris (1984) in their analysis of children's literature argue that most children do not know these famous individuals and if they did, 'It is hard to believe that simply citing names of Albert Einstein, Woodrow Wilson, Winston Churchill, Nelson Rockefeller, and General Patton ... would inspire pride of association in an elementary school child' (p. 90). There is a third reason to question the mention of these famous individuals. Even if children knew these individuals and their accomplishments, the posthumous diagnosis of LD has been greatly disputed (Adelman & Adelman, 1987). Therefore, living examples who have expressed their personal experiences with LD, such as Bruce Jenner, Tom Cruise, Whoopi Goldberg, and Cher, are more appropriate models. (p. 59)

Even though including topics related to disability in the curriculum is vital and doing so can be empowering for disabled students, if not done from a critical disability studies perspective a lesson such as the one that Mr. Daniels teaches can place unreasonably high expectations on disabled students. This can result in further marginalization of disabled students when they fail to live up to these unattainable standards. Teachers can address this concern by including the historical experiences of disabled people in their curricula (Baglieri & Lalvani, 2019). Even though Mr. Daniels does presume Ally's competence (Biklen & Burke, 2006) and works with her to improve her literacy skills (Hunt, 2015, p. 167) the text frames Ally's story as an overcoming narrative by portraying Mr. Daniels as the saviour abled character. This is because

Mr. Daniels first recognises and then helps Ally to overcome her impairment by helping her to improve her literacy skills (Dolmage, 2014).

In their separate articles reviewing the portrayals of learning-disabled characters in children's and young adult texts, Prater (2003) and Altieri (2006) note the diverse ways that, because of their impairments, fictional characters experience frustration when completing reading and writing tasks. Throughout the novel, Ally describes how difficult reading and writing are for her when she states, "I stare at the letters and watch them dance and move on the bright, white page. My eyes ache and my head hurts" (Hunt, 2015, p. 89). In a second quotation Ally explains, "When I write, I press on the paper too hard, but I can't help it. It makes my hand hurt. I try to spell as best I can. It takes me an hour and a half to write two paragraphs" (Hunt, 2015, pp. 200-201). As a disabled student, I had to dedicate significantly more time to completing academic tasks in secondary school while only earning average grades. I also had the harmful mantra that "You have to be better to be equal" which placed a lot of unnecessary stress on me because of the internalized ableism that I was experiencing. This also required that I spent a lot of time at school as well as at home learning cursive writing, printing, and proper keyboarding. As an adult, I believe each of these were well-intentioned but ultimately futile efforts because I still have largely illegible printing, I cannot read or write in cursive, and I am unable to touch-type. At the time I understand that computers, audiobooks, and other contemporary alternatives to manual literacy skills were either prohibitively expensive or unavailable but by 2015, when *Fish in a Tree* was published, manual literacy skills had, in my view, become increasingly unnecessary due to the almost universal availability of computers and other forms of digital technology. Further, I will suggest that by having Ally struggle to obtain literacy skills, *Fish in a Tree* supports the pathologization (Dolmage, 2014) of disability by

making the argument that it is the responsibility of disabled people (or characters in this case) to overcome their impairments through medical means or individual effort.

From an inclusive education standpoint, Jocius and Shealy (2018) show how *Fish in a Tree* (Hunt, 2015) can be used in the classroom using critical book clubs and reader response assignments. Of the five novels that I have examined in this chapter, *Fish in a Tree* offers young readers the most complete picture of what inclusive education looks like, from the moment that Mr. Daniels arrives. The novel also describes the academic and social difficulties that learning disabled students such as Ally often experience while also showing how Ally changes and grows as a character throughout the narrative.

In their article, Kleekamp and Zapata (2018) ask four guiding questions for teachers to consider when choosing disability-themed books for language arts units:

> How is the life of the character with a disability presented as multidimensional? Whose voice is represented and emphasized in the telling of this story? How are readers positioned to think and feel about the character with a disability? What steps has the author taken to create and present authentic relationships? (p. 591)

Based on Ally's characterization in *Fish in a Tree*, I believe that she is a multidimensional character who develops and grows throughout the narrative. Second, *Fish in a Tree* is told from Ally's first-person perspective and therefore it is from her standpoint that readers interact within the world of the novel. Third, the research that I have previously cited regarding the depictions of learning-disabled characters by Altieri, (2006) and Prater, (2003) suggests that Ally's characterization in *Fish in a Tree* is similar to the representations of other learning-disabled characters in children's and young adult literature. Finally, Hunt's novel believably portrays Ally's friendships and family relationships. When Kleekamp and Zapata's

(2018) criteria are combined with my analysis of the different representations of Ally as a disabled character, I have only located minor problematic elements. These include Ally's initial isolation at the beginning of the narrative, and the fact that Ally needs to overcome or compensate (Dolmage, 2014) for her impairment by learning manual literacy skills. Even with these minor criticisms, I would encourage teachers to continue teaching *Fish in a Tree* in their middle grade classrooms. However, if teachers are looking for alternative texts that examine similar themes to *Fish in a Tree* (Hunt, 2015), *The Science of Angry* (Melleby, 2022), and *The Fifty-Four Things Wrong with Gwendolyn Rogers* (Carter, 2021) could be good options.

Common Representational Themes

The five disabled first-person protagonists whose characterizations I have analysed in this chapter had numerous impairments. These include: Max in *Freak the Mighty* (Philbrick, 1993), who has a learning disability or a developmental disability (the text can support either interpretation (Carico & Stanley, 1999; Meyer, 2013), Melody in *Out of My Mind* (Draper, 2010), and August in *Wonder* (Palacio, 2012), who have physical disabilities, Ambrose in *Word Nerd* (Nielsen 2010), who has a life-threatening allergy, and Ally in *Fish in a Tree* (Hunt, 2015) who is suspected of having a learning disability but is not formally diagnosed by the conclusion of the novel.

Across the five novels, numerous deficit-based representations of disability were communicated to readers in keeping with a medical model understanding of disability. These include: "disability as pathology, Overcoming or Compensation, Kill or Cure, Disability as Object of Pity and/or Charity, Disability Drift, [and] Disability as Isolating and Individuated" (Dolmage, 2014, pp. 43-45), "*Disability as the interface with otherness* (*race, class, sexuality,*

and social identity),[57] *Disability as bearer of moral deficit/evil*, *Disability as epiphany*" (Quayson, 2007, pp. 39, 42, 45), "The Disabled Person as an Object of Violence" (Barnes, 1992, p. 10), "The Disabled Person as an Object of Ridicule" (Barnes, 1992, p. 13), "Monster", "Villain", [and] the "Inspirational" (Connor, 2017, p. 205) disabled character.

When these deficit-based portrayals of disabled protagonists are combined with ableist language, social stigma, in addition to social, institutional, and physical barriers, it was difficult for me to locate characters whose narratives suggest "The Everyday and Therefore No Big Deal Portrayal of Disability" (Connor, 2017, p. 205).[58] This is because all five protagonists began their narratives without friends, and experienced social stigma and bullying due to their disabilities (Draper, 2010; Hunt, 2015; Nielsen, 2010; Palacio, 2012; Philbrick, 1993). More troubling, however, is that by the end of each novel only August in *Wonder* (Palacio, 2012) and Ally in *Fish in a Tree* (Hunt, 2015) have developed reciprocal friendships with same age peers. Even though Ambrose in *Word Nerd* (Nielsen, 2010) has made friends with Cosmo and the other adult members of the Scrabble Club, he does not have any friends his own age which highlights the social difficulty that disabled people have forming and maintaining friendships (Shakespeare, 2014). The social isolation that each character experiences is linked to the social stigma that they endure as well as the "courtesy stigma" (Goffman, 2009, p. 31) that abled characters may acquire by befriending them. Moreover, the social stigma that each protagonist encounters is an example of Quayson's (2007) theory of "aesthetic nervousness" (p. 15) because social stigma governs the literary interactions between the abled and disabled characters in each narrative.

[57] The italics are in the original.
[58] The capitals are in the original.

Second, all five disabled protagonists experience ableism within their educational systems. For instance, Max's tutor questioned whether Max had a disability (Philbrick, 1993, p. 81). Second, after a bullying incident that led to Ambrose having a severe allergic reaction at school, the principal responded by removing him from the school (Nielsen, 2010, p. 39). In a third demonstration, Melody is placed in segregated special education classrooms where age- and grade-inappropriate curriculum is being taught (Draper, 2010). In this environment Melody must repeatedly demonstrate her intelligence before being placed in an integrated classroom, where she must continually earn the right to remain in the general education classroom (Draper, 2010, pp. 56, 57, 58, 107, 110). In a fourth example, August does not receive any academic accommodations from his private school, while being treated like a test case to determine if disabled students can keep up with the academic demands of Beecher Prep (Palacio, 2012, p. 51). Then, when August succeeds, he is given The Henry Ward Beecher Medal for just being himself while living with the social stigma and other forms of ableism that he experiences daily at school (Palacio, 2012, pp. 21, 22, 25, 37, 51, 81, 93-95). Lastly, Ally needs to employ numerous "techniques of information control" (Goffman, 2009, p. 93) including being socially constructed as a troublemaker in order to hide the fact that she has difficulty reading and writing due to her undiagnosed learning disability (Hunt, 2015, pp. 11-15, 22, 135). Each of these examples reveals how educational and social barriers impact the social and educational experiences of the disabled protagonists whose experiences I have documented in this chapter.

When considering teaching disability-themed texts in the classroom that contain problematic elements, Andrews (1998) argues that these novels still have an important role in inclusive language arts units when she states:

> Books that include sensitive issues, such as cruelty to persons with disabilities, should not be discounted because of the unpleasantness of the issue, but rather should be selected for the realistic portrayal of the situation and certainly should not encourage or approve of the inappropriate behavior. (p. 424)

By presenting students with negative depictions of disability in literature to teach students to think critically about the harmful messages that are being communicated through them, teachers can begin to challenge the literary ableism that is present in the text. Part of this can include encouraging their students to think about the relationship between disability representation in fiction and society's beliefs and attitudes toward disabled people in the real world. However, doing so requires that teachers be knowledgeable about the numerous ways that ableism is pervasively present throughout society and be able to effectively address these negative societal beliefs and attitudes without further alienating disabled students.

The Protagonist's Family Demographic and Identity Information

In this section I will examine the family structures and socio-economic realities of the disabled first-person protagonists whose experiences I have documented in this chapter, together with numerous aspects of their identities. I have included this content in my analysis in order to highlight that the experiences of white, straight, cis-gender characters whose first language is English are overrepresented in the disability-themed children's novels being taught in Ontario schools. With this being the case, three alternative texts that centre the experiences of racially and culturally diverse disabled first-person protagonists are *Each Tiny Spark* (Cartaya, 2019), *Rain Rising* (Comrie, 2022), and *Aniana Del Mal Jumps In* (Mendez, 2023), each of which examines the intersections of disability, race, and linguistic diversity. If teachers are looking for disability-themed children's novels that examine the intersections of disability with gender and

sexual diversity, some recent examples include, *The Year My Life Went Down the Toilet (*Arlow, 2023), *The Trouble with Robots* (Mohrweis, 2022), *Thanks a Lot, Universe* (Lucas, 2021),[59] *The Science of Angry* (Melleby, 2022), and *Jude Saves the World* (Riley, 2022).

When discussing sibling relationships, Dyches et al., (2009) state, "The sibling relationship is reciprocal. The sibling(s) are not given unusually burdensome household and family duties" (p. 307). Even though Dyches et al.'s (2009) discussion refers to the relationship between an abled and a developmentally disabled sibling, I believe that their work can also apply to the depictions of abled and disabled siblings in general. The three children's novels that I examined in my study which contain sibling relationships include August in *Wonder* (Palacio, 2012) who has an older sister, Ally in *Fish in a Tree* (Hunt, 2015) who has an older brother, and Melody from *Out of My Mind* (Draper, 2010) who has a younger sister. Max in Freak the *Mighty* (Philbrick, 1993), and Ambrose in *Word Nerd* (Nielsen, 2010) are only children. Regarding their relationship, Via in *Wonder* (Palacio, 2012) believes that her brother August's disabilities have negatively impacted her life (p. 26). This is contrasted by the mutually beneficial sibling relationship that Ally and Travis have in *Fish in a Tree* (Hunt, 2015, pp. 30-34, 229-230, 268). Due to there being a significant age gap between Melody and her younger sister Penny in *Out of My Mind* (Draper, 2010, p. 71), I cannot determine if Melody's disabilities impact their relationship. Three examples of disability-themed children's novels that focus on the relationship between an abled and disabled sibling are *The Bridge Home* (Venkatraman, 2019), *Daisy Woodworm Changes the World* (Hart, 2022), and *Breathing Underwater* (Allen, 2021).

[59] This novel has a sequel *You Owe Me One, Universe* (Lucas, 2023).

The five disability-themed children's novels that I examined in my study portrayed numerous relationships between the disabled child protagonists and their parents or guardians. For example, Max's grandparents in *Freak the Mighty* (Philbrick, 1993) appear to be supportive (pp. 1, 73-75, 134, 136). Ambrose's mother in *Word Nerd* (Nielsen, 2010) is overprotective and controlling, which prevents him from participating in age-appropriate activities (pp. 40, 51, 52, 80-85, 157, 177, 206, 210-214, 218-219). In contrast, Ally's mother in *Fish in a Tree* (Hunt, 2015) tries to be involved in her children's lives but she is prevented from doing so due to her husband being deployed, as well as needing to work to support her family (pp. 17, 19, 24, 27-28). Of the five disabled protagonists, Melody's parents in *Out of My Mind* (Draper, 2010) are the most involved and supportive of their disabled child (pp. 23, 57, 90, 104, 130-131, 199, 229, 234, 235, 243-261, 264) which the parents of disabled children in the real world should emulate.

In addition to the presence of numerous deficit-based understandings of disability in the five novels that I surveyed in this chapter, these texts also portray a limited range of experiences regarding both the representation of disability and intersectionality. Of the five first-person protagonists, only August in *Wonder* (Palacio, 2012) who is mixed-race Brazilian-American (pp. 26, 32) is a visible minority. However, August's intersectional identity is rarely mentioned in the text which may be due to his family's economic status, as they live in Manhattan and can afford to send August and his sister Via to private schools (Palacio, 2012, pp. 1, 3-4, 11). In contrast, Ambrose in *Word Nerd* (Nielsen, 2010) experiences bullying because of his family's poverty as well as his disability (pp. 3-5, 73-74). Melody in *Out of My Mind* (Draper, 2010) and Ally in *Fish in a Tree* (Hunt, 2015) live in two-parent middle-class households (Draper, 2010, pp. 13, 18; Hunt, 2015, pp. 19, 168-171) and Max lives with his grandparents (Philbrick, 1993, p. 1). The gender breakdown between the five novels is balanced with there being three boys and two

girls depicted as disabled first-person narrators; however, there are no gender or sexual minority characters and only two of the protagonists, Max, and Ambrose, are portrayed as experiencing sexual desire (Philbrick, 1993, p. 7), (Nielsen, 2010, pp. 42, 89, 193, 196, 235). This could be due to the young age of the protagonists, or it could be an example of the assumed asexuality of disabled characters (Biklen & Bogdan, 1977, p. 9). None of the disabled first-person protagonists is an immigrant or an English language learner, and all five novels are set in North America.

Conclusion

In this chapter, I have critically evaluated the depictions of five disabled first-person protagonists in the children's novels from Bates' (2017) data that met the inclusion criteria of my study. These include *Freak the Mighty* (Philbrick, 1993), *Word Nerd* (Nielsen, 2010*), Out of My Mind* (Draper, 2010), *Wonder* (Palacio, 2012), and *Fish in a Tree* (Hunt, 2015). Additionally, I have discussed the common representational themes that I have located across the five narratives and the protagonists' demographic and identity information. My analysis of the five disabled first-person protagonists who met the inclusion criteria for my study from Bates' (2017) data revealed that each of the protagonists was portrayed in a deficit-based manner to differing degrees. I reached this conclusion by applying the scholarship regarding the categorization of disability in literature and other media that I have discussed in detail in Chapters 3 and 4 to the five children's novels from Bates' (2017) data that met the criteria for my dissertation. Additionally, I have provided recommendations for alternative disability-themed children's novels that I suggest teachers use in their language arts classrooms in place of *Freak the Mighty*, *Word Nerd*, *Out of My Mind*, *Wonder*, and *Fish in a Tree* that explore similar themes because these children's novels depict their disabled protagonists' experiences in a more disability affirming manner. In the next chapter, I will critically examine the representations of seven

disabled first-person protagonists in the seven young adult novels that were being taught in grades 7-12 in Ontario schools from Bates' (2017) data that met the inclusion criteria of my study.

Chapter 6: In What Ways are Disabled First-Person Protagonists Being Depicted in the Young Adult Literature Being Taught in Grades 7-12 in Ontario Schools?

In this chapter, I will evaluate the representations of the seven disabled first-person protagonists in the seven disability-themed young adult novels from Bates' (2017) study that have met the inclusion criteria for my dissertation by conducting an independent character study of each text's protagonist. Thereafter, I will conclude this chapter by discussing the common representational themes that I have located across the seven narratives, and the protagonist's family demographic and identity information. The young adult novels whose protagonists have met my inclusion criteria are: Melinda in *Speak* (Anderson, 2019), Charlie in *The Perks of Being a Wallflower* (Chbosky, 1999), Troy in *Fat Kid Rules the World* (Going, 2004), Christopher in *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), Craig in *It's Kind of a Funny Story* (Vizzini, 2010), Arnold in *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007), and Hazel in *The Fault in Our Stars* (Green, 2012). Due to each of the disabled characters whose experiences I am examining in this chapter being the text's only first-person protagonist, each novel has met the requirements to be included in my study. Moreover, each narrative has met the criteria recommended by Menchetti et al. (2011) when they suggest that the novel be "written from the perspective of the character with a disability" (p. 61). By identifying and demonstrating that each of the seven texts has met this criterion, I will exclude this content from my analysis of each individual novel.

Disability Representation in *Speak*

In *Speak* (Anderson, 2019), readers learn about the life of Melinda Sordino, who narrates her experiences as a friendless teenager during her first year of high school. Melinda identifies herself as a social "outcast" (Anderson, 2019, p. 4) because her former friends blame her for

calling the police while they were at a party and have stopped talking to her. As a result, Melinda experiences both social stigma and social exclusion due to her actions which additionally impacts her mental health. Moreover, Melinda's experience throughout the text is an example of the social isolation that disabled characters often encounter in fiction (Dolmage, 2014).[60]

Even though she does not self-identify as disabled, Melinda engages in self-harm (Anderson, 2019, pp. 5, 87), has difficulty sleeping (Anderson, 2019, pp. 113, 130), experiences anxiety (Anderson, 2019, pp. 28, 81, 110, 132), and has stopped talking (Anderson, 2019, p. 114). However, her parents are only concerned about Melinda's low grades and the fact that she has been skipping school, without identifying the underlying cause of her unusual behaviour (Anderson, 2019, pp. 35-36, 86, 114-116). Moreover, when Melinda's mother sees that she has been engaging in self-harm, instead of asking Melinda about it her mother tells her "I don't have time for this" (Anderson, 2019, p. 87). Even when other students ask Melinda what is wrong (Anderson, 2019, pp. 45, 105) she does not disclose the reason for her behaviour. In fact, readers do not learn that Melinda was raped at the party she attended the previous summer until nearly three-quarters of the way through the text (Anderson, 2019, p. 164). This revelation is an example of "*Disability as epiphany*" (Quayson, 2007, p. 45) because when Melinda finally discloses that she was raped at the party, the reason for her uncharacteristic behaviour is revealed. The literary scholars Latham (2006) and Tannert-Smith (2010) have interpreted Melinda's experience as a sexual assault survivor through the lens of trauma theory and concluded that she is experiencing Post-Traumatic Stress Disorder. In contrast, Snider (2014) describes Melinda's experience as "selective mutism" (p. 300) even though she does not have a

[60] According to Bates (2017) *Speak* (Anderson, 2019) was the 46th most commonly taught novel in grades 7-12 in Ontario schools.

mental health label applied to her experience by the conclusion of the novel. Thus, *Speak* is an example of Bérubé's (2015) argument that fiction can contain themes related to disability without the characters needing to self-identify as disabled.

Throughout the novel, Melinda creates a safe space for herself in an abandoned janitor's closet (Anderson, 2019, pp. 26, 50, 51, 85, 130, 150) while using her art assignments to help her to process the physical and emotional impact of experiencing sexual violence (Anderson, 2019, pp. 31, 64, 196). Snider (2014) describes the therapeutic power that art has for Melinda in the novel when she writes:

> When drawing leaves, gathering sticks, or carving trees, Melinda is confronting her trauma. Melinda's hands reveal her secret even while her tongue remains inert. Art, with its ability to simultaneously subvert authority and speak of the truest things, therapeutically allows Melinda to morph from trauma victim to trauma survivor in her own time and on her own terms. (p. 309)

As Snider's (2014) work demonstrates, art therapy can be an effective tool for addressing the trauma of surviving sexual violence, not only in fiction such as *Speak* but also in the real world. Likewise, Ressler and Giannet (2004) suggest some ways that *Speak* can be used by teachers and therapists with adolescents as part of "creative expression therapies" (p. 185) in classrooms and clinical settings. Alsup (2003) argues that young adult novels such as *Speak* should be taught in language arts classrooms because:

> While reading *Speak*, perhaps students will see a little of themselves in Melinda or in her friends, and after reading, writing about, and discussing the book in the classroom they might act a little differently the next time a classmate seems unnaturally withdrawn or when they witness violence at a weekend party – or even at school. They might even

> begin to acquire a mature "narrative imagination" that will help them be better citizens and more empathetic human beings. (p. 166)

Moreover, Malo-Juvera's (2014) work shows that *Speak* can be used to teach students about sexual violence in the middle school classroom. Even though Alsup (2003) and Malo-Juvera's (2014) work demonstrate the effectiveness of using *Speak* in the language arts classroom, to date no education scholarship has examined the impact of teaching the novel *Speak* from a mental health disability perspective. This contrasts with the work of literary scholars Latham, (2006), Snider (2014), Tannert-Smith (2010), and therapists Ressler and Giannet (2004) whose publications provide an opportunity for teacher-educators to discuss the impact that sexual violence can have on the mental health of sexual assault survivors through the use of the novel, *Speak* (Anderson, 2019). By doing so, teacher candidates will learn about the relationship between sexual violence and mental health disabilities, and additionally acquire teaching strategies that will enable them to teach their students about both sexual violence and mental health disabilities in the language arts classroom.

From a mental health disability perspective, *Speak* (Anderson 2019) portrays the impact that experiencing sexual violence has on the mental health of sexual assault survivors (Richmond, 2019). Melinda's symptoms communicate the feelings and actions of a sexual assault survivor, which is strengthened by the author's experience (Anderson, 2020). Furthermore, *Speak* has only minor occurrences of derogatory language or deficit-based representations regarding disability. As a result of this analysis, I recommend that *Speak* continues to be taught in language arts classrooms due to the important connections that the text makes between sexual violence and mental health. However, if teachers are looking for a more

recently published alternative to *Speak* (Anderson, 2019), *Girl Made of Stars* (Blake, 2018), and *The Way I Used to Be* (Smith, 2016)[61] are thematically similar options.

Disability Representation in *The Perks of Being a Wallflower*

In *The Perks of Being a Wallflower*[62] (Chbosky, 1999) readers meet "Charlie" (no last name given), the text's 15-year-old protagonist, on the evening before his first day of high school (p. 6).[63] Monaghan (2016) suggests that *Perks* belongs to a genre of young adult literature that Elman (2012) describes as "teen sick-lit" (p. 33). Elman (2012) defines "teen sick-lit" as, "a genre of adolescent fiction that fused illness and romance narrative to reinforce the independent norms of able-bodiedness, heteronormativity, emotional management, and maturity among American youth" (p. 175). Moreover, Monaghan (2016) argues for the academic and educational value of teen sick-lit for both scholars and young adults when she states:

> Sick-lit, then, offers a narrative medicine scholar a prolonged and authentic view into what it's like to be a teenager and to be dealing in some way with illness. For a teen experiencing depression, a novel about another teen going through a similar situation may be all that that reader needs to feel less alone or to convince him to confide in a friend or parent. Another teen may read a book like *Thirteen Reasons Why* and it might help him to understand a friend's suicide, or how to look out for warning signs. (p. 34)

Even though Monaghan (2016) has identified the importance of teen sick-lit as a topic of inquiry in diverse areas such as medical humanities, critical disability studies, and education due to the genre's popularity with young adult readers, I challenge her conclusion because I do not

[61] This novel has a sequel *The Way I Am Now* (Smith, 2023).
[62] Hereafter referred to as *Perks*.
[63] *Perks* (Chbosky, 1999) was the 91st most commonly taught text in grades 7-12 in Ontario schools (Bates, 2017). "Charlie" is a pseudonym used by the novel's protagonist throughout the text.

consider *Perks* to be an example of the genre. From my analysis, *Perks* is not a romance novel but rather the text is more concerned with Charlie's personal development as he comes of age. Moreover, most frequently novels that are described as "teen sick-lit" contain characters living with terminal illnesses that are usually narrated from the perspective of female protagonists (Elman, 2012), not mental health disabilities.

Even though Monaghan (2016) does not discuss Rosenblatt's (1995) transactional theory of literature, it is present in the way she describes the students' responses to having read a text containing a character with a mental health disability. Rosenblatt (1995) examines the relationship between a reader's lived experiences and the content of a literary work when she writes,

> the literary experience has been phrased as a *transaction* between the reader and the author's text. … there will be selective factors moulding the reader's response. He comes to the book from life. He turns for a moment from his direct concern with the various problems and satisfactions of his own life. He will resume his concern with them when the book is closed. Even while he is reading, these things are present as probably the most important guiding factors in his experience. (p. 34)

Due to the relatability of young adult texts to adolescent readers, teachers need to be aware of the ways that mental health disabilities are communicated to students in the texts that they are teaching in their classrooms. To help teachers include content related to mental health disabilities in the language arts classroom, some examples of recent scholarship in this area include Haughey (2021), Olan and Richmond (2020) and Richmond (2019). Additionally, Monaghan (2016) recommends that teachers use the following four criteria when evaluating the representations of mental health disabilities in young adult literature. She states:

> 1. The protagonist/narrator accurately reflects the knowledge of someone his age under the circumstances in which he finds himself. 2. The protagonist's/narrator's illness experiences allow the reader to draw parallels between her life and experiences and those represented in the narrative. 3. The protagonist's/narrator's story rings true: if Point A is connected to Point B, it does so according to the logic of the narrative. 4. Somewhere in the narrative, the illness or condition is explicitly articulated. (p. 39)

In her article, Monaghan (2016) uses *Perks* (Chbosky, 1999) to illustrate how a young adult novel can meet each of her criteria, such as the way in which Charlie describes his experience with a mental health disability. However, Charlie does not disclose his diagnosis, which evades Monaghan's fourth criteria. Even so, I believe that characters in literature do not need to self-identify as disabled based on Bérubé's (2015) assertion that literature "can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged with a specific diagnosis" (p. 19). Moreover, precluding a character's diagnosis does not exclude *Perks* from needing to present Charlie's experiences in a medically correct manner which numerous scholars including Andrews (1998) and Menchetti et al., (2011) argue is the most vital aspect of disability-themed classroom literature. Andrews (1998) elaborates on her position with regard to teaching medically accurate disability-themed content in the language arts classroom when she states:

> Teachers must select materials that accurately portray the [character's] disability lest they succeed only in perpetuating society's myths and stereotypes. Just as authors of inclusion literature have an obligation to provide works that accurately depict disabilities with acceptable terminology, teachers are obliged to select works that are accurate and appropriate. (p. 422)

Even though Charlie does not disclose his disability, readers learn that he is seeing a psychiatrist, that he is taking medication, and that he receives in-patient treatment in a mental health facility (Chbosky, 1999, pp. 103, 139, 208). By not disclosing Charlie's impairment, Chbosky demonstrates that fictional characters can experience the social stigma associated with being disabled without needing to self-identify as disabled or disclose their diagnosis in the narrative (Bérubé, 2015). Furthermore, Chbosky's novel communicates to readers "The Everyday and Therefore No Big Deal Portrayal of Disability" (Connor, 2017, p. 205), which enables Charlie to avoid the social stigma that other characters in my study experience due to their impairments.

Moreover, Charlie can "pass" (Goffman, 2009, p. 74) as an abled individual for most of the novel but this does not diminish the impact that his impairment has on him. For example, Charlie experiences prolonged periods of sadness (Chbosky, 1999, pp. 2, 75, 77, 86, 92, 148), he experiences blackouts (Chbosky, 1999, pp. 99, 208), he has suppressed memories (Chbosky, 1999, p. 208), he experiences nightmares (Chbosky, 1999, pp. 204-205), and he is unable to engage in consensual sexual relationships (Chbosky, 1999, p. 202). Additionally, since the age of seven, Charlie has blamed himself for his Aunt Helen's death because she died in a car accident while shopping for his birthday present (Chbosky, 1999, p. 92). Charlie's sense of grief is increased at the beginning of the narrative when he informs the reader that his best friend Michael committed suicide during the previous school year (Chbosky, 1999, p. 3) and that Susan, Michael's girlfriend, has stopped talking to him (Chbosky, 1999, p. 7) which results in Charlie being friendless from the time of Michael's death the previous spring (Chbosky, 1999, p. 3) until he meets Patrick and Sam on October 6, 1991 (Chbosky, 1999, p. 19). This is another example of the social isolation that disabled characters often experience in cultural texts because

Charlie spends several months without friends or social interactions outside of his family (Dolmage, 2014).

Two scholars whose work examines the therapeutic role that the epistolary form of Chbosky's (1999) novel has as part of Charlie's personal development are Wasserman (2003) and Matos (2013). Wasserman (2003) writes:

> As a forum for Charlie to speak his mind and to record his observations, the epistolary form is essential to the novel. … Here, Charlie's letters provide him with a space in which he can reflect and construct his own way of thinking, a space necessary for human development. It is in these letters where he confronts his particular demons. Charlie seems to recognize the importance of his writing and comments at one point, 'Also, when I write letters, I spend the next two days thinking about what I figured out in my letters.' (Chbosky 28). (p. 50)

Matos (2013) builds on Wasserman's (2003) work by highlighting the philosophical and therapeutic purpose for Charlie's writing practice in addition to its role as part of his personal development when he argues:

> Charlie's first epistle opens with his reasoning behind sending the letters: he heard that the recipient is a good listener, is capable of understanding the complexities of life, and more important, the recipient is in a position such that he/she cannot take advantage of the information depicted in the letters (Chbosky, 1999, p. 2). The reader of the novel is expected to assume the position of this recipient, and by engaging with the narrative, he/she is expected to listen, understand, and not jump into judgment. Much like a patient visiting a psychologist's office, Charlie is expected to speak and the reader is expected to listen and assess his accounts. (p. 87)

By demonstrating the therapeutic role of the epistolary form of *Perks,* (Chbosky, 1999) Wasserman's (2003) and Matos's (2013) scholarship reveals how essential letter writing can be as a tool of self-discovery and identity development for adolescents. Matos (2013) suggests the following classroom activities as part of a novel study using *Perks*:

> • While reading the novel, ask students to write a set series of letters (addressed to an anonymous recipient) in which they discuss problems or difficulties that they are currently facing, similar to what Charlie does in Perks. • Ask students to create an online blog in which they discuss situations they have faced that resemble the experiences of the characters in the literary texts that are discussed in your class. • After reading Perks, ask students to create an audio-narrative essay or a video blog in which they share and analyze a past experience that has shaped who they are. • Ask students to keep a weekly diary or journal in which they record their thoughts and interpretations of the texts and assignments given in class. Toward the end of the semester, ask students to analyze their journal entries in order to write an analysis essay on how the texts and assignments have transformed their lives. (Matos, 2013, p. 95)

Matos (2013) has provided numerous examples of classroom activities that highlight the importance of writing to both Charlie's personal development, as well as for students as they analyse their personal experiences while reflecting on *Perks,* which enables them to gain an appreciation for the epistolary form of the text while using writing as a tool for critiquing past experiences or to gain insights into the current situations that they are experiencing in their own lives. In Charlie's case, it is through his therapeutic letter writing that he uncovers the reason for the negative emotions that he experiences or, as Charlie describes it, "I can already feel myself going to a bad place" (Chbosky, 1999, p. 74). Charlie narrates, "I'm starting to feel like what I

dreamt about her (Aunt Helen) last night was true. And my psychiatrist's questions weren't weird after all" (Chbosky, 1999, p. 205). It is this suspicion that leads Charlie to conclude that his Aunt Helen sexually abused him when he was a young child, as Charlie explains:

> I don't really want to talk about the questions and the answers. But I kind of figured out that everything I dreamt about my aunt Helen was true. And after a while, I realized that it happened every Saturday night when we would watch television. (Chbosky, 1999, p. 205)

Charlie's revelation that his mental health has been negatively impacted by the sexual abuse that he experienced as a child, and that he had subsequently supressed as a coping mechanism, is another example of Quayson's (2007) "*Disability as epiphany*" (p. 45). In Charlie's case, however, the epiphany is his realization that the negative feelings and other symptoms that he is experiencing have been caused by the sexual abuse that he survived and then subsequently suppressed during his childhood, thus making Charlie's moment of realization an "epiphany" (Quayson, 2007, p. 45) for not only the abled characters and the reader but for Charlie himself.

The fear and loneliness that Charlie describes in the opening pages of *Perks* (Chbosky, 1999, pp. 6, 18) about starting high school is something that I can relate to as when I transitioned from a residential special education school to a public elementary school, I was nervous because the only things I knew about public schools were based on my previous negative experience in public school. Even though my last few months in elementary school went smoothly and I started making friends, I needed to repeat this process only a few months later because none of my friends went to the same secondary school that I did. I remember feeling as though my first day of high school was one of the loneliest days of my life because I did not have any friends. My

experience was also similar to Charlie's because a teacher played an important role in my personal and emotional development in numerous ways. In Charlie's case, his English teacher Bill (no last name given) gives Charlie books to read and extra essays to write to support his personal development (Chbosky, 1999, p. 9) and explains to Charlie that "It's just that sometimes people use thought to not participate in life" (Chbosky, 1999, p. 24). In my case, on the second day of high school I asked my first period teacher to inquire if any of my classmates were in my second period class. By asking this question, my first period teacher dramatically changed the course of my high school experience from being one of loneliness and isolation to one of meaningful friendships and extracurricular participation in a similar way that Charlie's friendships with Patrick and Sam do for him (Chbosky, 1999, p. 19).

Based on my analysis of *The Perks of Being a Wallflower*, I have concluded that Chbosky's novel effectively depicts Charlie's experience living with a mental health disability in a disability "culturally authentic" (Brown, 2020, p. 141) manner which Connor (2017) describes as, "The Everyday and Therefore No Big Deal Portrayal of Disability" (p. 205). The novel also explores themes such as friendship, family relationships, sexuality, romantic relationships, mental health disabilities, and sexual abuse in a manner that is accessible to and representative of the experiences of contemporary young adults. However, if teachers are looking for a replacement text that explores similar themes to *The Perks of Being a Wallflower* (Chbosky, 1999), *Cursed* (Silverstein, 2019), and *The Luis Ortega Survival Club* (Reyes, 2023) are two recently published alternatives.

Disability Representation in *Fat Kid Rules the World*

In *Fat Kid Rules the World* (Going, 2004) readers are introduced to Troy Billings, who the novel's peritext describes as, "depressed, suicidal, and weighing nearly 300 pounds" (Going,

2004, unpaginated), which supports the deficit-based understanding of disability that disabled people are "suicidal" (Connor, 2017, p. 205).[64] Throughout the novel, Troy does not self-identify as disabled nor does he receive a formal diagnosis even though he has had "eighteen sessions with two different psychologists" (Going, 2004, p. 55). Thus, Troy's characterization in Going's (2004) text supports Bérubé's (2015) claim that literary characters do not need to be formally diagnosed with disabilities in order for them to experience the social stigma that is related to living with an impairment. Furthermore, Going's text supports this reading of Troy's character due to his internalized ableism, evidence of which includes Troy's frequent pejorative references to himself as "fat kid" throughout the narrative (Going, 2004, pp. 1, 2, 3, 6, 8, 10, 14, 24, 26, 36, 41, 55, 62, 85, 92, 113, 132, 149, 150, 172, 179).

From the text's opening page readers learn that Troy is contemplating committing suicide by jumping in front of a subway train (Going, 2004, p. 1), thus implying that his life as a disabled person is not worth living (Connor, 2017). Other deficit-based representations of Troy as a disabled character are present throughout the novel, such as when Troy states, "I annoy and bewilder my only living parent, mortify my little brother, and have no friends" (Going, 2004, p. 9). Troy's friendlessness is an example of the social isolation that disabled characters commonly experience in literature and film (Dolmage, 2014). After meeting Curt, he convinces Troy to become the drummer of his band (Going, 2004, p. 23), invites Troy to concerts (Going, 2004, p. 83), and Troy begins playing shows (Going, 2004, p. 182). Throughout the novel, Troy experiences social stigma and is stared at because of his physical appearance. One example occurs when Troy states, "I pass them and the man turns around to stare. 'Holy shit, Hazel. You

[64] *Fat Kid Rules the World* (Going, 2004) was only being taught in one Ontario school in grades 7-12 (Bates, 2017).

see that kid? That kid was like, three hundred pounds'" (Going, 2004, p. 44). This moment in the narrative is not only an instance of Quayson's (2007) theory of "aesthetic nervousness" (p. 15) due to it being an interaction between disabled and abled characters but is also an illustration of his assertion that disability is associated with societal otherness (p. 39), as well as verbal violence and ridicule (Biklen & Bogdan, 1977; Barnes, 1992). Furthermore, this scene is an example of what Foucault (2012) refers to as "the normalizing gaze" (p. 184). Foucault (2012) elaborates on this concept when he explains,

> the examination combines the techniques of an observing hierarchy and those of normalizing judgment. It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates and judges them. (p. 184)

By commenting negatively on Troy's physical appearance, the unnamed man in the previous quotation has socially constructed Troy's body as abnormal through his pathologizing use of the normalizing gaze. This results in his comment that socially stigmatizes Troy's bodily difference from the man's socially constructed understanding of what constitutes bodily normalcy.

In a second understanding of Troy's impairment, his father blames him for not participating fully in the interventions that he has provided for him to address his weight. Troy narrates:

> I think of all the opportunities my father has given me that I've failed to take advantage of. …Two gym memberships paid in full, a complete weight set given to me for Christmas, eighteen sessions with two different psychologists, a year and a half with a

> nutritionist, eleven diet books, two healthy-eating videos, a free consultation with a personal trainer, two summers at fat camp, and nearly healthy genes. (Going, 2004, p. 55)

In blaming Troy for not taking advantage of the opportunities that his father has given him to address his weight and body image, Going is propagating the deficit-based assumption that "The Disabled Person …[is] Their Own Worst and Only Enemy" (Barnes, 1992, p. 14). This depiction of disability suggests that disabled characters in fiction and people in the real world can overcome our impairments in keeping with the individualized medical model perspective of disability (Barnes, 1992; Dolmage, 2014). However, this perspective denies the physical, attitudinal, social, political, and other barriers that prevent disabled individuals from participating in society. Furthermore, disabled characters in cultural texts and people in the real world should not be required to overcome or compensate for our impairments (Dolmage, 2014) which implies that we must conform to a second deficit-based understanding of disability, the inspirational supercrip (Grue, 2016; Schalk, 2016). To illustrate my claim, I will provide an example that demonstrates this dichotomy. Throughout my educational journey from elementary school through graduate school people have congratulated me as though my ability to gain an education is an exceptional personal achievement because I am a disabled person, in keeping with the inspirational discourse regarding disability (Grue, 2016). However, I consider my educational attainment to be an economic necessity because it increases my ability to participate in a society that considers disabled people to be a burden (Barnes, 1992). Thus, in order for disabled people to not be viewed as a burden by society we need to continuously be perceived by abled people to be overcoming our impairments, in keeping with the deficit-based supercrip understanding of disability (Schalk, 2016). Otherwise, we are denied the right to participate in society due to the

socially constructed requirement prerequisite requiring "compulsory able-bodiedness" (McRuer, 2006, p. 2) to participate in society.

In a third illustration from the narrative, Troy discusses the first time that girls have paid any attention to him when he states:

> She drapes herself over my arm and smiles drunkenly…Their skin is actually touching my skin. On purpose. Voluntarily. … I tell myself I *must* enjoy the feeling of three girls hanging on me. I must because it may never, ever, ever, happen again. (Going, 2004, p. 98)

This perspective is an example of what Barnes (1992) refers to as "The Disabled Person as Sexually Abnormal" (p. 16) which occurs when a disabled character is believed to be incapable of having sexual desires or is perceived to be incapable of engaging in sexual activity due to their impairment. In Troy's case, his weight and subsequent physical appearance lead girls to assume that he is sexually undesirable, which is never challenged in the narrative.

From a critical standpoint, to date I have only been able to locate one academic publication regarding Going's (2004) novel. Quick (2008) states:

> Like Myrtle, Troy does not, in the end, simply accept his body and his life as a fat person in a thin world. Instead, he embraces his size as the essence of punk rock and as a legitimate, 300-pound representation of an ideal: … In this punk rock context, being a freak is the ideal. While skinny people pierce themselves and shape their hair into Mohawks to become freaks, Troy is the natural freak, the embodiment of the punk rock ideal, what they all want to be – a living defiance of the societal norm. His size, rather than being a disability, is his greatest asset and, even more so than his role as drummer, the basis of his identity as a punk rocker. He is indeed the king of the freaks. (p. 61)

Even though Quick (2008) rightly points out how learning to play the drums has positively impacted Troy's beliefs about himself through his music and by playing on stage, (Going, 2004, pp. 113-118, 182-183) there is no textual evidence that this change has occurred in other areas of his life or in his relationships. This is because at the conclusion of the novel Curt remains Troy's only friend, girls have not begun being interested in him romantically, and he continues to make negative statements about himself regarding his weight. Moreover, the novel ends before readers are shown how Troy's music skills and self-confidence on stage have transferred to other areas of his life. Two alternatives to Going's (2004) novel that explore similar themes are *Then Everything Happens at Once* (Girard, 2023), and *Watch Us Rise* (Watson & Hagan, 2019).

Disability Representation in *The Curious Incident of the Dog in the Night-Time*

In *The Curious Incident of the Dog in the Night-Time*[65] (Haddon, 2004) readers meet 15-year-old Christopher Boone. Even though the novel's peritext uses the words "autism – fiction Savants (Savant syndrome)" (Haddon, 2004, unpaginated) as descriptive terms, they are not used by Christopher or other characters in the narrative to describe his impairment.[66] Moreover, Christopher's depiction is an example of Bérubé's (2015) claim that novels can explore themes related to disability without characters needing to have disability labels applied to them. Bérubé's (2015) work is significant because it enables disabled characters to forgo the labelling, pathologization, and social stigma that often accompanies diagnosis. However, in Christopher's case, his portrayal highlights his differences from the unquestioned abled norm (Quayson, 2007).

[65] Hereafter referred to as *Curious Incident*.
[66] *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004) is the 38th most commonly taught text in grades 7-12 in Ontario schools (Bates, 2017).

One encounter that highlights Christopher's socially constructed difference from the assumed abled norm, as well as being an example of Quayson's (2007) theory of "aesthetic nervousness" (p. 15), occurs when Christopher has a negative interaction with a police officer. Christopher states:

> The policeman said, 'I am going to ask you once again'. … I rolled back onto the lawn and pressed my forehead to the ground again and made the noise that Father calls groaning. I make this noise when there is too much information coming into my head from the outside world. …The policeman took hold of my arm and lifted me onto my feet. I didn't like him touching me like this. And this is when I hit him. …The policeman looked at me for a while without speaking Then he said, 'I am arresting you for assaulting a police officer'. (Haddon, 2004, pp. 7-9)

In this example, Christopher's violent response to being touched by the police officer is misinterpreted as a deliberate act of resistance when his stimming is believed by the officer to signify Christopher's refusal to answer his question. Additionally, this scene is also an example of the "evil or sinister" depiction of disability (Connor, 2017, p. 206).

Throughout the novel, Christopher does not have any positive interactions with his peers or classmates due to his belief that he is intellectually superior to them. In the first example Christopher explains:

> I cared about dogs because they were faithful, honest, and some dogs were cleverer and more interesting than some people. Steve for example, who comes to school on Thursdays, needs help to eat his food and could not even fetch a stick.
> (Haddon, 2004, p. 6)

In a second example Christopher states, “All the other children at my school are stupid. Except I’m not meant to call them stupid, even though that is what they are. I’m meant to say that they have learning difficulties or that they have special needs” (Haddon, 2004, p. 43). In a third illustration that highlights Christopher’s beliefs regarding his intellectual superiority he argues:

> I am good at chess and maths and logic because most people are almost blind and they do not see most things and there is lots of spare capacity in their heads and it is filled with things which aren’t connected and are silly, like, ‘I’m worried that I might have left the gas cooker on’. (Haddon, 2004, p. 144)

The previous examples document Christopher’s beliefs regarding his intelligence that isolates him from others, which is a common disability myth (Dolmage, 2014). Additionally, Christopher’s belief that he is intellectually superior to others is an example of the overcoming or supercrip representation of disability (Dolmage, 2014), due to Christopher’s depiction as a mathematics genius (Haddon, 2004, pp. 44, 61, 64, 101, 144, 146). When critiquing *Curious Incident*, Wheeler (2019) explains,

> [Christopher’s] academic goals reflect the need to separate himself from the other kids at school: ‘I’m not a spazzer, … like Francis, and even though I probably won’t become an astronaut, I am going to go to university … because I like mathematics and physics and I’m very good at them’ (Haddon, 2004, p. 26). A string of jokes in the novel plays on Christopher’s desire to distance himself from his classmates. Like the animal studies philosophers discussed in Chapter 2, Christopher defends the worth of an animal’s life at the expense of a disabled child’s. [Wheeler gives the example from (Haddon, 2004, p. 6) that I cited earlier]. (p. 112)

Moreover, Christopher's characterization communicates other prejudicial beliefs, for instance, that derogatory humour is appropriate (Haddon, 2004, p. 6; Barnes, 1992), disabled people are violent (Haddon, 2004, pp. 8, 171, 184; Connor, 2017), and a burden (Haddon, 2004, pp. 106-110; Connor, 2017), which leads to the breakup of his parents' marriage (Haddon, 2004, pp. 106-110). However, the experiences of parents of disabled children contradict the societal discourse that raising a disabled child is necessarily burdensome (Kittay, 2019; Lalvani, 2019). Furthermore, disabled people are significantly more likely to be victims of violence than propagators of violence (Mueller et al., 2019). In her analysis of Christopher's interactions with the people that he meets during his trip to London, Orlando (2018) argues:

> The treatment Christopher encounters when he leaves home and ventures through public spaces suggest that neurological difference is something to fear or scorn. While to some extent this may provide a critique of the society that fails to accept him, there is little indication by neurotypical characters that neurodiversity could or should be valued by society. (p. 328)

By not arguing for the acceptance of Christopher by society, Haddon's (2004) novel propagates the myth that it is appropriate to socially stigmatize disabled people, which Quayson (2007) describes as, "*disability as the interface with otherness* (*race, class, sexuality, and social identity*)" (p. 39).[67]

Two scholars who self-identify as autistic, Burks-Abbott (2007) and Loftis (2015), have also criticized Haddon's (2004) depiction of Christopher as an autistic character. Loftis (2015) argues:

[67] The italics are in the original.

> Christopher's character is a conglomeration of stereotypes presenting autism as the public eye would imagine it to be: his character is more consistent in sticking to general perceptions of the spectrum than any real individual person would be resulting in a figure who is overdrawn to the point of caricature. (pp. 124-125)

Loftis's (2015) negative assessment of Christopher as an autistic character corresponds with my view that the novel conforms to numerous deficit-based understandings of him as a disabled character. Moreover, Burks-Abbott (2007) suggests:

> Although *Curious Incident* has generated widespread interest in the autism spectrum, an interest that could foster an increased demand for autistic perspectives, the author's conclusions and the book's reception actually militate against autistic self-representation. In declaring that people like Christopher are unfathomable unless written about, as Haddon does in the epigraph to this chapter, at the same time claiming that Christopher would have trouble writing for himself, Haddon has relegated the autistic to otherworldliness while establishing a non-autistic author like himself as the necessary medium between autistic and non-autistic reality. (p. 295)

Even more problematically, however, Haddon's (2004) narrative has become neurotypical individual's authoritative cultural text when it comes to understanding autism and autistic people. As Burks-Abbott (2007) explains, "*The Curious Incident of the Dog in the Night-Time* is the new *Rain Man*, the new definitive, popular account of the autistic condition" (p. 294). In order to address the concerns raised by Loftis (2015) and Burks-Abbott (2007) regarding Christopher's portrayal as an autistic character in *Curious Incident* (Haddon, 2004), teachers should consider teaching novels written by autistic authors whose texts portray the experiences of their autistic characters in a more disability "culturally authentic" (Brown, 2020, p. 141)

manner. Two examples of young adult novels that contain autistic first-person protagonists that have been written by autistic authors include *The Many Half-Lived Lives of Sam Sylvester* (MacGregor, 2022) and *When My Heart Joins the Thousand* (Steiger, 2018).

Disability Representation in *It's Kind of a Funny Story*

In Vizzini's (2010) semi-autobiographical novel *It's Kind of a Funny Story*, readers learn about the life of 15-year-old Craig Gilner who is living with clinical depression for which he has been prescribed Zoloft and is seeing a therapist (Vizzini, 2010, pp. 81, 86, 15).[68] The novel examines how the pressure to gain admittance into an elite selective high school, together with the school's high academic standards, negatively impacts Craig's mental health. Craig states, "I got an 800 on the [admissions] test, out of 800. The day I got those test results … was my last good day" (Vizzini, 2010, p. 42). Additionally, the school requires that Craig completes "four hours of homework a night" (Vizzini, 2010, p. 74) as well as participating in extracurricular activities. Craig narrates, "other kids did *everything:* they were on student government; they played sports, they worked for the school newspaper; they had film club; they had literature club; they had chess club; they entered nationwide competitions for building robots out of tongue depressors …" (Vizzini, 2010, p. 75). Craig continues, "I didn't do anything but Tae Bo, where I hit a plateau. They humored me in class, letting me fake-fight … I quit" (Vizzini, 2010, p. 76). Craig also describes his teacher's expectations and reaction to his first math test grade when he writes:

> There were freshman taking calculus, while I was stuck in the math that came after algebra, which the teacher announced on the first day was 'ding-dong' math and there

[68] *It's Kind of a Funny Story* (Vizzini, 2010) was only being taught in one Ontario school in Bates' (2017) study.

> was no reason for us not to get 100 in everything. I got an 85 on my first test and a small frowny face. (Vizzini, 2010, p. 75)

Later Craig continues:

> That's not to say I did terrible in high school – I got 93's. That looked good to my parents. Problem is, in the real world, 93 is the crap grade; colleges know that it means – you do just well enough to stay in the 90's. You're average … if you're not doing any extracurriculars you're *done*. You can change things in later years, but with 93's your freshman year, you're going to have a lot of dead weight. (Vizzini, 2010, p. 76)

Each of Craig's previous statements highlights the impact that schools as social institutions place on adolescents, together with the perceived negative implications of not meeting their exceedingly high standards, and the mental health related effects of trying to live up to these expectations. This results in Craig contemplating committing suicide after he stops taking his medication, before admitting himself to the emergency room (Vizzini, 2010, pp. 94, 96, 116). Afterwards Craig is admitted to the adult psychiatric unit of the hospital, Six North, for five days (Vizzini, 2010, pp. 131-132, 138). For the remainder of the novel, Vizzini (2010) describes the five days that Craig spends on Six North, including sessions with his psychiatrist and his therapist, as well as music therapy and art therapy (Vizzini, 2010, pp. 174-176, 221-228, 241-243, 208-214). Vizzini is able to capture Craig's experience as a patient in a contemporary mental health facility in detail because the novel's postscript explains that "*Ned Vizzini spent five days in adult psychiatric in Methodist Hospital, Park Slope, Brooklyn 11/29/04-12/03/04. Ned wrote …* [the novel between] *12/10/04-1/6/05* (Vizzini, 2010, p. 320). However, it should also be noted that "Ned took his own life at age thirty-two" (Cohn, "Foreword" quoted in Vizzini, 2010, p. 9). Vizzini does so by showing readers that anyone, regardless of age, can have a mental

health disability, as well as highlighting how effective modern forms of psychiatric medication can be (Vizzini, 2010, pp. 88, 227). In a second example, Nia confides to Craig that she is taking medication and seeing a therapist (Vizzini, 2010, p. 91). In a final demonstration, Craig's principal, Mr. Janowitz, explains to him that many students at his school have mental health disabilities (Vizzini, 2010, p. 227). By the end of his stay at Six North, Craig has decided to transfer to a less academically rigorous school and has made plans for his future (Vizzini, 2010, pp. 282-283, 298-299, 316-319).

From an educational perspective, *It's Kind of a Funny Story* (Vizzini, 2010) meets each of the four criteria established by Monaghan (2016) regarding the representation of an adolescent character living with a mental health disability. Monaghan (2016) states:

> 1. The protagonist/narrator accurately reflects the knowledge of someone his age under the circumstances in which he finds himself. 2. The protagonist's/narrator's illness experiences allow the reader to draw parallels between her life and experiences and those represented in the narrative. 3. The protagonist's/narrator's story rings true: if Point A is connected to Point B, it does so according to the logic of the narrative. 4. Somewhere in the narrative, the illness or condition is explicitly articulated. (p. 39)

By portraying Craig as being knowledgeable about his mental health disability and giving him agency to make his own decisions regarding which therapist he sees (Vizzini, 2010, pp. 84-87). Vizzini's narrative is able to not only document Craig's experiences, but also shows the ramifications of his decisions, both positively and negatively, throughout the text, such as Craig's negative decision to stop taking his medication without consulting his psychiatrist or admitting himself to the hospital when he was having suicidal thoughts (Vizzini, 2010, pp. 93-94, 116). In addition to discussing Craig's clinical depression, and the medication that he has

been prescribed (Vizzini, 2010, pp. 77, 86), prior to being hospitalized Craig is shown attending school and spending time with friends, which challenges the social isolation and educational exclusion that disabled people commonly experience (Vizzini, 2010, pp. 11, 46, 74: Dolmage, 2014).

A second myth that Craig challenges is the idea that disabled characters are not interested in or capable of participating in romantic or sexual relationships. Barnes (1992) describes this deficit-based understanding of disability as, "The Disabled Person as Sexually Abnormal" (p. 16). In Craig's case, however, even though he is portrayed as having sexual desire and engages in consensual make-out sessions with Nia and Noelle while he is a patient on Six North (Vizzini, 2010, pp. 253, 310-311) this may give readers the impression that adolescent patients engage in romantic and or sexual relationships while receiving in-patient treatment in a mental health facility, which distracts from their individual treatment. Further, this portrayal of a character living with a mental health disability reinforces the myth that disabled people are hypersexual which is a problematic representation of disability (Barnes, 1992, pp. 16-17). Nia lends support to this myth when she tells Craig "I have always wanted to hook up in a hospital" (Vizzini, 2010, p. 253). At the conclusion of the novel, Craig and Noelle decide to continue their relationship after she is released from the hospital (Vizzini, 2010, p. 314).

After having analysed Craig's portrayal as a disabled character in *It's Kind of a Funny Story*, I have concluded that the text represents his experience in a disability "culturally authentic" (Brown, 2020, p. 141) manner, which Andrews (1998), and Landrum (2001) have argued is the most important consideration when teachers are selecting a disability-themed novel for their language arts classroom. Moreover, Vizzini's novel challenges numerous myths regarding disability, which supports "The Everyday and Therefore No Big Deal Portrayal of

Disability" (Connor, 2017, p. 205). However, if teachers are looking for a thematically similar alternative to *It's Kind of a Funny Story* (Vizzini, 2010), *When Reason Breaks* (Rodriguez, 2015), and *Darius the Great is Not Okay* (Khorram, 2018) are good options.

Disability Representation in *The Absolutely True Diary of a Part-Time Indian*

In Alexie's (2007) semi-autobiographical novel *The Absolutely True Diary of a Part-Time Indian*[69] readers meet Arnold Spirit Jr. who is Indigenous and self-identifies as having multiple disabilities.[70] *True Diary* opens with Arnold documenting his multiple impairments when he explains:

> I was born with water on the brain. … I was actually born with too much cerebral spinal fluid inside my skull… the doctors cut open my skull and sucked out all that extra water … I was only six months old. And I was supposed to croak during the surgery. And even if I somehow survived the mini-Hoover, I was supposed to suffer serious brain damage during the procedure and live the rest of my life as a vegetable. (pp. 1-2)

Arnold continues:

> … I have all sorts of physical problems. ... I ended up with forty-two teeth. … My brain damage left me nearsighted in one eye and farsighted in the other. … I get headaches because my eyes are, like enemies you know, like they used to be married to each other but now hate each other's guts. …With my big feet and pencil body I looked like a capital L walking down the road. And my skull was enormous. … I had seizures. At least twice a week. So I was damaging my brain on a regular basis. … I haven't had a seizure in seven

[69] Hereafter referred to as *True Diary*.
[70] Alexie's (2007) novel was the 27th most commonly taught text in grades 7-12 in Ontario schools (Bates, 2017).

> years but the doctors tell me that I am 'susceptible to seizure activity'. … I also had a stutter and a lisp. (Alexie, 2007, pp. 2-4)

In a second theme that is directly related to Arnold's experience as a disabled character he describes the bullying that he endures, which is a common form of violence experienced by disabled characters in literature and other media (Barnes, 1992). Arnold states:

> Some of the kids called me Orbit. And other kids called me Globe. The bullies would pick me up, spin me in circles, put their finger down on my skull and say, 'I want to go there.' … Everybody on the rez calls me a retard about twice a day. They call me retard when they are pantsing me or stuffing my head in the toilet or just smacking me upside the head. (Alexie, 2007, pp. 3-4)

In response to the regular bullying that Arnold experiences, he needs to physically defend himself, about which Arnold writes, "Yeah maybe it was just a stupid and immature schoolyard fight. Or maybe it was the most important moment of my life. Maybe I was telling the world that I was no longer a human target" (Alexie, 2007, p. 65). Due to the long history of violence perpetrated against disabled people, (Mueller et al., 2019; Shakespeare, 2014) I believe that Arnold's use of force to physically defend himself in Alexie's novel was justified within the context of the narrative, even though it also supports the myth that disabled people are "evil or sinister" (Connor, 2017, p. 206).

In addition to documenting his medical history in the novel's opening pages Alexie (2007) also highlights the intersectional realities of Arnold's identity as a poor, disabled, Indigenous adolescent, including the impact that discriminatory healthcare and education policies have on him. Arnold describes the impact that his Reservation's racist healthcare system has on him when he explains:

> I went to the Indian Health Service to get some teeth pulled so I could eat normally … But the Indian Health Service funded major dental work only once a year, so I had to have all ten extra teeth pulled *in one day*. And what's more, our white dentist believed that Indians only felt half as much pain as white people did, so he only gave us half the Novocain. … Indian Health Service also funded eyeglass purchases only once a year and offered one style: those thick black plastic ones. (Alexie, 2007, pp. 2-3)

In his previous statement, Arnold articulates the intersecting realities of being both Indigenous and disabled regarding his treatment by the healthcare system, which reveals how racism and ableism intersect to create multiple levels of oppression. In a second example, Mr. P. informs Arnold about the assimilationist philosophy of education that had formally been implemented by the teachers at his school and recommends that Arnold transfer to a secondary school outside of the Reservation when he states:

> You have to leave this reservation. …You were right to throw that book at me. I deserved to get smashed in the face for what I've done to Indians. Every white person on this rez should get smashed in the face. But, let me tell you this. All the Indians should get smashed in the face, too. … The only thing you kids are being taught is how to give up. … All these kids have given up. … And me and every other teacher here. We're all defeated. … But not you. ... You can't give up. You won't give up. … If you stay on this rez … they're going to kill you. …You've been fighting since you were born. ... You fought off that brain surgery. You fought off those seizures. You fought off all the drunks and drug addicts. You kept your hope. And now you have to take your hope and go somewhere where other people have hope. (Alexie, 2007, pp. 42-43)

As a disabled person who attended a residential special education school, I can think of many parallels between Arnold's fictional experience and my lived experience attending alternative school placements. The first of these are the dual identities we developed in response to our positionality. For Arnold this meant deciding to use his given name while he was at school in Reardan but continuing to go by Junior at home (Alexie, 2007, pp. 60-61). In my case, my dual identity centred on the fact that I attended a highly structured residential special education school where the lives of the students were strictly governed; this contrasted with my experience at home on the weekends and during school vacations where my life was significantly less structured. A second similarity between Arnold's and my experiences in education was that we both needed to leave our exclusionary educational environments to gain access to better educational opportunities. However, we did so in opposite ways. In Arnold's case, he needed to leave his community's failing Reservation school to gain an appropriate education from a public secondary school (Alexie, 2007, p. 46). In contrast, I returned to my community to attend a local secondary school to receive an inclusive education.

After reading Arnold's extensive medical history in *True Diary's* opening chapter, readers may conclude that Arnold's intersectional identity as a disabled Indigenous character is the novel's central theme. However, even though *True Diary* is semi-autobiographical, based on Alexie's experience as an Indigenous disabled person, Arnold's disabilities are mostly incidental to the narrative. Although Arnold's impairments are discussed at the beginning of the novel Alexie does not show readers how Arnold's disabilities affect his character throughout the remainder of the text. Wheeler (2019) suggests that disability gets relegated to the background of Alexie's narrative when she writes:

> Impairment fades away because *The Absolutely True Diary of a Part-Time Indian* puts race before disability and because it belongs to the genre of young adult novels that depict their characters headed for conventional success. Arnold fits the narrow personality profile of many disabled protagonists: book smart, charming, and quick with a comeback. The main dynamic of the story is the balancing act between tribal identity and individual success. The silencing of disability allows race to take over as the main form of embodiment and lets Arnold succeed on his own. The silencing of disability allows Arnold to become the conventional individualist hero of young adult novels who overcomes obstacles as he comes of age. (p. 134)

By requiring Arnold to "succeed on his own" (Wheeler, 2019, p. 134) *True Diary* (Alexie, 2007) denies the reality of Arnold's impairments by insisting that he overcome or compensate (Dolmage, 2014) for his disabilities while living at the intersection of "*disability as the interface with otherness (race, class, sexuality, and social identity*)"[71] (Quayson, 2007, p. 39). This shows how the different facets of Arnold's identity: indigeneity, poverty, masculinity, and disabilities intersect to form the totality of his character. Furthermore, Alexie's authorial decision to make Arnold's impairments a secondary concern in the novel causes "The silencing of disability" (Wheeler, 2019, p. 134) which Dolmage (2014) describes as "disability drop" (p. 45).

Moreover, Alexie (2007) fails to discuss the educational accommodations that Arnold is legally entitled to under IDEA (Colker, 2013) or the limitations that his disabilities impose on him as a varsity basketball player. Instead, Alexie chooses to depict Arnold as both an

[71] The italics are in the original.

intellectual and athletic supercrip which enables Arnold to overcome or compensate for his disabilities both academically and athletically (Dolmage, 2014). Even though, from a representational standpoint, Alexie has portrayed Arnold's character in ways that reinforce deficit-based understandings of disability, his perspective is informed by his lived experience as a disabled person (Wheeler, 2019). Thus, even though Arnold's depiction in *True Diary* is problematic from a critical disability studies perspective, Arnold's characterization is based on Alexie's beliefs about himself as a disabled person. He states:

> It's strange, … you think about the brain damage that almost killed me. I think that in order to survive it, it instilled in me this will to live that was stronger than most people's, this competitive instinct … I think my brain damage actually made me stronger, a sort of Nietzschean hydrocephalus, I guess. (Alexie, 2008, cited in Wheeler, 2019, p. 135)

From a critical disability studies perspective, Alexie's (2007) novel communicates problematic messages to readers about disability and disabled people. However, I am not in a position to criticize the personal beliefs or experiences of other individuals. Thus, even though I find Alexie's decision to depict Arnold's character in *True Diary* in ways that I cannot support from an academic standpoint, I am in no way challenging the validity of Alexie's experience or his beliefs about himself as a disabled person.

Regarding his intelligence Arnold states, "First of all, I learned that I was smarter than most of those white kids. …I was way smarter than 99 percent of the others. And not just smart for an Indian, Okay? I was smart, period" (Alexie, 2007, p. 84). In relation to his basketball skills Arnold writes, "Heck, I ended up on the varsity [basketball team]. As a freshman. Coach said I was the best shooter who'd ever played for him" (Alexie, 2007, p. 142). Additionally, Arnold's portrayal as a disabled character is even more unrealistic as the minor concussion that he

receives while playing basketball is not taken seriously even though Arnold has a history of brain injuries (Alexie, 2007, p. 147). Worse, however, is that when his mother brings up his medical history her concerns are dismissed. Arnold narrates, "Of course, I was worried that I'd further damaged my already damaged brain; the doctors said I was fine. Mostly fine" (Alexie, 2007, p. 147). Even though *True Diary* opens with Arnold self-identifying as having a visual disability and he is shown "attend[ing] public school and [having] contemporary teenage experiences" (Carroll & Rosenblum, 2000, p. 626), the text fails to address "issues specific to teenagers with visual impairment in the 21st century" (Carroll & Rosenblum, 2000, p. 626). For example, Wheeler (2019) documents some of the numerous experiences that visually disabled students have in school that are not present in Alexie's (2007) narrative. She writes, "Despite his visual impairment and chronic headaches, Arnold requires no adaptations to read: no large print, no audiobooks, no screen-reading software, no need to limit his reading time" (p. 135). Wheeler (2019) continues:

> Strategic disembodiment erases the kinds of adaptations Arnold would probably need in order to become a phenomenal shooter. Because his eyes don't work together, he would have to create strategies for eye-hand coordination, focusing on the basket, and identifying the lines on the court. For instance, visually impaired basketball players usually use a ball that jingles or beeps and a different color or surface for offsides and the center square of the backboard. (p. 137)

As a visually disabled academic reader of disability-themed texts, I agree with Wheeler's (2019) criticisms of Alexie's (2007) novel, not only because the text fails to communicate to readers the lived experiences of the novel's visually disabled protagonist in a disability "culturally authentic" (Brown, 2020, p. 141) manner. Likewise, Andrews (1998) and Menchetti

et al., (2011) consider the representation of the protagonist's disability to be the most important factor when teachers are selecting a disability-themed novel for a language arts unit. Moreover, Arnold's portrayal also prevents visually disabled readers from reading about the experiences of a character whose depiction "mirrors" (Bishop, 1990) their experiences. Caroll and Rosenblum (2000) elaborate on this perspective when they explain, "Adolescents with visual impairment need realistic role models with whom they can identify, even in literature" (p. 626). By introducing Arnold's impairments at the beginning of the narrative but not discussing how they impact him throughout the novel, Alexie ignores the reality of Arnold's experience as a disabled character; therefore, teachers should consider teaching texts that more authentically represent the experiences of disabled characters. Three disability-themed young adult novels that examine the intersectional identities of the protagonists relating to race and disability that can be taught as alternatives to *True Diary* (Alexie, 2007) are *Breathe and Count Back from Ten* (Sylvester, 2022), *The Sea in Winter* (Day, 2021), and *Forever is Now* (Lockington, 2023).

Disability Representation in *The Fault in Our Stars*

In *The Fault in Our Stars*[72] (Green, 2012) readers are introduced to Hazel Grace Lancaster, who has been living with terminal cancer for the past three years (Green, 2012, pp. 4-5, 24).[73] Hazel describes her diagnosis as she introduces herself during a support group meeting when she states, "I'm Hazel, …Thyroid [cancer] originally, but with an impressive and long-settled satellite colony in my lungs" (Green, 2012, p. 5). Later in the text, Hazel explains that she has been able to live this long due to an experimental medication (Green, 2012, p. 25). *The Fault*

[72] Hereafter referred to as *The Fault*.
[73] According to Bates (2017) *The Fault* (Green, 2012) was only being taught in one Ontario school in grades 7-12.

(Green, 2012) is an example of teen sick-lit which Elman (2012) defines as, "a genre of adolescent fiction that fused illness and romance narrative to reinforce the independent norms of able-bodiedness, heteronormativity, emotional management, and maturity among American youth" (p. 175). This is because the narrative primarily focuses on the romantic relationship between Hazel and Augustus, both of whom have terminal cancer (Green, 2012, pp. 24, 215). At the beginning of the novel, readers learn that Hazel has chosen to socially isolate herself due to her diagnosis, thus preventing her from attending school for the previous three years (Green, 2012, p. 45). Hazel informs the reader that "My parents were my two best friends" (Green, 2012, p. 12) which further reinforces the myth that disabled people need to be isolated from society because of our impairments (Barnes, 1992; Dolmage, 2014). Moreover, Hazel views herself negatively because she considers herself to be a "professional sick person" (Green, 2012, pp. 38, 100), as well as being a burden on her parents (Barnes, 1992; Connor, 2017). Hazel states:

> It occurred to me that the reason my parents had no money was because of me. I'd sapped the family savings with Phalauxifor [a cancer medication] copays, and Mom couldn't work because she had taken on the full-time profession of Hovering Over Me.[74] (Green, 2012, p. 79)

By viewing herself as a "professional sick person" (Green, 2012, pp. 38, 100) Hazel is also medicalizing and pathologizing herself (Dolmage, 2014), due to Hazel's impairments being the central aspect of her character's identity throughout the novel. This is a deficit-based assumption regarding disability because even individuals with the most severe impairments have interests that make their lives meaningful apart from their disabilities (Bickenbach et al., 2014).

[74] Capitals in the original.

However, through her romantic relationship with Augustus, Hazel becomes less socially isolated. Two examples of this occur in the narrative when Augustus invites Hazel to his house to watch *V for Vendetta*, and when they have a picnic (Green, 2012, pp. 17, 84-90).

In addition to participating in normative adolescent activities, Hazel and Augustus also behave in ways that Nykvist (2016) describes as giving the "… children citizenship in a country into which their parents' rule cannot reach. Terminal illness makes for autonomy" (p. 124). A first demonstration of Nykvist's (2016) argument that occurs in Green's (2012) novel is when Augustus decides to go to Amsterdam even though his parents do not think that he is well enough to go (Green, 2012, p. 139). In a second example from the narrative Hazel, Augustus, and Isaac decide to vandalize Isaac's ex-girlfriend's car for dumping him after he had to have his second eye removed (Green, 2012, pp. 227-229). In the novel's final demonstration of this behaviour, Hazel decides to go to Augustus's pre-funeral against the wishes of her parents (Green, 2012, pp. 255-256). Each of these illustrations show how the characters in *The Fault* use their "citizenship … in the Kingdom of the sick" (Sontag, 2013, p. 3) to subvert parental authority while exercising their autonomy in ways that living with a terminal illness permits.

Later in the novel, Hazel explains her decision to isolate herself from social and romantic relationships when she narrates:

> I'm not going on dates, … I don't want to go on dates with anyone. It's a terrible idea and a huge waste of time and … I'm like a *grenade,* Mom … and at some point I'm going to blow up and I would like to minimize the casualties, okay … I just want to stay away from people and read books and think and be with you guys because there's nothing I can do about hurting you; you're too invested so just please let me do that, okay? I'm not

> depressed. I don't need to get out more. And I can't be a regular teenager because I'm a grenade. (Green, 2012, p. 99)

In this quotation, Hazel is expressing her belief that she should isolate herself from others due to her terminal cancer diagnosis because her death will cause pain to the people she leaves behind.

Near the end of the novel Hazel expresses her concern by saying, "I want you guys [her parents] to have a life, … I worry that you won't have a life, that you'll sit around here all day with no me to look after and stare at the walls and want to off yourselves" (Green, 2012, p. 297). In response, her mother states "I don't want you to think I'm imagining a world without you. But if I get my MSW, I can counsel families in crisis or lead groups dealing with illness in their families" (Green, 2012, p. 297). To which Hazel replies, "This is fantastic!" (Green, 2012, p. 297).

However, when Hazel's parents require her to attend a cancer support group for children and adolescents she states:

> The Support Group, of course, was depressing as hell. … and listened to Patrick recount for the thousandth time his depressingly miserable life story – how he had cancer in his balls and they thought he was going to die but he didn't die and now here he is, a full-grown adult in a church basement in the 137th nicest city in America, divorced, addicted to video games, mostly friendless, eking out a meager living by exploiting his cancertastic past, slowly working his way towards a master's degree that will not improve his career prospects, … (Green, 2012, pp. 4-5)

By negatively portraying the support group that she attends, Hazel is denying the positive impact that attending a support group may have for people in the real world, not only regarding

cancer but also other forms of disability. Moreover, Hazel's problematic assessment of the support group that she attends is also based on a medical model understanding of disability because she judges the level of wellness of the group's participants based on whether they use the elevator or take the stairs (Green, 2012, pp. 8, 11).

Hazel's physical difference from the assumed abled norm is portrayed when she is approached by a child in the mall who expresses curiosity due to her use of a portable oxygen tank. This moment in the narrative occurs due to Hazel having "a stareable body" (Garland-Thomson, 2009, p. 58) in addition to being an example of Quayson's (2007) theory of "aesthetic nervousness" (p. 15) because this scene describes an interaction between a disabled and two abled characters in the text. Hazel documents this encounter as follows:

> This little girl with barretted braids appeared in front of me and said 'What's in your nose?' And I said, 'Um, it's called a cannula. These tubes give me oxygen and help me breathe.' Her mother swooped in and said 'Jackie' disapprovingly, but I said 'No, no, it's okay', because it totally was, and then Jackie asked 'Would it help me breathe, too?' 'I dunno. Let's try it. …' 'Tickles' she said. 'I know right?' 'I think I'm breathing better' she said. … 'Thanks for letting me try it.' … 'No problem.' (Green, 2012, pp. 46-47)

In this short scene, Green's (2012) novel captures the first time that Jackie meets a disabled person, during which she respectfully asks Hazel about her supplemental oxygen. Hazel's decision to answer Jackie's question is important because it destigmatizes disability by teaching Jackie that being disabled is simply another way of being in the world. A similar moment also occurs later in the novel when Augustus's young cousins meet Hazel for the first time. Hazel narrates:

> ‘I’m Hazel’ ‘Gus has a *Girlfriend,’* one of the kids said. ‘I am aware that Gus has a girlfriend,’ I said. ‘She’s got boobies’ another said. ‘Is that so?’ ‘Why do you have that?’ the first one asked pointing at my oxygen cart. ‘It helps me breathe’, I said. ‘Is Gus awake?’ ‘No, he’s sleeping.’ (Green, 2012, p. 249)

Both of the previous scenes of childhood “aesthetic nervousness” (Quayson, 2007, p. 15), can be contrasted with the disability as public spectacle response to disability (Garland-Thomson, 2009) that occurs when Hazel and Augustus visit the Anne Frank House in Amsterdam. Hazel writes:

> It was fourteen steps. I kept thinking about the people waiting behind me – they were mostly adults speaking a variety of languages – and feeling embarrassed or whatever, feeling like a ghost that both comforts and haunts, but I finally made it up, …my brain was telling my lungs *it’s okay it’s okay calm down* and my lungs telling my brain *oh God, we’re dying here*.[75] (Green, 2012, pp. 198-199)

After Hazel climbs the first set of stairs Augustus congratulates her when he states, “You’re a champion” (Green, 2012, p. 199). Shortly afterwards Hazel climbs a second set of even steeper stairs (Green, 2012, p. 199). In the previous two examples, Green’s (2012) text employs the deficit-based overcoming narrative representation regarding disability (Barnes, 1992; Dolmage, 2014) which describes disability as a negative form of individual physical or mental difference that disabled people need to overcome to participate in society. Further, Green’s narrative supports the supercrip (Schalk, 2016) rendition of the overcoming narrative because Augustus suggests to Hazel that “We should team up and be this disabled vigilante duo

[75] Italics in the original.

roaring through the world, righting wrongs, defending the weak, protecting the endangered" (Green, 2012, p. 202). By portraying Hazel's decision to climb two flights of stairs as part of an overcoming narrative, *The Fault* conveys the problematic message that disability can be overcome through physical effort instead of arguing for an inclusive society by identifying the social and environmental conditions that limit the participation of disabled people.

Once Hazel reaches the upper level of the Anne Frank House, Green gives readers and spectators a voyeuristic demonstration of "inspiration porn" (Grue, 2016, p. 838) when Hazel and Augustus kiss (Green, 2012, p. 203) as their reward for waiting for Hazel to climb the stairs. Hazel describes her thoughts during this moment in addition to the responses of the spectators to their kiss when she writes:

> Thinking that you cannot kiss anyone in the Anne Frank House, and then thinking that Anne Frank, after all, kissed someone in the Anne Frank House and that she would probably like nothing more than for her home to have become a place where the young and irreparably broken sink into love. … The kiss lasted forever … a crowd of people three deep had sort of circled around us. They were angry, I thought. Horrified. These teenagers, with their hormones, making out beneath a video broadcasting the shattered voice of a former father. … And then they started clapping All the people, all these adults, just started clapping, and one shouted 'Bravo!' (Green, 2012, pp. 202-204)

By presenting Hazel and Augustus's kiss at the top of the stairs as an inspirational moment in keeping with the charity discourse regarding disability (Dolmage, 2014; Longmore, 2016), instead of viewing their kiss as an ordinary part of being human, Green's text transforms an ordinary occurrence into an extraordinary spectacle (Garland-Thomson, 2009) due to Hazel and Augustus's extraordinary disabled bodies (Garland-Thomson, 1997). This moment is the

second occurrence in Green's (2012) novel that highlights the fact that both Hazel and Augustus have "stareable bodies" (Garland-Thomson, 2009, p. 8) which adds a voyeuristic quality to an otherwise uneventful kissing scene. The uniqueness of Hazel and Augustus's relationship is also demonstrated earlier in the narrative as Isaac's girlfriend leaves him when his cancer returns and he must have his second eye removed (Green, 2012, p. 60), thereby demonstrating society's prejudicial beliefs regarding the romantic and sexual lives of disabled people (Elman, 2012; Loftis, 2015).

A few pages after Hazel describes their kiss at the Anne Frank House (Green, 2012, pp. 202-204), they have sex in his hotel room (Green, 2012, pp. 206-208). By placing these events side by side in the narrative, Green is highlighting the difference between society's perceptions regarding the sexuality of disabled people and the mundane reality of disabled sexuality, which Tobin Seibers (2008) suggests needs to occur in order to create what he refers to as "A sexual culture for disabled people" (p. 135). Hazel narrates the ordinariness of her first sexual experience when she writes:

> The whole affair was the precise opposite of what I figured it would be: slow and patient and quiet and neither particularly painful nor particularly ecstatic. There were a lot of condomy problems that I did not get a particularly good look at. No headboards were broken. No screaming. Honestly, it was probably the longest time we'd ever spent together without talking. (Green, 2012, pp. 207-208)

Even though engaging in sexual activity is a common trope in teen sick-lit (Elman, 2012) the adolescent characters in these narratives do so as both an act of love as well as being a demonstration of their autonomy which their terminal illnesses permit. Nykvist (2016) explains:

> Being terminally ill makes waiting to be sexually active a bad choice in a society where sex is regarded as a key ingredient in life. The teenagers of these books also all choose to have premarital sex. The sexual act is, however, strongly connected to romantic love and follows the rule of the romance genre. The narratives may seem liberal in regards to sexuality, but are actually fundamentally conservative: sex is obviously a monogamous activity to be enjoyed by people who love each other. (p. 128)

The sex scene between Hazel and Augustus in *The Fault* (Green, 2012) is described in a similar manner to the sex scenes between the terminally ill adolescent characters in the young adult novels that Nykvist (2016) examines in her study. Additionally, Green's (2012) text challenges the myth that disabled people are "sexually abnormal" (Barnes, 1992, p. 16). However, Hazel and Augustus's moment of sexual intimacy could also be interpreted as a form of compensation (Dolmage, 2014), which enables them to consummate their relationship before Augustus dies. (Green, 2012, p. 261). Landrum (2001) warns teachers against selecting disability-themed young adult novels that portrays the disabled adolescent characters' sexuality in the manner that *The Fault* does when she states, "Whenever emotionally or sexually charged scenes appear, they are critical to the plot and theme, not to manipulate the reader's emotions" (p. 255). This is because *The Fault* depicts Hazel and Augustus's moment of sexual intimacy as the literal and literary climax of both their relationship, and the novel as a whole, before the falling action which leads to Augustus's tragic death (Green, 2012, p. 261). This scene is also an example of Quayson's (2007) "*Disability as epiphany*" (p. 45) representation of disability because at the beginning of the novel Augustus tells Hazel that he no longer has cancer (Green, 2012, p. 11). However, immediately after they have sex Augustus informs Hazel that his cancer has returned (Green, 2012, pp. 213-215) which is an epiphany for both Hazel and the reader.

Augustus then apologizes to Hazel for not telling her that his cancer had returned when he states, "I kind of conned you into believing that you were falling in love with a healthy person" (Green, 2012, p. 216). This revelation not only begins the plot's downward spiral leading to Augustus's death (Green, 2012, p. 261) but is an important element of teen sick-lit because in these narratives health and romantic attractiveness are linked (Elman, 2012). This representation of disability is problematic because it reinforces the deficit-based assumption that the lives of disabled people are tragic, in keeping with the "kill or cure" (Dolmage, 2014, p. 43) depiction of disability. Even though terminal illnesses are different from stable forms of impairment because they cause the premature deaths of those who live with them, fictional depictions of terminal illnesses often portray the "disability as pathology" (Dolmage, 2014, p. 43) and the "kill or cure" (Dolmage, 2014, p. 43) deficit-based representations of disability. Instead, terminally ill characters in fiction can be shown living their lives in ways that challenge or otherwise subvert these discourses. Nykvist (2016) highlights the moralizing role that Augustus's character has within the narrative as a contemporary representation of the dying child trope that commonly occurs in 19th century literature (Keith, 2001). Nykvist (2016) explains:

> That Augustus first shows up in church indicates that he can be seen as a Christ figure. He brings comfort to those he meets, as well as guides them to learn what is most important in life. As it turns out, he is also the deathbed child of this story – not, as the reader first is made to believe, the terminally ill narrator, Hazel. The impact he makes can be regarded as a secular take on Christian redemption. When the gift is life rather than the afterlife, the challenge is to live to the fullest, a challenge taken on by the protagonists of all my titles. The bucket lists testify to a wish to experience as much as possible, mentally as well as physically. This celebrates an individualist view: life is about your body, your

> senses, and your experience. This is, however, paradoxically joined with the idea of the deathbed child as redeemer. Through its example, others learn how to live their individual lives, too. (p. 130)

Additional examples of Augustus fulfilling this role within *The Fault* (Green, 2012) are witnessed through the social, emotional, and experiential impact that he has on Hazel throughout the narrative. For example, prior to them meeting Hazel chose to socially isolate herself due to her diagnosis, but through her relationship with Augustus she begins to participate more fully in the world outside her home (Green 2012, pp. 17, 84-90, 136-218). Second, as a result of her relationship with Augustus Hazel also gets to know Isaac better, and Hazel reconnects with her old friend Kaitlyn (Green, 2012, pp. 55-63, 132-135, 224-229, 279-282, 301-303). Each of these examples demonstrates the social and experiential role that Augustus plays in Hazel's life in his role as the moralizing dying child (Keith, 2001). Moreover, Augustus's death is depicted as a tragedy which is further explored in Hazel's eulogy for Augustus when she states, "Augustus Waters was the great star-crossed love of my life. Ours was an epic love story" (Green, 2012, p. 259). The phrase "star-crossed love" is an allusion to the prologue of *Romeo and Juliet* (Shakespeare, 1993) "A pair of star-cross'd lovers take their life" (1.1. 6) which reinforces the fact that Green's (2012) novel is to be read as a romantic tragedy. Even though Hazel is still alive at the conclusion of *The Fault*, her eulogy for Augustus documents her desire to have died before him. She states, "I'd hoped that he'd be eulogizing me, because there's no one I'd rather have" (Green, 2012, p. 259). Even though Green's novel portrays the lives of his adolescent disabled characters using numerous deficit-based representations of disability, Kirkman et al., (2018) argue that *The Fault* (Green, 2012) is a vital text for helping medical professionals who are working with terminally ill adolescents in four key areas:

> *TFIOS* [*The Fault in Our Stars*] can be examined and used as a means for understanding the unique struggles of dying adolescents. Undoubtedly, the contextual features of *TFIOS* elucidate certain thematic structure, and learners are encouraged to explore diverse works related to this subject matter. Despite its limitations, *TFIOS* provides insight into the conflict between emerging autonomy and dependence and demonstrates that teens have a specific and authentic thought process about [end of life] EOL preferences. Four major themes of Adolescent EOL Narrative – 1) the paradox of emerging autonomy and limited lifespan, 2) intensity of emotions, 3) the desire to have significant, sometimes expedited experiences, and 4) preferences around legacy – can serve as guideposts for adults and adolescents to organize their thoughts and make sense of an abridged life journey. (p. 12)

Even though I agree with Kirkman et al., (2018) that *The Fault* (Green, 2012) can be used by terminally ill adolescents and their families to help them to examine the four areas of their lives that the authors discuss, their (2018) work fails to recognise the numerous problematic representations of disability that are communicated to readers throughout the text.

Second, Marks and Merse (2018) suggest that *The Fault* (Green, 2012) and *Princes* (Levithan, 2008),

> … update and transform ELT pedagogy in terms of greater sociocultural diversity. We further argue that the topic of love provides an ideal locus for dialogic deep reading in that love is both a culturally universal phenomenon and a phenomenon contingent on discourse. (p. 160)

I agree with Marks and Merse (2018) that examining love in the language arts classroom from the perspectives of disabled and sexual minority characters is one strategy that teachers can use to increase the diversity of the language arts content they teach. However, I am concerned

that without the inclusion of content regarding the literary portrayals of disabled characters from a critical disability studies perspective in teacher preparation programs, language arts content related to disability will continue to be taught uncritically in schools. With this in mind, teachers can consider teaching *This is My Brain in Love* (Gregorio, 2020), or *Full Disclosure* (Garrett, 2019), both of which focus on the romantic relationships of their disabled protagonists. However, if teachers are looking for young adult novels that examine the experiences of characters living with terminal illnesses, *You'll Miss Me When I'm Gone* (Solomon, 2018), and *The Coldest Winter I Ever Spent* (Jacobus, 2023) are more disability-affirming options.

Common Representational Themes

In this chapter I have analyzed the depictions of seven disabled first-person protagonists in the seven disability-themed young adult novels that were being taught in grades 7-12 in Ontario schools that met the inclusion criteria for my study from Bates' (2017) data. The disabled first-person protagonists whose experiences I examined in this chapter include, Arnold in *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007) (who self-identifies as having numerous physical disabilities), Melinda in *Speak* (Anderson, 2019) (who I argue is living with an undiagnosed mental health disability), Charlie in *The Perks of Being a Wallflower* (Chbosky, 1999) (who is living with an undisclosed mental health disability), Troy in *Fat Kid Rules the World* (Going, 2004) (who is living with the physical and mental health related impact of obesity), Hazel in *The Fault in Our Stars* (Green, 2012) (who is living with terminal cancer), Christopher in *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004) (who has an unidentified developmental disability), and Craig in *It's Kind of a Funny Story* (Vizzini, 2010) (who is living with clinical depression). Across the seven texts that I surveyed in this chapter, I noted numerous deficit-based representations of disability. These include, "Disability as

Pathology, Disability as Isolating and Individuated, Overcoming or Compensation, Disability Drop" (Dolmage, 2014, pp.43-45), "The Disabled Person as an Object of Ridicule", "The Disabled Person as Burden",[76] "The Disabled Person as Sexually Abnormal" (Barnes, 1992, pp. 13, 15-16), "*disability as the interface with otherness* (*race, class, sexuality, and social identity*)",[77] "*Disability as epiphany*" (Quayson, 2007, pp. 39, 45), and that disabled characters are "evil or sinister" (Connor, 2017, p. 206), each of which negatively impacts readers' beliefs regarding disability. As Garland-Thomson (1997) reminds us:

> If we accept the convention that fiction has some mimetic relation to life, we grant it power to further shape our perceptions of the world, especially regarding situations about which we have little direct knowledge. Because disability is so strongly stigmatized and is countered by so few mitigating narratives, the literary traffic in metaphors often misrepresents or flattens the experience real people have of their own or others' disabilities. (p. 10)

The most common representation of disability that I located in five of the seven texts that I surveyed in this chapter is "Disability as Isolating and Individuated" (Dolmage, 2014, p. 44) which applies to Melinda in *Speak* (Anderson, 2019, p. 4), Charlie in *Perks* (Chbosky, 1999, pp. 3, 7), Christopher in *Curious Incident* (Haddon, 2004, p. 43), Troy in *Fat Kid Rules the World* (Going, 2004, p. 9), and Hazel in *The Fault* (Green, 2012, p. 12) because they have no friends or limited contact with their friends at the beginning of the novel. By depicting their disabled characters in this manner, the authors of these texts are communicating to readers the myth that disabled individuals are socially isolated due to their impairments, instead of examining the

[76] The capitals are in the original.
[77] The italics are in the original.

social and physical barriers that have led to their social exclusion. Moreover, only two of the disabled first-person protagonists whose characterizations I have surveyed in this chapter, Arnold in *True Diary* (Alexie, 2007, pp. 5, 230) and Craig in *It's Kind of a Funny Story* (Vizzini, 2010, pp. 11, 318) begin and end their narratives with pre-existing long-term friendships.

Positively, five of the seven disabled first-person protagonists, Charlie in *Perks* (Chbosky, 1999, p. 20), Troy in *Fat Kid Rules the World* (Going, 2004, p. 98), Craig in *It's Kind of a Funny Story* (Vizzini, 2010, p. 90), Arnold in *True Diary* (Alexie, 2007, p. 25), and Hazel in *The Fault* (Green, 2012, p. 12) express romantic or sexual desires. Three of these, Charlie (Chbosky, 1999, p. 202), Craig (Vizzini, 2010, pp. 253, 310-311), and Hazel (Green, 2012, pp. 206-208) participate in consensual intimate relationships, which challenges the myth that disabled people are "sexually abnormal" (Barnes, 1992, p. 16). However, as I noted in my discussion of Chbosky's (1999), Vizzini's (2010), and Green's (2012) narratives, each instance reinforced other deficit-based representations of disability. Conversely, Melinda in *Speak* (Anderson, 2019) and Christopher in *Curious Incident* (Haddon, 2004) are not depicted as being interested in romantic or sexual relationships.

A third theme that I found in *Speak* (Anderson, 2019, pp. 5, 28, 81, 87, 110, 113, 130, 132), and *Perks* (Chbosky, 1999, pp. 2, 74, 77, 86, 92, 99, 148, 202, 204-205, 208) is that experiencing sexual violence can lead to symptoms that are associated with mental health disabilities. In both novels, surviving sexual violence negatively impacts the protagonist's social relationships, as well as other aspects of their identities. Problematically, however, neither text shows how receiving appropriate counselling or other forms of mental health treatment can support survivors of sexual violence.

A fourth common representation of disability that I located in four of the seven narratives that I examined in this chapter is "Overcoming or Compensation" (Dolmage, 2014, p. 44). This portrayal of disability occurs in *Fat Kid Rules the World* (Going, 2004, p. 55), *Curious Incident* (Haddon, 2004, pp. 6, 43, 61, 64, 101, 143- 144, 146), *True Diary* (Alexie, 2007, pp. 84, 142), and *The Fault* (Green, 2012, pp. 198-199) which problematically suggests that disabled individuals need to overcome their impairments in order to participate in society.

Fifth, three of the seven protagonists whose experiences I have documented in this chapter, Melinda in *Speak* (Anderson, 2019), Craig in *It's Kind of a Funny Story* (Vizzini, 2010), and Charlie in *Perks* (Chbosky, 1999) are represented in a disability "culturally authentic" (Brown, 2020, p. 141) manner due to their depictions being similar to the lives of white, straight, cis-gender, middle-class, disabled adolescents in the real world. Moreover, Melinda, Craig, and Charlie's portrayals in relation to disability could be an example of what Connor (2017) describes as "The Everyday and Therefore No Big Deal Portrayal of Disability" (p. 205). By communicating the experiences of their disabled protagonists in this manner, all three authors have challenged numerous problematic representations of disability by showing readers that living with a disability can (for some people) be considered a meaningful part of their identities.

A final theme that I found in four of the seven novels examined in this chapter is the prevalence of characters living with undiagnosed or undisclosed disabilities. At no point in their narratives do Charlie in *Perks* (Chbosky, 1999), Melinda in *Speak*, (Anderson, 2019), Troy in *Fat Kid Rules the World* (Going, 2004), or Christopher from *Curious Incident* (Haddon, 2004), self-identify as disabled. Moreover, each of these protagonist's beliefs about themselves supports Bérubé's (2015) argument that fiction "can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged

with a specific diagnosis" (Bérubé, 2015, p. 19). By doing so, the aforementioned young adult novels highlight the fact that many characters in literature and people in the real world are living with undiagnosed disabilities or do not consider themselves to be disabled.

Protagonist Demographic and Identity Information

Across the seven disability-themed young adult novels that I have surveyed in this chapter the gender breakdown consisted of five male and two female protagonists, only one of whom, Arnold Spirit Jr. from *True Diary* (Alexie, 2007, pp. 2-3), is a racial minority.

Of the seven disabled first-person protagonists whose experiences I have discussed in this chapter, three – Melinda in *Speak* (Anderson, 2019), Christopher in *Curious Incident* (Haddon, 2004), and Hazel in *The Fault* (Green, 2012) – are only children. This is in contrast to the family relationships of Charlie in *Perks* (Chbosky, 1999, p. 5), (who has two older siblings), Troy in *Fat Kid Rules the World* (Going, 2004, p. 9) (who has a younger brother), Craig, in *It's Kind of a Funny Story* (Vizzini, 2010, p. 81) (who has a younger sister), and Arnold in *True Diary* (Alexie, 2007, p. 9) (who has an older sister). Based on my analysis of each text, I have concluded that the protagonists' disabilities had little impact on the relationships between the disabled protagonists and their abled siblings, which communicates to readers that having a disabled sibling does not necessarily affect the sibling relationship. Moreover, the depiction of these sibling relationships also supports Dyches et al.'s (2009) argument regarding the portrayal of sibling relationships between abled and disabled characters. They state, "The sibling relationship is reciprocal. The sibling(s) are not given unusually burdensome household and family duties" (Dyches et al., 2009, p. 307). By depicting the relationships between the four disabled protagonists and their abled siblings in this manner, each author has challenged the deficit-based

assumption that having a disabled sibling will be burdensome; instead, these texts convey the message that having a disabled sibling does not necessarily impact their relationship.

In contrast to the representations of the relationships between the disabled protagonists and their abled siblings, the portrayals of the relationships between the disabled protagonists and their parents were mixed. Across the seven narratives, Charlie in *Perks* (Chbosky, 1999, p. 209), Arnold in *True Diary* (Alexie, 2007, p. 46), and Craig in *It's Kind of a Funny Story* (Vizzini, 2010, pp. 81, 123, 299, 314) come from largely supportive two-parent families. This contrasts with the relationship that Melinda in *Speak* (Anderson, 2019) has with her parents because they are absent from her life (p. 14). On the other hand, Troy in *Fat Kid Rules the World* (Going, 2004, p. 9), and Christopher in *Curious Incident* (Haddon, 2004, pp. 22, 82-85, 108, 134, 192, 195) live in single-parent households and have strained relationships with their parents. Lastly, Hazel in *The Fault* (Green, 2012) believes that she is a burden to her parents (p. 79).

From a socio-economic perspective, Arnold in *True Diary* (Alexie, 2007, pp. 7-13) and Hazel in *The Fault* (Green, 2012, p. 79) are economically disadvantaged while the other five protagonists appear to live in middle class households.

In relation to the representations of the protagonist's sexual identity, none of the disabled first-person protagonists in my study self-identify as being gender or sexual minorities and only one protagonist, Arnold in *True Diary* (Alexie, 2007), is a racial minority. This has a direct impact on the silencing of disabled characters who are members of racial, sexual, religious, and immigrant communities in the disability-themed young adult narratives that are being taught in grades 7-12 in Ontario schools.

Conclusion

In this chapter, I have critically critiqued the portrayals of seven disabled first-person protagonists in seven disability-themed young adult novels that are being taught in grades 7-12 in Ontario schools according to Bates (2017). These include *Speak* (Anderson, 2019), *The Perks of Being a Wallflower (*Chbosky, 1999), *Fat Kid Rules the World* (Going, 2004), *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004), *It's Kind of a Funny Story* (Vizzini, 2010), *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007), and *The Fault in Our Stars* (Green, 2012). From my analysis of these seven narratives, I have determined that Melinda in *Speak*, Charlie in *Perks*, and Craig in *It's Kind of a Funny Story* are largely depicted in a disability "culturally authentic" (Brown, 2020, p. 141) manner. I have made this determination based on the academic scholarship that I have reviewed regarding the representation of disability in cultural texts and my experience as a white, straight, middle-class, disabled, academic reader of disability-themed literature. However, by making this claim, I recognize the fact that Charlie in *Perks*, Melinda in *Speak*, and Craig in *It's Kind of a Funny Story* are white, straight, and middle-class characters living with either diagnosed or undiagnosed mental health disabilities, which excludes the experiences of readers whose identities are not represented in the novels by Anderson, Chbosky, and Vizzini. In contrast, Troy in *Fat Kid Rules the World*, Christopher in *The Curious Incident of the Dog in the Night-Time*, Arnold in *The Absolutely True Diary of a Part-Time Indian*, and Hazel from *The Fault in Our Stars* were represented in a deficit-based manner. In addition, I have discussed the common representational themes that I located across the seven texts, and the protagonist's demographic and identity information. In the next chapter, I will answer the second research question of my study: How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to

teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner? This will include discussing how asset-based pedagogies can be used to teach disability-themed content in the language arts classroom by using the middle grade novel *A Kind of Spark* (McNicoll, 2020) as a demonstration.

Chapter 7: Teaching About Disability in the Language Arts Classroom Using Asset Based Pedagogies from a DSE Perspective

Introduction

For more than a century, teaching literature has been a vital component of the language arts curriculum in schools (Aston, 2020; Hill & Malo-Juvera, 2019). This trend is also present in Ontario schools where canonical classroom literature is being taught alongside contemporary children's and young adult novels (Bates, 2017). In previous chapters, based on the work of Bates (2017), I have critically examined the ways in which 12 disabled first-person protagonists are portrayed in 12 disability-themed children's and young adult novels that are currently being taught in grades 7-12 in Ontario schools. In this chapter, I will address the second research question of my study: How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner? The answer to this question is vital to my dissertation because it builds on the conclusions that I reached regarding my first research question which I examined in Chapters 5 and 6 of my study: How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? I examined this question by critiquing the representations of 12 disabled first-person protagonist in 12 disability-themed children's and young adult novels that are being taught in grades 7-12 in Ontario schools, as based on the work of Bates (2017).

My analysis of the depictions of the 12 disabled first-person protagonists whose portrayals I have evaluated in my study revealed that many of these narratives represent disability in a deficit-based manner. For example, only two of the 12 protagonists in my study –

Craig, in *It's Kind of a Funny Story* (Vizzini, 2010) and Arnold in *True Diary* (Alexie, 2007) – began their texts with pre-existing friendships, which communicates the myth that disabled characters are socially isolated (Dolmage, 2014). A second key finding was that the experience of disability was often represented through bullying, social stigma, and ableism in educational settings. The disabled first-person protagonists who experienced social stigma due to their impairments were Max in *Freak the Mighty* (Philbrick, 1993), Ambrose in *Word Nerd* (Nielsen, 2010), Melody in *Out of My Mind* (Draper, 2010), August in *Wonder* (Palacio, 2012), Ally in *Fish in a Tree* (Hunt, 2015), Troy in *Fat Kid Rules the World* (Going, 2004), and Christopher in *Curious Incident* (Haddon, 2004). Of these, only Troy in *Fat Kid Rules the World* and Christopher in *Curious Incident* do not experience bullying. Max in *Freak the Mighty*, Ambrose in *Word Nerd*, Melody in *Out of My Mind*, August in *Wonder*, Ally in *Fish in a Tree*, and Arnold in *True Diary* encounter bullying. Moreover, Max in *Freak the Mighty*, Ambrose in *Word Nerd*, Melody in *Out of My Mind*, August in *Wonder*, and Ally in *Fish in a Tree* experience systemic ableism in educational settings.

Due to the numerous deficit-based representations of disability that I located during my analysis of the 12 disability-themed children's and young adult novels that met the inclusion criteria of my study, I am proposing that teachers adopt an "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) informed approach when teaching disability-themed literature in the language arts classroom. Waitoller and King Thorius (2023) define "asset-based pedagogies" as "an umbrella term for various pedagogical approaches that privilege, value, and sustain the cultural and linguistic practices of minoritized students" (p. xv). An asset-based approach to pedagogy is vital because it enables teachers to teach content related to disability using

disability-themed literature that challenges deficit-based understandings of disability and portrays disability in a disability "culturally authentic" (Brown, 2020, p. 141) manner.

Moreover, in this chapter, I will demonstrate how teachers can use culturally relevant pedagogy (Ladson-Billings, 1995), and culturally responsive teaching (Gay, 2018)[78] (CRRP) from a disability studies in education (DSE) perspective, both of which are "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv). Throughout this chapter, I have used the disability-themed children's novel *A Kind of Spark* (McNicoll, 2020) to demonstrate how these methods of instruction can be used concurrently while beginning to address the absence of curriculum content that views disability as a socio-cultural political identity category within schools (Hansen et al., 2022; Mueller, 2021). Moreover, by showing how disability can be represented as both an individual experience, in addition to being a multi-faceted cultural community, my work in this chapter can serve as a framework through which teachers can move from the initial stages of Banks' (2006) work regarding multicultural education: "(1) content integration, (2) the knowledge construction process, [or] (3) prejudice reduction" (p. 133). Instead, teachers can view curriculum content in relation to disability as an aspect of multicultural education that considers disability through the lens of "(4) an equity pedagogy, and [as a form of] (5) … empowering school culture and social structure" (Banks, 2006, p. 133) within the language arts classroom.

Defining Asset-Based Pedagogies

As I noted previously, Waitoller and King Thorius (2023) define asset-based pedagogies as, "an umbrella term for various pedagogical approaches that privilege, value, and sustain the

[78] I have combined Ladson-Billings (1995) culturally relevant pedagogy and Gay's (2018) culturally responsive teaching using the acronym CRRP.

cultural and linguistic practices of minoritized students" (p. xv). Two examples of asset-based pedagogies include culturally relevant pedagogy (Ladson-Billings, 1995) and culturally responsive teaching (Gay, 2018). Ladson-Billings (1995) outlines culturally relevant pedagogy when she states:

> Culturally relevant pedagogy rests on three criteria or propositions: (a) Students must experience academic success; (b) students must develop and/or maintain cultural competence; and (c) students must develop a critical consciousness through which they challenge the status quo of the current social order. (Ladson-Billings, 1995, p. 160)

Culturally relevant pedagogy has been used by teachers with African American students (Brooks, 2006; Brooks & Browne, 2012; Ladson-Billings, 1995), Indigenous students (Savage et al., 2011), LGBTQ students (Helmer, 2015; Malo-Juvera, 2016), and religiously diverse students (Aronson et al., 2016), as well as in diverse subject areas (Aronson & Laughter, 2016; Martell, 2018). However, only recently have asset-based pedagogies begun being theorized in relation to disability with the publication of Waitoller and King Thorius's (2023) edited collection *Sustaining Disabled Youth: Centering Disability in Asset Pedagogies*. However, due to the theoretical nature of this work there continue to be, to the best of my knowledge, no applied studies regarding the use of asset-based pedagogies in relation to disability.

In contrast, Gay (2018) describes culturally responsive teaching as, "using the cultural knowledge, prior experiences, frames of reference, and performance styles of ethnically diverse students to make learning encounters more relevant to and effective for them" (p. 36). Gay (2010) further divides her theory of culturally responsive teaching into six key areas:

> •• Culturally responsive teachers are *socially and academically empowering* by setting high expectations for students with a commitment to every student's success; ••

> Culturally responsive teachers are *multidimensional* because they engage cultural knowledge, experiences, contributions, and perspectives; •• Culturally responsive teachers *validate every student's culture*, bridging gaps between school and home through diversified instructional strategies and multicultural curricula; •• Culturally responsive teachers are *socially, emotionally, and politically comprehensive* as they seek to educate the whole child; •• Culturally responsive teachers are *transformative of schools and societies* by using students' existing strengths to drive instruction, assessment, and curriculum design; •• Culturally responsive teachers are *emancipatory and liberating from oppressive educational practices and ideologies* as they lift 'the veil of presumed absolute authority from conceptions of scholarly truth typically taught in schools'.[79] (Gay, 2010, cited in Aronson & Laughter, 2016, p. 165)

By highlighting each facet of culturally responsive teaching Gay's (2010) work, in addition to Ladson-Billings' (1995) scholarship, has the potential to be transformative when applied to the teaching of disability-themed content for disabled students in the language arts classroom, as it has been for other student populations (Aronson et al., 2016; Malo-Juvera, 2016; Savage et al., 2011). However, in order for disability affirming content to be taught within the language arts curriculum using CRRP, teacher education programs need to begin including discussions of disability-themed content as part of teacher preparation programs and graduate education courses when CRRP is being discussed as a pedagogical approach.

[79] Italics in the original.

Teaching about Disability Rights, Identity, and Activism from a DSE Perspective in the Middle Grade Language Arts Classroom Using CRRP

In *A Kind of Spark* (McNicoll, 2020), readers are introduced to Addie, an autistic 11-year-old girl who lives with her parents and older twin sisters (one of whom is also autistic). When Addie discovers that her small Scottish village used to accuse and then execute women for being witches, she draws parallels between society's beliefs about her and other autistic people and the historical treatment of the women who were accused of, and later executed for, being witches (McNicoll, 2020, pp. 20, 21, 51-58). She does this by advocating for her community to construct a memorial as a form of disability rights activism (McNicoll, 2020, pp. 29-31, 101-102, 122-124, 167-171, 174-175). Throughout the novel, Addie experiences ableism, both at school and in her community (McNicoll, 2020, pp. 1, 46, 95, 131, 136-141), while advocating for her rights and identity as an autistic person. The text also explores other educational themes including friendship, family relationships, bullying and the treatment of disabled students in schools, ableism, ableist language, as well as self-advocacy and social change. Due to the importance of the themes of disability identity, disability history, and disability rights activism in the novel, *A Kind of Spark* (McNicoll, 2020) can be paired with non-fiction children's books that examine similar themes, such as *Emily Included* (McDonnell, 2011) which examines the *Eaton v. Brant County* Canadian Supreme Court case, or *Rolling Warrior* (Heumann & Joiner, 2021) which examines the life and disability rights activism of Judy Heumann.

Educational Themes

A Kind of Spark (McNicoll, 2020) contains numerous important educational themes that can be taught in the language arts classroom using CRRP from a DSE perspective, including ableism, disability as identity, disability rights, friendship, bullying, family relationships, and

education as a social institution. Moreover, DSE informed teachers can enhance students' knowledge of disability history, culture, and pride through discussions of disability language, disability representation in literature, and other cultural texts, as well as teaching students about the historical and contemporary lives of disabled people. By doing so, teachers will be providing their students with the information they need to understand and engage more fully with Addie's experience throughout the novel. Furthermore, DSE informed teachers will have effectively applied the tenets of CRRP by ensuring that, "(a) students must experience academic success; (b) students must develop and/or maintain cultural competence; and (c) students must develop a critical consciousness through which they challenge the status quo of the current social order" (Ladson-Billings, 1995, p. 160). Additionally, teachers will have shown that they "are *multidimensional* … are *socially and academically empowering … [by] validat[ing] every student's culture …* are *socially, emotionally, and politically comprehensive*…[and] are *emancipatory and liberating from oppressive educational practices and ideologies*" (Gay, 2010, p. 38 cited in Aronson & Laughter, 2016, p. 165).[80] Each of the previously cited components of CRRP can be applied by language arts teachers while teaching *A Kind of Spark* (McNicoll, 2020) by teaching the novel in a manner that is at the appropriate academic level so that the content and themes of the text are accessible for the students in their classroom. This allows teachers to maintain high but realistic academic standards in student scholastic achievement while not setting unrealistic academic expectations. Second, by teaching *A Kind of Spark* from a DSE informed standpoint, teachers will be increasing their students' knowledge of disability and disabled people in numerous ways, such as: the appropriate use of language regarding disability,

[80] Italics in the original.

the representations of disability in literary and other cultural texts, the historical and contemporary experiences of disabled people in society, disability rights and activism, as well as the development of disability pride as a vital aspect of disabled people's identities. Third, by discussing disability activism and disability rights from a DSE informed standpoint, teachers will be helping their students to "develop a critical consciousness through which they challenge the status quo of the current social order" (Ladson-Billings, 1995, p. 160) regarding disability. Furthermore, by teaching *A Kind of Spark* (McNicoll, 2020) from a DSE standpoint teachers will be "*socially and academically empowering*" (Gay, 2010, p. 38 as cited in Aronson & Laughter, 2016, p. 165)[81] their students by engaging in discussions of disability from a social model perspective, as doing so highlights the socially constructed nature of disability. Second, by introducing their students to aspects of disability history, culture, and pride throughout the unit, teachers will be "*validat[ing]* [disability as one of many communities that fit under the umbrella of] *every student's culture*" (Gay, 2010, p. 38 cited in Aronson & Laughter, 2016, p. 165).[82] By making this curricular choice, teachers will be providing their students with examples of disability culture such as fiction, and life-writing created by the disability community. Finally, DSE informed teachers can be "*socially, emotionally, and politically comprehensive…*[and] *are emancipatory and liberating from oppressive educational practices and ideologies*" (Gay, 2010, p. 38 cited in Aronson & Laughter, 2016, p. 165)[83] by recognising and challenging problematic policies and practices in their school, and by supporting the inclusion of disabled students in their classrooms. From a curricular standpoint, this could include discussing disability language,

[81] Italics in the original.
[82] Italics in the original.
[83] Italics in the original.

ableism, and disability rights in the classroom when content related to disability is being taught. Second, teachers can support the development of disability culture and pride in their school by being the faculty advisor for their school's disabled students organization where topics related to students' experiences as disabled people or allies can be discussed and disability culture is explored.

In Appendix I, I have developed a language arts unit that focuses on the themes of disability rights, culture, and identity which I have constructed from a DSE perspective using CRRP. To achieve these curricular goals, I have framed the unit around a critical questions-based approach to pedagogy which is inspired by the work of Curwood, (2013) and Tondreau and Rabinowitz (2021) to guide students' literary responses to the text. Using critical questions as a pedagogical approach provides the scaffolding upon which students can examine their response to *A Kind of Spark*, thereby enabling students to think critically about the text's themes while writing reader response assignments, which is an application of Rosenblatt's (1995) transactional theory of literature.

Conclusion

In this chapter, I have examined the second research question of my study: How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner? By doing so, I have demonstrated one approach to CRRP, from a DSE perspective, that teachers can use while teaching the middle-grade disability-themed novel *A Kind of Spark* (McNicoll, 2020) in the language arts classroom. This aims to highlight how CRRP can be applied as an instructional strategy while teaching disability-themed content in the language arts classroom by

demonstrating that disabled people are a minority cultural community. My work in this chapter goes beyond the often-shallow portrayal of minority communities, such as those that focus on community heroes or celebrations (Banks, 2006). Rather, my use of disability history, culture, and pride is an example of what Banks (2006) describes as implementing "an equity pedagogy, … [to create] an empowering school culture and social structure" (p. 133) in relation to disability in the language arts classroom. In the next chapter, I will conclude my study by discussing the conclusions that I have reached and by making recommendations regarding teacher preparation and future directions that scholarship regarding the representation of disabled characters in literary studies and education can take from a critical disability studies perspective. Finally, I will conclude this chapter by documenting the limitations of my study and making a concluding statement regarding the work that I have undertaken throughout my dissertation.

Chapter 8: Conclusions, Recommendations and Directions for Future Research

In Chapter 1, I began my study by showing how the uncritical selection and teaching of disability-themed language arts texts negatively impacted how I felt about myself as a disabled person. This oversight served as the impetus for my research into the ways that disabled first-person protagonists are depicted in contemporary realistic children's and young adult literature being taught in Ontario schools. Based on data collected by Bates (2017), I located and analyzed 12 disability-themed children's and young adult novels that met my inclusion criteria, based on established criteria for evaluating books with disabled characters (Andrews, 1998; Connor, 2017; Dolmage, 2014). In this chapter, I first summarize the major findings of my study; next, I engage in a broader discussion of my analyses regarding the prominent theoretical underpinnings of my work, including Foucault's (1990, 2012) social constructivist theories of "bio-power" (p. 140) and the "normalizing gaze" (p. 184), and Goffman's (2009) stigma theory. Thereafter, I describe the applications of Foucault's and Goffman's scholarship by the critical disability studies scholars Davis (1995) and Garland-Thomson (1997), whose publications have informed the work that I have undertaken in this study. Following this discussion, I offer implications for teacher preparation and recommendations for future research. Lastly, I conclude by describing the limitations of my study and providing a critical reflection on my dissertation as a whole.

Disability-themed Literature as Mirrors and Windows on the World

In her 1990 keynote address to the 14th annual California State University, San Bernardino Reading Conference, Rudine Sims Bishop argues that literature serves as both "mirrors, and windows" on the world. She states, "A book can sometimes be a window. … When lighting conditions are just right, a window can also be a mirror, reflecting back for us the joys and sorrows, the loves and hates, the pain and pleasure of living" (Bishop, 1990, p. 3). Building

on Bishop's (1990) premise that literature is both a mirror and a window on the world, I will demonstrate how society's beliefs and attitudes regarding disability can either be reproduced or subverted through the texts that are being taught in the language arts classroom, as well as how these narratives impact readers' beliefs and attitudes about disability. In earlier chapters, I described the negative impact being assigned *Heidi* (Spyri, 1994), *The Cay* (Taylor, 2011), and *The Giver* (Lowry, 1993) had on me as a disabled person as part of my assigned language arts education. By teaching texts uncritically from a disability perspective, my teachers were unknowingly reinforcing deficit-based beliefs and attitudes regarding disability through their curricular and pedagogical choices. Bishop (1990) describes the unintended consequences that can result from the uncritical selection and teaching of language arts texts, as well as the negative impact that it can have on students when she writes, "When children cannot find themselves in books, or when they see themselves presented only as laughable stereotypes, they learn a powerful lesson about how much they are undervalued in the society in which they are a part" (p. 5). Bishop's (1990) warning about the negative impact that teaching books uncritically can have on students was confirmed by my experience as a disabled student when I was assigned *Heidi* (Spyri, 1994), *The Cay* (Taylor, 2011), and *The Giver* (Lowry, 1993) without important critical contextualization. In Chapter 3, I highlighted the deficit-based representations of disability that I located in these three novels. Some of these include that: it is better to be dead than disabled, *The Giver* (Lowry, 1993, pp. 15-18, 148-152), disabled characters need to be cured, *The Cay* (Taylor, 2011, pp. 100-101), and disability needs to be overcome, *Heidi* (Spyri, 1994, p. 192), each of which are deficit-based societal understandings of and responses to disability (Dolmage, 2014).

My experience was not an isolated case, as Reid (2010) describes the social and academic impact that being taught disability-themed content uncritically had on her daughter during middle school when she writes:

> In seventh grade, in the mid-1990s, Abby [her daughter] found no accurate representation of herself in literature, no room for her voice in writing. The ELA curriculum at her middle school proved a minefield for a young woman of color who wore a leg brace and walked with crutches. Her teachers were all well intentioned, but the pervasive public sensitivity of the period had some gaping holes. (Reid, 2010, p. 105)

Reid (2010) continues:

> Abby's grades started falling, and she finished eighth grade a very unhappy kid. Some years later when she was in graduate school, she wrote that middle school was 'a period in my life when I felt as though life as I knew it should cease to exist right then and there. I was tired of the rejection. I was tired of being cast out by my peers for the fact that I was different. I was disabled. ... I tried so hard to fit in with the girls that continued to deny me as being human'. (Reid, 2010, p. 106)

Thus, the depiction of disability that is present in the literature being taught in schools can negatively impact the beliefs and attitudes that students have about disability. Fortunately, however, the opposite can also be the case when disability-themed content is taught critically in the language arts classroom (Cameron & Rutland, 2006; Ware, 2001, 2002). Ware (2002) describes the positive impact that learning about disability in the language arts classroom from a critical disability studies perspective had for Karen, who self-identifies as a disabled person. Karen writes, "I remember when we got to talk about our first encounter with disability because that really gave me a chance to tell everybody in my writing, not just out loud, but in my writing,

something about me" (Karen, cited in Ware, 2002, p. 158). Moreover, when language arts content is taught in a disability "culturally authentic" (Brown, 2020, p. 141) manner it can provide readers with disability affirming "mirrors, and windows" (Bishop, 1990, p. 3) in the language arts classroom. The disability studies in education scholars, Baglieri and Lalvani (2019), Connor and Bejoian (2007), and Dunn (2013) have suggested numerous approaches that teachers can take when teaching about disability in their language arts classrooms, the aim of which is to enable teachers to include disability-themed content in a manner that provides students with disability affirming "mirrors, and windows" (Bishop, 1990, p. 3). The importance of doing so is communicated by Karen (one of the students in Ware's (2002) study). When she is asked "how best to educate society about disability" (Ware, 2002, p. 159) Karen replies, "You just bring it out in the open. You can't hide from it cause it's there – it's always going to be there – you know, you just can't keep ignoring it. I can't ignore my disability, why would you?" (Karen, cited in Ware, 2002, p. 159). To further Karen's suggestion to "bring it [disability] out in the open" (Karen, cited in Ware, 2002, p. 159), I have provided lists of disability "culturally authentic" (Brown, 2020, p. 141) middle grade and young adult novels in Appendices G and H.

Theories of Power and Social Stigma

In Chapter 2 I described the ways in which Foucault's (1989, 1990, 2012) theories of normalization, power, and social control and Goffman's (2009) work regarding stigma theory have been applied by scholars in critical disability studies (Davis, 1995; Garland-Thomson, 1997) and disability studies in education (Allan, 2015; Brantlinger, 2006), which serve as societal gatekeepers regarding normalcy. Davis (1995) problematizes the social construction of normalcy when he argues "…the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (p. 24). Moreover, Garland-Thomson, (1997) has shown the

impact that literary portrayals have on society's socially constructed understanding of disability in the form of literary ableism. She writes, "Most disabled characters are enveloped by the otherness that their disability signals in the text. … Consequently, literary texts necessarily make disabled characters into freaks, stripped of normalizing contexts, and engulfed by a single stigmatic trait" (pp. 10-11). In this section, I discuss the ways in which Foucault and Goffman's theories were present across the 12 disability-themed children's and young adult novels being taught in grades 7-12 in Ontario schools that met the criteria for my study, based on the work of Bates (2017).

Foucault's Theories of Bio-Power, Social Control, and the Normalizing Gaze

Throughout my study Foucault's (1990, 2012) theories of power, normalization, and social control were present in different contexts across the 12 disability-themed children's and young adult narratives that I have examined in my dissertation. Two examples of this are Foucault's concepts of "bio-power" (1990, p. 140)[84] and "the normalizing gaze" (2012, p. 184).[85] Both "bio-power" and "the normalizing gaze" occur in *Word Nerd* (Nielsen, 2010). "Bio-power" is witnessed in *Word Nerd* when Ambrose is removed from school by his principal Mr. Acheson after a bullying incident that results in Ambrose having a severe allergic reaction at school (Nielsen, 2010, pp. 5-7, 39). As a result of this incident, Mr. Acheson decides that Ambrose should receive his education through "correspondence schooling" (Nielsen, 2010, p. 39), due to his life-threatening allergy. Mr. Acheson's decision demonstrates the power that principals have over the educations of their students, which is a form of educational "bio-power" (Foucault, 1990, p.140) that principals yield over the "docile (educational) bodies" (Foucault, 2012, p. 135)

[84] For Foucault's (1990) definition of "bio-power" refer to page 25.
[85] For Foucault's (2012) definition of "the normalizing gaze" refer to page 24.

of their students regarding their educational placements. Mr. Acheson's belief that Ambrose should receive his education through "correspondence schooling" (Nielsen, 2010, p. 39) is due to his "normalizing [administrative] gaze" (Foucault, 2012, p. 184) through which he socially constructs and then resolves "the 'problem' of the disabled person" (Davis, 1995, p. 24) by removing Ambrose from the school. Thus, Mr. Acheson views Ambrose's life-threatening allergy through a deficit-based medical model perspective that considers Ambrose's allergy to be an individual medical concern which requires an individualized medical response instead of a wider societal one. Based on this perspective, Mr. Acheson decides to exercise his "bio-power" (Foucault, 1990, p. 140) over Ambrose's "docile" (Foucault, 2012, p. 135) educational body based on his "normalizing [administrative] gaze" (Foucault, 2012, p. 184) which he uses to pathologize (Dolmage, 2014) Ambrose before removing him from the school.

In a second example, Foucault's concepts of "bio-power" (Foucault, 1990, p. 140) and "the normalizing gaze" (2012, p. 184) are also witnessed in *Wonder* (Palacio, 2012). In the novel, August's principal Mr. Tushman uses his "normalizing [administrative] gaze" when he informs Julian's mother that "He [August] is neither disabled, handicapped, nor developmentally delayed in any way, so there was no reason to assume anyone would take issue with his admittance to Beecher Prep – whether it is an inclusion school or not" (Palacio, 2012, p. 51). In this case, Mr. Tushman is demonstrating his administrative power over the lives of his students because he determines who is admitted to Beecher Prep, which is a private school.

A third example of "bio-power" (Foucault, 1990, p. 140), and "the normalizing gaze" (2012, p. 184) occurs in *Out of My Mind* (Draper, 2010) when Mrs. Brooks is given Melody's diagnosis and educational options by Dr. Hugely (Draper, 2010, p. 22), who recommends that Melody be placed in either a special education school or a residential facility (Draper, 2010, p.

24). However, Mrs. Brooks wants her daughter to attend her community's elementary school (Draper, 2010, p. 24). Both of these examples show how Foucault's concepts of "bio-power" (1990, p. 140) and "the normalizing gaze" (2012, p. 184) can be used by medical professionals, together with the impact that their medical power can have on the lives of disabled people.

In this section, I have discussed how Foucault's theories of "bio-power" (1990, p. 140) and "the normalizing gaze" (2012, p. 184) are used by doctors and principals in *Word Nerd* (Nielsen, 2010), *Wonder* (Palacio, 2012), and *Out of My Mind* (Draper, 2010) to construct and address what Davis (1995) refers to as "the 'problem' of the disabled person" (p. 24) socially, medically, and educationally. By doing so, Nielsen's (2010), Palacio's (2012), and Draper's (2010) novels reveal the role that medical and educational institutions have as constructors, maintainers, and disseminators of society's socially constructed beliefs regarding normalcy (Davis, 1995).

When novels such as *Word Nerd*, *Out of My Mind*, and *Wonder* are taught uncritically in the language arts classroom, students are unknowingly being introduced to Foucault's concepts of "bio-power" (1990, p. 140) and "the normalizing gaze" (2012, p. 184) which create and then resolve "the 'problem' of the disabled person" (Davis, 1995, p. 24) in ways that support deficit-based understandings and responses to disability and disabled people. When this occurs, both abled and disabled students learn that being disabled is a pathologized form of negative societal difference that needs to be overcome or compensated for (Dolmage, 2014) through medical intervention or individual effort instead of considering disability to be a "mere-difference" (Barnes, 2016, p. 7). The impact of this is that both abled and disabled students have society's deficit-based socially constructed understanding of disability and normalcy reinforced (Davis, 1995) in the language arts classroom. This supports instead of challenges the pathologization,

stigmatization, and social exclusion that disabled students experience in schools, which can negatively impact disabled students academically, socially, and emotionally (Reid, 2010).

Goffman's Stigma Theory

It could be argued that all 12 of the disabled first-person protagonists in the disability-themed children's and young adult novels whose experiences I have discussed throughout my study experience social stigma to differing degrees. In this section, I will focus on five notable illustrations. In my first example, Max in *Freak the Mighty* (Philbrick, 1993) experiences a "courtesy stigma" – that is, stigma by association (Goffman, 2009, p. 31) – by linking Max's physical appearance and violent behaviour to that of his father (Philbrick, 1993, pp. 1, 4, 25-26, 40), who is in prison for killing Max's mother. Max and Kevin also experience social stigma due to their physical appearances because of their "stareable bodies" (Garland-Thomson, 2009, p. 8), when Tony D. describes Max and Kevin as "Andre the giant and the dwarf" (Philbrick, 1993, p. 30) which reinforces their physical differences from society's socially constructed beliefs regarding bodily norms.

A second, prominent instance of how Goffman's (2009) theory of social stigma occurs relates to education. Goffman (2009) writes:

> Thus, public school entrance is often reported as the occasion of stigma learning, the experience sometimes coming very precipitously on the first day of school, with taunts, teasing, ostracism, and fights. Interestingly, the more the child is "handicapped" the more likely he is to be sent to a special school for persons of his kind, and the more abruptly he will have to face the view which the public at large takes of him. He will be told that he will have an easier time of it among "his own," and thus learn that the own he thought he possessed was the wrong one, and that this lesser own is really his. (p. 33)

Social stigma within educational settings is a common source of ableism encountered by the disabled protagonists in my study. In the first example, Melody in *Out of My Mind* (Draper, 2010) describes the social stigma that she and the other students in her special education class experienced during recess. Melody states, "They [the abled students] look like they're having so much fun. They ask one another to play, but no one's ever asked any of us" (Draper, 2010, p. 28). Melody continues, "We get treated like we're invisible" (Draper, 2010, p. 29) or as Goffman (2009) describes this form of social othering, "we may try to act as if he were a 'non-person', not present at all" (p. 18). This is a common technique used by non-stigmatized individuals when they need to be in the same physical environment as individuals with socially stigmatizing traits or identities. Melody also experiences social stigma as Rose, with whom Melody initially becomes friends, only wants to spend time with her during class or on the weekend (Draper, 2010, pp. 100, 146) due to the "courtesy stigma" (Goffman, 2009, p. 31) that she is afraid that will be applied to her due to her friendship with Melody (Draper, 2010, p. 119).

The third protagonist in my study who experiences social stigma due to his appearance is August in *Wonder* (Palacio, 2012). August's physical appearance results in him being feared and bullied throughout the novel (Palacio, 2012, pp. 1, 7, 25, 37, 81). Two strategies that August uses as forms of "stigma management" (Goffman, 2009, p. 53) include having had numerous surgeries to reduce the social stigma that his physical appearance causes (Palacio, 2012, pp. 1, 21) and using humour (p. 21) to alleviate the discomfort or "aesthetic nervousness" (Quayson, 2007, p. 15) that his appearance causes other characters throughout the narrative. Similarly to August in *Wonder* (Palacio, 2012), Ally *in Fish in a Tree* (Hunt, 2015) uses "techniques of information control" (Goffman, 2009, p. 93) as a form of "stigma management" (Goffman, 2009, p. 53), unlike Max in *Freak the Mighty,* (Philbrick, 1993), Melody in *Out of My Mind* (Draper,

2010), and August in *Wonder* (Palacio, 2012) who experience social stigma due to having "stareable bodies" (Garland-Thomson, 2009, p. 8) which create moments of "aesthetic nervousness" (Quayson, 2007, p. 15) due to their interactions being an "encounter between a starer and a staree" (Garland-Thomson, 2009, p. 3). In contrast, Ally encounters bullying and social stigma due to her undiagnosed learning disability (Hunt, 2015, pp. 22, 49, 50, 61, 77, 163, 303, 304, 306) when she uses "techniques of information control" (Goffman, 2009, p. 93) to conceal from classmates and teachers the fact that she struggles with reading (Hunt, 2015, pp. 11-15, 22, 135).

Unlike the other characters whose experiences with social stigma I have discussed thus far, Melinda's stigmatization in *Speak* (Anderson, 2019) has occurred due to her actions because she called the police after being raped while attending a party (Anderson, 2019, p. 164) which has led to her becoming a social "outcast" (Anderson, 2019, p. 4). Even though Melinda does not self-identify as having a mental health disability, after she was raped at the party she experiences many symptoms that are associated with having a mental health disability such as engaging in self-harm (Anderson, 2019, pp. 5, 87), has difficulty sleeping (Anderson, 2019, pp. 113, 130), experiences anxiety (Anderson, 2019, pp. 28, 81, 110, 132) and has stopped talking (Anderson, 2019, p. 114), each of which negatively impacts her mental health and wellbeing to differing degrees throughout the novel. However, as Bérubé's (2015) work suggests, cultural texts "can involve ideas about disability, and ideas about the stigma associated with disability, regardless of whether any specific character can be pegged with a specific diagnosis" (p. 19). Melinda can thus, as a sexual assault survivor, experience the social stigma and othering that is correlated with having a mental health disability without having a mental health label applied to her experience or considering herself to be disabled. Two forms of "stigma management" (Goffman,

2009, p. 53) that Melinda uses throughout the novel are repurposing an abandoned janitor's closet to create a safe space for herself (Anderson, 2019, pp. 26, 50, 51, 85, 130, 150), and using her art assignments to help her to process her experience as a sexual assault survivor (Anderson, 2019, pp. 31, 64, 196).

A final young adult character in my study who experiences social stigma throughout the text is Troy in *Fat Kid Rules the World* (Going, 2004). Similarly to Max in *Freak the Mighty*, Melody in *Out of My Mind* and August in *Wonder*, Troy's stigmatizing trait is visible, making it impossible for him to "pass" (Goffman, 2009, p. 74) as a form of "stigma management" (Goffman, 2009, p. 53). Throughout the novel, Troy experiences social stigma because of his weight which negatively impacts his mental health (Going, 2004, p. 1). Like Melinda in *Speak* (Anderson, 2019), Troy does not self-identify as disabled, but he does experience both external and internalized stigma due to his appearance. Two examples of the external stigma that Troy encounters occur when he is stared at because of his appearance (Going, 2004, pp. 44, 47, 50, 137). Troy also experiences social othering at home because he is a disappointment to his father (Going, 2004, pp. 19, 55, 76) when he is compared unfavourably to his athletic younger brother Dayle (Going, 2004, pp. 17, 38, 47, 51). One example of his father's stigmatizing behaviour towards Troy occurs in the novel when Troy describes the forms of "stigma management" (Goffman, 2009, p. 53) that his father has provided to him in an attempt to reduce his weight, which have not been successful. Troy feels as though his father is blaming him for the failure of these interventions. Troy states:

> I think of all the opportunities my father has given me that I've failed to take advantage of. … Two gym memberships paid in full, a complete weight set given to me for Christmas, eighteen sessions with two different psychologists, a year and a half with a

> nutritionist, eleven diet books, two healthy-eating videos, a free consultation with a personal trainer, two summers at fat camp, and nearly healthy genes. (Going, 2004, p. 55)

Troy's failure to have the physical appearance that his father expects, in addition to the other examples of external stigma that Troy describes throughout the novel, cause Troy to view himself negatively. The most prominent demonstration of this can be seen as Troy constantly refers to himself as "fat kid" throughout the narrative (Going, 2004, pp. 1, 2, 3, 6, 8, 10, 14, 24, 26, 36, 41, 55, 62, 85, 92, 113, 132, 149, 150, 172, 179). This example not only indicates how Troy engages in self-stigmatizing behaviour, but also shows how "the normalizing gaze" (Foucault, 2012, p. 184) impacts Troy's beliefs about himself.

Drawing on Goffman's (2009) work regarding stigma theory, I have demonstrated that many of the disabled first-person protagonists whose stories have been included in my study experience social stigma to differing degrees, which negatively impacts them in numerous ways.

In response to their stigmatization, Max in *Freak the Mighty*, Ambrose in *Word Nerd*, Melody in *Out of My Mind*, August in *Wonder*, Ally in *Fish in a Tree*, Melinda in *Speak*, and Troy in *Fat Kid Rules the World*, use "techniques of information control" (Goffman, 2009, p. 93) as well as other "stigma management" (Goffman, 2009, p. 53) strategies to compensate (Dolmage, 2014) for their impairments. However, doing so is problematic from a critical disability studies perspective because requiring disabled characters to conceal or compensate for their impairments communicates to readers that being disabled is a negative socially stigmatizing form of societal difference instead of being considered a meaningful aspect of disabled people's identities.

In this section, I have shown how Foucault's (1990, 2012) theories of "bio-power" (Foucault, 1990, p. 140) and "the normalizing gaze" (2012, p. 184) as well as Goffman's (2009)

work on social stigma have not only been foundational to the theoretical framework of my study but have also been recurring themes throughout my dissertation. As such, "bio-power" (Foucault, 1990, p. 140) and "the normalizing gaze" (2012, p. 184) have frequently reinforced society's socially constructed beliefs regarding disability in the narratives that I have examined throughout my study. Thus, Davis's (1995) argument regarding the role that novels can have as societal tools of normalization continues to be the case in some of the texts that I have examined. Davis (1995) writes:

> In thinking through the issue of disability, I have come to see that almost any literary work will have some reference to the abnormal, to disability and so on. I would explain this phenomenon as a result of the hegemony of normalcy. This normalcy must constantly be enforced in public venues (like the novel) and must always be creating and bolstering its image by processing, comparing, constructing, deconstructing images of normalcy and the abnormal. In fact, once one begins to notice, there really is a rare novel that does not have some characters with disabilities. (pp. 43-44)

By demonstrating that Foucault's (1990, 2012) and Goffman's (2009) theories of power, normalization, and social stigma are present in the disability-themed children's and young adult texts that contain disabled first-person protagonists that are being taught in grades 7-12 in Ontario schools (Bates, 2017), my work builds on Davis's (1995) scholarship in which he argues that novels can be societal tools of normalization. This idea is communicated in *Freak the Mighty* (Philbrick 1993), *Out of My Mind* (Draper, 2010), and *Wonder* (Palacio, 2012). However, societal norms and expectations can also be challenged, as in *Speak* (Anderson, 2019), *Perks* (Chbosky, 1999), and *It's Kind of a Funny Story* (Vizzini, 2010). Thus, the disability-themed narratives that I have examined in my study portray numerous representations and responses to

disability, some of which conform to deficit-based understandings and responses to disability within society, while others subvert societal expectations regarding disability.

Literary Ableism and Authorial Intent

Fiction is a cultural tool that can either reinforce or challenge society's beliefs and attitudes regarding disability. One example of how society's negative assumptions regarding disability can be communicated through cultural texts is literary ableism. I have defined literary ableism as, 'the discrimination experienced by fictional characters in a literary work due to having, or being perceived to have, one or more disabilities'. Literary ableism is witnessed in educational settings in many of the children's and young adult novels that I have critiqued, when the principals in *Word Nerd* (Nielson, 2010, p, 39) and *Wonder* (Palacio, 2012, p. 51) and the teachers in *Out of My Mind* (Draper, 2010, pp. 53, 56, 178, 264) and *Fish in a Tree* (Hunt, 2015, pp.1-6, 185-186) exercise their "bio-power" (Foucault, 1990, p. 140) over the "docile (educational) bodies" (Foucault, 2012, p. 135) of their disabled students. Literary ableism is also present in non-educational settings due to the social stigma and isolation that many of the protagonists in my study encounter, such as Max in *Freak the Mighty,* Ambrose in *Word Nerd*, Melody in *Out of My Mind*, August in Wonder, Ally in *Fish in a Tree*, Troy in *Fat Kid Rules the World*, and Christopher in *Curious Incident*. However, depending on the intentions of the author, the presence of literary ableism is not always problematic.

In a first example of how literary ableism is used deliberately by an author to inform readers about the social, educational, and physical barriers that disabled people experience, Draper (2010) states:

> I suppose the character of Melody came from my experiences in raising a child with developmental difficulties. But Melody is not my daughter. … Out of My Mind is the

> story of a ten-year-old girl who cannot walk or talk. She has spirit, determination, intelligence, and wit and no one knows it. But in dealing with hardships – from buildings that are not wheelchair accessible to classmates who make fun of her – she finds a strength within herself she never knew existed. I was fiercely adamant that nobody feel sorry for Melody. I wanted her to be accepted as a character and as a person, not as a representative for people with disabilities. Melody is a tribute to all the parents of disabled kids who struggle, to all those children who are misunderstood, to all those caregivers who help every step of the way. It's also written for people who look away, who pretend they don't see, or who don't know what to say when they encounter someone who faces life with obvious differences. (p. 309)

Even though I support Draper's (2010) intentions in writing *Out of My Mind*, her focus on the need for Melody to find "a strength within herself" (Draper, 2010, p. 309) and "be accepted as a character … not as a representative for people with disabilities" (Draper, 2010, p. 309) is concerning from a disability perspective. This is because the emphasis is largely placed on Melody's ability to overcome the ableism that she experiences with the support of her parents (Draper, 2010, pp. 26, 56-60, 103-104, 131), Catherine (her educational assistant) (Draper, 2010, pp. 105, 126, 128-129, 148-150, 164-166, 179), and Mrs. V. (her neighbour) (Draper, 2010, pp. 46-47, 107, 130-131, 137-142, 161-162, 167), without addressing the social exclusion (Draper, 2010, pp. 28, 146, 257-264, 291) that Melody encounters in school. Instead, Melody is portrayed as "an intellectual supercrip" (Wheeler, 2019, p. 109) with a "photographic memory" (Draper, 2010, p. 13) that she uses to overcome or compensate academically (Dolmage, 2014) for her impairments (Draper, 2010, pp. 110, 151). Draper set out to write a children's novel that realistically depicts the barriers that disabled people experience in school while being "accepted

as a character and as a person, not as a representative for people with disabilities" (p. 309). However, my review of *Out of My Mind* demonstrates that the text does the opposite, due to the social exclusion that Melody experiences throughout the narrative, while requiring her to continually demonstrate her intelligence to earn the right to be placed in an integrated educational environment.

In addition to Draper (2010), other authors in my study such as Hunt (2015) *Fish in a Tree*, Palacio (2012) *Wonder*, Vizzini (2010) *It's Kind of a Funny Story*, and Anderson (2019) *Speak* deliberately wrote their texts to inform readers about the topics they discuss in their novels. In a letter to the reader, Hunt explains that Ally's character in *Fish in a Tree* is based on her own experience as a struggling reader and that the support that Ally receives from Mr. Daniels is similar to the support that she received from her sixth-grade teacher (2015, pp. 275-276). In a second example, Palacio writes in her acknowledgments about a chance meeting that she had with a girl in front of an ice cream shop who served as the inspiration for August's character in *Wonder* (2012, p. 97). Even though Hunt and Palacio wrote their novels to raise awareness of the experiences of disabled children in school, my reviews of both texts reveals that Hunt (2015, pp. 146-149, 164-167) and Palacio (2012, pp. 1, 22, 25, 37, 42, 81, 93) use the deficit-based individualized overcoming myth (Dolmage, 2014) in relation to disability instead of emphasising the need for the wider social acceptance of their disabled characters by portraying a more inclusive society. Despite Hunt and Palacio setting out to raise awareness of the obstacles that disabled children experience in schools, both *Fish in a Tree* (Hunt, 2015), and *Wonder* (Palacio, 2012) do so in problematic ways, because both texts reinforce deficit-based understandings of disability.

The depictions of disability by these two authors are in contrast to the representations of disability in *It's Kind of a Funny Story* (Vizzini, 2010), and *Speak* (Anderson 2019) because Vizzini and Anderson intended to use their novels to raise readers' awareness about mental health disabilities and sexual violence, based on their own experiences. In her foreword to the 2010 edition of *It's Kind of a Funny Story* Rachel Cohn explains:

> *It's Kind of a Funny* story was written soon after Ned's (Vizzini's) own experience in a psychiatric hospital, where he admitted himself on the advice of a suicide hotline counselor. … The book throws a lifeline to those dealing with depression, as if Ned is there to reassure them: Your pain is real. I understand. … Ned spoke openly and honestly about his own mental health issues, and strived to educate and help others. (p. 8)

Throughout the narrative, Vizzini achieves his objective of writing a young adult novel that depicts the experience of a teenager living with depression. Moreover, Vizzini's text achieves this while portraying Craig's experience in a manner that challenges numerous deficit-based representations of disability. Anderson did not initially intend to write *Speak* (2019) based on her own experience as a sexual assault survivor. Instead, Anderson describes her initial inspiration for writing the book when she states:

> I woke up one night – panicked because I could hear a girl sobbing. … The crying girl was in my head, a bad dream. … The next morning I listened to that voice again and the character of Melinda Sordino unfolded. When I first started writing, I had no idea what had happened to her. It wasn't until she was comfortable with me that she let her secret out. (Anderson, 2019, p. 199)

However, in her memoir *Shout* (2020) Anderson writes, "Finding my courage to speak up twenty-five years after I was raped, writing Speak, and talking with countless survivors of sexual

violence made me who I am today" (Anderson, 2020, p. 1). Throughout her 2020 memoir, Anderson describes what her life was like before being raped during the summer prior to ninth grade as well as numerous ways that surviving sexual violence impacted her physically, emotionally, socially, and educationally (pp. 52-79), many of which are similar to the experiences that Melinda has in *Speak* (Anderson, 2019). Some of these include having difficulty sleeping (Anderson, 2019, pp. 113, 130) skipping school (pp. 97, 115), experiencing academic difficulties (Anderson, 2019, pp. 36, 60, 75, 114), and engaging in self-harm (Anderson, 2019, pp. 5, 87). Even though Anderson did not initially intend to write *Speak* based on her own experience as a sexual assault survivor, many of Melinda's experiences in *Speak* (2019) parallel Anderson's experiences in her memoir *Shout* (2020) which increases the realism present in the novel.

Summary of Findings

1. The results of my study revealed that the protagonists' impairments fit within numerous disability categories. Seven of the 12 protagonists self-identify as having diverse impairments. These include Max in *Freak the Mighty* (Philbrick, 1993), who has a learning disability or a developmental disability (the text can support either interpretation (Carico & Stanley, 1999; Meyer, 2013), Melody in *Out of My Mind* (Draper, 2010), Arnold in *True Diary* (Alexie, 2007), and August in *Wonder* (Palacio, 2012), have physical disabilities, Hazel in *The Fault* (Green, 2012), is living with terminal cancer, Ambrose in *Word Nerd* (Nielsen, 2010), has a life-threatening allergy, and Craig in *It's Kind of a Funny Story* (Vizzini, 2010) has clinical depression. Conversely, five of the 12 protagonists do not self-identify as disabled. These characters include, Ally in *Fish in a Tree* (Hunt, 2015) (who is suspected of having a learning disability but she is not formally diagnosed in the text),

Troy in *Fat Kid Rules the World* (Going, 2004) (who lives with the physical and mental health related effects of obesity), Christopher in *Curious Incident* (Haddon, 2004) (who has an unnamed developmental disability), and Melinda in *Speak* (Anderson, 2019), and Charlie in *Perks* (Chbosky, 1999) (both of whom may be living with undiagnosed mental health disabilities). The fact that the protagonists in my study self-identify as having diverse impairments, while others do not consider themselves to be disabled, or are living with undiagnosed disabilities (Bérubé, 2015) is an important finding because it reflects the diversity of perspectives and lived experiences of disabled people in society. However, more work needs to be done to increase the diversity and intersectionality of the disabled characters in the literature being taught in Ontario schools to represent the experiences of disabled characters whose identities are currently not being portrayed in Ontario classrooms so that more disabled students can have their experiences "mirrored" (Bishop, 1990) back to them in a disability "culturally authentic" (Brown, 2020, p. 141) manner.

2. To differing degrees, all 12 novels contain deficit-based depictions of disability.

   (1) In *Freak the Mighty* (Philbrick, 1993), "Disability as Pathology, Disability Drift, Disability as Isolating and Individuated, Overcoming or Compensation, Kill or Cure" (Dolmage, 2014, pp. 43-45), "Disability as bearer of moral deficit/evil, *Disability as the Interface with Otherness* (*race, class, sexuality, and social identity*), *Disability as Epiphany*"[86] (Quayson, 2007, pp. 38-39, 45), "Villain, Monster, Inspirational" (Connor, 2017, p. 205).

[86] The italics are in the original.

(2) In *Word Nerd* (Nielsen, 2010) I located the following deficit-based representations of disability, “The disabled person as object of violence” (Biklen & Bogdan, 1977, pp. 6-7), “Disability as Pathology, Disability as Isolating and Individuated” (Dolmage, 2014, pp. 43-44).

(3) In *Out of My Mind* (Draper, 2010) I found the following deficit-based depictions of disability, “*Disability as the Interface with Otherness* (*race, class, sexuality, and social identity*)” (Quayson, 2007, p. 39), “Disability as Isolating and Individuated, Disability Drift, Overcoming or Compensation, Disability as Pathology” (Dolmage, 2014, pp. 43-45), “The disabled person as burden” (Biklen & Bogdan, 1977, p. 8), “inspirational” (Connor, 2017, p. 205).

(4) In *Wonder* (Palacio, 2012), I noted the following deficit-based portrayals of disability, “*Disability as the Interface with Otherness* (*race, class, sexuality, and social identity*) (Quayson, 2007, p. 39), “Kill or Cure, Disability as Pathology, Disability as Isolating and Individuated, Overcoming or Compensation”, (Dolmage, 2014, pp. 43-44), “the disabled person as an object of ridicule” (Barnes, 1992, p. 13), “inspirational” (Connor, 2017, p. 205), “inspiration porn” (Grue, 2016).

(5) In *Fish in a Tree* (Hunt, 2015) I located the following deficit-based representations of disability, “Disability as Isolating and Individuated, Disability as Pathology, Overcoming or Compensation” (Dolmage, 2014, pp. 43-44), “the disabled person as an object of ridicule” (Barnes, 1992, p. 13), “inspirational” (Connor, 2017, p. 205).

(6) In *Speak* (Anderson, 2019), the following deficit-based portrayals were present, "Disability as Isolating and Individuated" (Dolmage, 2014, p. 44), and "*Disability as epiphany*" (Quayson, 2007, p. 45).

(7) In *Perks* (Chbosky, 1999) I located the following deficit-based representations of disability, "Disability as Isolating and Individuated" (Dolmage, 2014, p. 44), and "*Disability as epiphany*" (Quayson, 2007, p. 45).

(8) In *Fat Kid Rules the World* (Going, 2004) I found the following deficit-based depictions of disability, "suicidal" (Connor, 2017, p. 205), "Disability as Isolating and Individuated, Overcoming or Compensation" (Dolmage, 2014, p. 44), "The disabled person as object of violence" (Biklen & Bogdan, 1977, pp. 6-7), "*Disability as the Interface with Otherness* (*race, class, sexuality, and social identity*)" (Quayson, 2007, p. 39), "The Disabled Person …[is] Their Own Worst and Only Enemy, The Disabled Person as Sexually Abnormal" (Barnes, 1992, pp. 14, 16).

(9) In *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004) I noted the following deficit-based portrayals of disability, "*Disability as the Interface with Otherness* (*race, class, sexuality, and social identity*)" (Quayson, 2007, p. 39), "Disability as Isolating and Individuated, Overcoming or Compensation" (Dolmage, 2014, p. 44), "the disabled person as an object of ridicule" (Barnes, 1992, p. 13), "The disabled person as burden" (Biklen & Bogdan, 1977, p. 8), and "evil or sinister" (Connor, 2017, p. 206).

(10) In *It's Kind of a Funny Story* (Vizzini, 2010) I located the following deficit-based depictions of disability, "The Disabled Person as Sexually Abnormal" (Barnes, 1992, pp. 16-17).

(11) In Alexie's (2007) semiautobiographical novel *The Absolutely True Diary of a Part-Time Indian* I identified the following deficit-based representations of disability, "The disabled person as object of violence" (Biklen & Bogdan, 1977, pp. 6-7), "evil or sinister" (Connor, 2017, p. 206), "disability drop, Overcoming or Compensation" (Dolmage, 2014, pp. 44-45).

(12) In *The Fault in Our Stars* (Green, 2012) I located the following deficit-based portrayals of disability, "Disability as Isolating and Individuated, Disability as Pathology, Overcoming or Compensation, Disability as Object of Pity and/or Charity, Kill or Cure" (Dolmage, 2014, pp. 43-44), "The disabled person as burden" (Biklen & Bogdan, 1977, p. 8), "*Disability as epiphany*" (Quayson, 2007, p. 45), "inspirational" (Connor, 2017, p. 205).

This finding is significant because it demonstrates that all of the 12 disability-themed children's and young adult novels portrayed their protagonists' disabilities in deficit-based ways to differing degrees, which illustrates how pervasive deficit-based representations of disability are in the disability-themed children's and young adult literature being taught in grades 7-12 in Ontario schools (Bates, 2017). The impact of these deficit-based representations of disability is the ongoing stigmatization of disabled people through the uncritical teaching of problematic texts in the language arts classroom. These narratives are not only pervasively present in the language arts classrooms of Ontario schools (Bates, 2017), but they silently condone instead of refuting the deficit-

based discourses in relation to disability that are being propagated through the uncritical teaching of problematic texts in the language arts classroom (Reid, 2010).

3. Only three of the 12 protagonists, namely Melinda in *Speak* (Anderson, 2019), Craig in *It's Kind of a Funny Story* (Vizzini, 2010) and Charlie from *Perks* (Chbosky, 1999) are represented in a disability "culturally authentic" (Brown, 2020, p. 141) manner. Moreover, the symptoms that Melinda, Craig, and Charlie describe experiencing in their narratives appear to be consistent with the experiences of individuals living with both diagnosed and undiagnosed mental health disabilities. As such, I have concluded that Melinda, Craig, and Charlie's depictions meet the criteria described by Connor (2017) as "The Everyday and Therefore No Big Deal Portrayal of Disability" (p. 205). Building off my previous finding, this result shows that three of the 12 protagonists in my study are represented in a disability affirming manner, thus highlighting the fact that some students are being assigned novels in their language arts classrooms that challenge deficit-based representations of disability. This suggests that other disability affirming children's and young adult novels can be included as part of language arts education in Ontario schools.

4. I noted an absence of racial, sexual, religious, and other forms of cultural diversity across the 12 novels, with only two protagonists, August in *Wonder* (Palacio, 2012, pp. 26, 32) and Arnold in *True Diary* (Alexie, 2007, pp. 2-3) being racial minorities. Only one, namely, Arnold in *True Diary* discusses or participates in aspects of non-western culture in keeping with his Indigenous identity (pp. 18-19). This finding shows that disabled students who are members of racial, religious, and sexual minority communities do not have their identities and experiences represented in the disability-themed children's and young adult novels being taught in grades 7-12 of Ontario schools. Thus, disabled

students who are members of racial, religious, and sexual minority communities experience marginalization due to not having characters whose experiences "mirror" (Bishop, 1990) their identities depicted in the children's and young adult literature being taught in schools, which is a form of identity erasure (Daniels, 2004; Hazlett et al., 2011).

5. The gender breakdown across the 12 texts was eight boys and four girls with there being no non-binary or genderqueer characters. All 12 protagonists either self-identify as straight or do not discuss their sexuality. This finding is significant, because it reveals that texts containing disabled characters who belong to gender or sexual minority communities are not represented in the novels containing disabled first-person protagonists (Hazlett et al., 2011). Thus, the experiences of disabled readers who also belong to gender or sexual minority communities are not present in the texts that met the inclusion criteria of my study, which prevents students from gender or sexual minority communities from having their experiences "mirrored" (Bishop, 1990) back to them in the literature being taught in the language arts classroom, which is a form of educational exclusion.

6. Diverse family organizations are present across the 12 texts. Beginning with the protagonists' parents or guardians, Christopher in *Curious Incident*, Troy in *Fat Kid Rules the World*, and Ambrose in *Word Nerd* live in single-parent homes, Max in *Freak the Mighty* lives with his grandparents and the other eight protagonists live in two-parent families. In relation to sibling relationships and their birth order, diverse family structures were present across the 12 narratives. In this regard, five disabled characters are only children, including Max in *Freak the Mighty*, Melinda in *Speak*, Christopher in *Curious Incident*, Ambrose in *Word Nerd*, and Hazel in *The Fault*. This contrasts with the diverse

sibling relationships that are present in the other seven narratives where Charlie in *Perks* has two older siblings, Arnold in *True Diary* and August in *Wonder* have older sisters, Ally in *Fish in a Tree* has an older brother, Troy in *Fat Kid Rules the World* has a younger brother, and Craig in *It's Kind of a Funny Story* and Melody in *Out of My Mind* have younger sisters. These findings are important because they reveal the different family structures that each protagonist experiences, which can impact the plot of each narrative in numerous ways. For example, in *Word Nerd*, the fact that Ambrose is a disabled only child in a single-parent family leads to his mother being overprotective (Nielsen, 2010, pp. 40, 51, 52, 80-85, 157, 177, 206, 210-214, 218-219). In a second example, Via in *Wonder* believes that her brother August's impairments have negatively impacted her life in numerous ways (Palacio, 2012, p. 26), which contrasts with the mutually beneficial sibling relationship that Ally and Travis have in *Fish in a Tree* (Hunt, 2015, pp. 30-34, 229-230, 268). In each case, however, the plots of *Word Nerd*, *Wonder*, and *Fish in a Tree* are informed by the different family structures and relationships that are present in each narrative whether positively, neutrally, or negatively in relation to disability. With this being the case, the presence of differing family structures across the 12 narratives provides opportunities for teachers and students to discuss the impact that having a disabled child or sibling could have on family relationships as part of the diverse family structures that are witnessed in these texts. This adds an important but underrepresented element to classroom discussions regarding family dynamics in the language arts classroom.

7. Social stigma, bullying, and friendship are common themes across the 12 narratives with Max in *Freak the Mighty*, Ambrose in *Word Nerd*, Melody in *Out of My Mind*, August in

Wonder, Ally in *Fish in a Tree*, Melinda in *Speak*, Troy in *Fat Kid Rules the World*, and Christopher in *Curious Incident* all experiencing social stigma due to their impairments. Additionally, Max in *Freak the Mighty,* Ambrose in *Word Nerd*, Melody *in Out of My Mind,* August in *Wonder,* Ally in *Fish in a Tree*, and Arnold in *True Diary* encounter bullying. When it comes to social relationships, only two protagonists, Craig in *It's Kind of a Funny Story*, and Arnold in *True Diary* began their novels with pre-existing friendships. However, by the end of their respective narratives, Ambrose in *Word Nerd*, August in *Wonder,* Ally in *Fish in a Tree*, Charlie in *Perks* and Troy in *Fat Kid Rules the World* have made friends, while Melinda in *Speak* and Hazel in *The Fault* have reconnected with former friends. Conversely, Max in *Freak the Mighty,* Melody in *Out of My Mind*, and Christopher in *Curious Incident* do not develop lasting friendships. The implications of this finding suggest that the protagonists in my study experienced social stigma, bullying, and exclusion which, if not addressed in the classroom, can reinforce these deficit-based beliefs and attitudes regarding disability in schools (Dunn, 2015; Reid, 2010). However, if taught critically, teachers can use these textual encounters as teachable moments to inform students about how pervasive bullying, social stigma, and exclusion are in the lives of disabled students by using the examples portrayed in these disability-themed narratives. By doing so, teachers will be raising students' awareness about the harmful impact that bullying, social stigma, and exclusion can have on disabled people, which may lead abled students to intervene positively in the lives of their disabled peers.

8. From a socio-economic perspective, my study revealed that three of the protagonists, Arnold in *True Diary,* Ambrose in *Word Nerd* and Hazel in *The Fault* are economically

disadvantaged, one protagonist, August in *Wonder*, is from a wealthy family and the remaining eight protagonists are considered to be middle class. This finding highlights the diversity of the economic realities that are present in society, along with the impact that socioeconomic factors have on the families of disabled characters in fiction and people in the real world. Moreover, this finding has implications for how socioeconomic class is discussed in the language arts classroom because of the ways disabled characters' socioeconomic circumstances impact their ability to access disability-related services. For instance, living in poverty leads to Arnold having difficulty accessing disability-related medical care in *True Diary* (Alexie, 2007, pp. 2-3).

9. From an education perspective, my study revealed that Max in *Freak the Mighty*, Ambrose in *Word Nerd*, Melody in *Out of My Mind*, August in *Wonder* and Ally in *Fish in a Tree* experienced systemic ableism in educational settings. By comparison, ableism in educational settings was not experienced by the protagonists of *True Diary*, *Speak*, *Perks*, *Curious Incident*, *Fat Kid Rules the World*, *The Fault*, or *It's Kind of a Funny Story*. Interestingly, this finding shows a clear divide between the five children's books and seven young adult novels in my study. However, I am not able to definitively explain this result. This finding demonstrates that ableism was pervasively present in the schools that the disabled child protagonists attended in the disability-themed children's novels that I examined in my study. Therefore, disability-themed children's and young adult novels must be taught critically in schools otherwise teachers may unknowingly be reinforcing deficit-based understandings about disability in the texts that they are teaching, which could further the marginalization being experienced by disabled students (Dunn, 2015; Reid, 2010). However, if taught critically, teachers can use textual

examples of systemic ableism in educational settings to raise questions about how ableism can be addressed in their schools.

10. Two protagonists, Melinda in *Speak* and Charlie in *Perks* acquire mental health disabilities after experiencing sexual violence. The sexuality of the disabled adolescent protagonists was depicted in a deficit-based manner in *The Perks of Being a Wallflower*, *It's Kind of a Funny Story*, and *The Fault in Our Stars*. The implications of these findings include the ongoing deficit-based assumptions regarding the sexuality of disabled people (Barnes, 1992) in the literature being taught in schools, which is a form of "sexual ableism" (Gill, 2015, p. 3). Moreover, this finding suggests that vital connections between sexual violence and mental health disability can be made in the language arts classroom, which could be an important resource for students whose mental health has been negatively impacted due to experiencing sexual violence (Ressler & Giannet, 2004; Richmond, 2019).

Taken together, the findings of my study collectively demonstrate the numerous deficit-based, as well as disability affirming ways, in which disabled protagonists are being depicted in the children's and young adult novels being taught in grades 7-12 in Ontario classrooms (Bates, 2017). These results have numerous implications for teachers, teacher educators, and students regarding the selection and teaching of disability-themed children's and young adult literature in the language arts classroom. The importance of this stems from the negative impact that teaching texts that contain deficit-based representations of disability can have on disabled students (Reid, 2010) as well as the erasure of identities which can result from not teaching texts that centre the experiences of disabled characters who have intersectional identities (Daniels, 2004; Hazlett et al., 2011). Positively, the results of my study also reveal that some disability "culturally

authentic" (Brown, 2020, p. 141) children's and young adult novels, namely, *Speak*, *It's Kind of a Funny Story*, and *Perks* are being taught in Ontario classrooms, which is supported by the ongoing development of disability studies in education informed approaches to curriculum and pedagogy (Baglieri & Lalvani, 2019; Waitoller & King Thorius, 2023). As a result, teachers can use the fictional encounters between abled and disabled characters in the disability-themed children's and young adult narratives they teach to expose the social stigma, bullying, and exclusion experienced by disabled characters, both in fiction and in the real world. This would enable students to critique the representations of disability that they encounter in the language arts classroom, thereby allowing both abled and disabled students to work collaboratively to create a disability affirming world.

Recommendations

Based on the findings of my study, I would make the following recommendations in relation to teacher preparation, in-service teachers, and future scholarship in literary disability studies and disability studies in education. In making these recommendations, my desire is to support teacher educators to develop curricula that will prepare future teachers to include disability-themed children's and young adult literature in their language arts classrooms in a disability-affirming manner, while identifying and challenging deficit-based portrayals of disability. Second, through these recommendations, I want to highlight the need for increased diversity in the disability-themed narratives that are being taught in Ontario schools, so that the experiences and perspectives of disabled students from minority communities are meaningfully included as part of multicultural education (Banks, 2006). Third, I recommend that when CRRP and other "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) are discussed in teacher preparation programs, disability representation, identity, and culture be included to

support future and current teachers when selecting and teaching disability-themed content in the language arts classroom. Fourth, I have recommended future directions for disability studies in education and literary disability studies scholarship regarding inclusive language arts instruction, as well as in the area of disability studies informed literary criticism of children's and young adult literature. I hope that my recommendations will be positively considered and built upon by scholars in the fields of inclusive education, disability studies in education, and literary disability studies that will improve the selection, analysis, and teaching of disability-themed language arts content in Ontario schools.

Recommendations for Teacher Preparation

1. Based on the findings of my study, Bachelor of Education and Graduate Studies in Education programs in Ontario post-secondary institutions should consider teaching current and future teachers how to identify and challenge deficit-based representations of disability by selecting and teaching texts in their classrooms that challenge deficit-based assumptions regarding disability. Two examples of recent scholarship from the United States which teacher educators in Ontario can build upon include work by Hansen et al., (2022) and Zepp et al., (2022). In their publications the previously cited scholars have begun implementing content in teacher education programs that prepares preservice teachers to teach disability-themed content in their language arts classrooms in a disability affirming manner. Moreover, this content can be taught using inclusive pedagogical approaches regarding disability from a critical disability studies perspective, one example of which is "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv).

Recommendations for in-service Teachers

1. As a result of the conclusions reached in my study, intermediate and senior division language arts teachers in Ontario schools should consider including more culturally diverse disability-themed children's and young adult novels in their language arts classrooms in order to represent the intersectional lives of disabled people more comprehensively in the real world. Moreover, doing so will enable disabled students to see their lives and experiences mirrored back to them in the literature they are reading in the classroom, and also provide windows for abled students to learn about the experiences of disabled individuals, which may reduce the social stigma that disabled people experience in schools (Bishop, 1990; Cameron & Rutland, 2006; Ware, 2001, 2002). For some examples of disability-themed children's and young adult novels that I suggest could be included as part of novel study units in Ontario schools refer to Appendices G and H.

Recommendations for Future Research

1. Future disability studies in education research can be undertaken regarding the sexuality of disabled characters in the young adult literature that is being taught in secondary schools. This recommendation stems from my finding that the sexuality of the disabled first-person protagonists whose experiences I have examined in this study was portrayed in a problematic manner. For example, the sexual relationship between Hazel and Augustus in *The Fault in Our Stars* was portrayed as a form of compensation (Dolmage, 2014; Nykvist, 2016) within the narrative before Augustus died. In a second example, Charlie's inability to have consensual sex with Sam in *Perks* was used as a plot device to reveal the cause of Charlie's mental health disability, or in Craig's case in *It's Kind of a Funny Story* the text supports the myth that adolescent patients receiving mental health treatment in in-patient

facilities engage in romantic or sexual relationships in keeping with the assumed hypersexuality of disabled people (Barnes, 1992). In contrast, Melinda in *Speak*, and Christopher in *Curious Incident* are portrayed as having no interest in forming or participating in romantic or sexual relationships, and Troy in *Fat Kid Rules the World* is largely portrayed as romantically and sexually undesirable because of his weight and physical appearance, all of which are deficit-based assumptions about disabled sexuality (Barnes, 1992). Thus, I recommend that intermediate and senior division language arts teachers select and teach novels in their language arts classrooms that challenge deficit-based representations of disabled sexuality (Barnes, 1992) as a means to "create a sexual culture for disabled people" (Siebers, 2008, p. 135) which challenges "sexual ableism" (Gill, 2015, p. 3).

2. Future scholarship can be undertaken to examine how content related to mental health disabilities is being taught from a critical disability studies perspective in elementary and secondary school language arts classrooms. I am making this recommendation owing to the recent societal interest in, and focus on, mental health as part of individual wellbeing as well as to further destigmatize mental health disabilities. One method through which this can be achieved is to teach content regarding mental health disabilities from a critical disability studies perspective in the language arts classroom. Some recent scholarship regarding the teaching of mental health related content in the language arts classroom includes work by Haughey (2021), Olan and Richmond (2020), and Richmond (2019). However, none of these scholars discuss teaching about mental health disabilities from a critical disability studies perspective.

3. Scholars in disability studies in education can investigate how language arts teachers in Ontario discuss the intersectional identities of disabled characters who are members of minority communities, as part of language arts units. By engaging in intersectional research within the language arts classroom scholars, teachers, and students may gain knowledge regarding how socioeconomic class, race, religion, gender, sexuality, and other identity categories intersect with disability in the children's and young adult novels being taught in Ontario schools. One benefit of this scholarship would be to enable students to study Arnold's character in *True Diary* from both Indigenous and disability perspectives. However, to the best of my knowledge, the scholarship regarding *True Diary* (Alexie, 2007) has been conducted from either an Indigenous (Suhr-Sytsma, 2018) or a disability (Wheeler, 2019) perspective, but not both simultaneously. Thus, I am proposing that future research regarding *True Diary*, as well as other novels that contain disabled characters with intersectional identities, be conducted from both literary disability studies and disability studies in education perspectives in Ontario schools.

Protagonist Identity, Diversity, and Intersectionality: Areas for Future Research

In this section, I will expand on some of the key findings of my study that I noted briefly in the Common Representational Themes sections of Chapters 5, and 6 as well as in my Summary of Findings section above regarding the portrayals of the 12 disabled first-person protagonists in the disability-themed children's and young adult novels being taught in grades 7-12 in Ontario schools based on the work of Bates (2017). Specifically, the content in this section will draw attention to the underrepresentation of racial minority, immigrant, gender, and sexual minority characters whose narratives are set in non-Western locations. Second, I will discuss the absence of scholarship regarding the intersection of disability and class in disability-themed

children's and young adult literature. Third, I will document the underrepresentation of disabled sexualities, identities, and experiences in disability-themed young adult narratives in general, while also examining the role that sexual violence can have as the underlying cause of mental health disabilities in young adult texts that centre the experiences of sexual assault survivors. Lastly, I will conclude this section by briefly discussing how CRRP can be applied by scholars and language arts teachers in future research as a pedagogical approach to the teaching of disability-themed content in the language arts classroom.

Race, Immigration, Disability, and the Absence of Non-Western Perspectives

Across the 12 disability-themed children's and young adult novels that met the inclusion criteria for my study, based on the work of Bates (2017), I noted the limited representation of character diversity, identity, and intersectionality regarding race, gender, sexuality, nationality, linguistic diversity, and religious beliefs. Even though I touched on this finding in the Common Representational Themes sections of Chapters 5 and 6, as well as in the previous section, Summary of Findings, this conclusion requires a more complete discussion.

In a first demonstration of the underrepresentation of protagonists with intersectional identities, only two of the 12 disabled first-person protagonists in my study were racial minorities – August in *Wonder* who is mixed-race Brazilian-American (Palacio, 2012, pp. 26, 32)[87] and Arnold in *True Diary* who is Indigenous (Alexie, 2007, pp. 2-3). The underrepresentation of the intersection of race and disability in children's and young adult literature in general, and in classrooms in particular, was noted by Daniels (2004), while more

[87] These are the only times in the text that August and Via's mixed-race identities are mentioned in the novel, both of which are narrated from Via's first-person perspective. Additionally, Palacio (2012) does not include any examples of August or his family participating in Brazilian culture.

recent scholarship in this area includes Connors and Seelinger Trites (2019), Kaplan and Garcia (2019), and Meacham et al., (2022). The limited portrayals of racially diverse characters in children's and young adult literature, such as the decisions made by publishers regarding the promotion and publication of the novels they produce, in addition to the decisions made by advertising agencies and booksellers. In the educational sphere, the decisions made by school leadership and the individual choices made by teachers and school librarians determine the novels that are taught in language arts classrooms and which are placed in school libraries. Recently, however, children's and young adult novels that explore the intersection of race and disability have become more widely available with the recent publication of novels such as *Aniana Del Mar Jumps in* (Mendez, 2023), and *This is My Brain in Love* (Gregorio, 2020). With the recent increase in the publication of children's and young adult novels that focus on the intersection of race and disability, teachers, school librarians, and scholars have more choices when selecting novels that examine the experiences of racialized disabled characters. Thus, based on the findings of my study, future research should be undertaken that examines the critical intersection between race and disability in the children's and young adult literature that is being taught in schools. One approach that scholars could use while examining the intersection of race and disability in the children's and young adult literature being taught in schools is "DisCrit" (Connor et al., 2016) which combines critical race theory and disability studies in education, thus enabling the intersectional analysis of race and disability in disability-themed children's and young adult novels.

Likewise, a similar and related finding was that the 12 novels included in my study were set in North America or the United Kingdom which have majority white populations. Moreover, none of the disabled first-person protagonists in my study was an immigrant, an English

language learner, or lived in a linguistically diverse household. To date, I have only been able to locate one academic publication that briefly discusses the experience of a disabled child immigrant protagonist (Wheeler, 2022) even though novels that centre on the experience of disabled children or adolescent immigrant characters exist, such as *Breathe and Count Back from Ten* (Sylvester, 2022).

Moreover, novels which centre the experiences of disabled children or adolescent characters that are set in non-Western settings such as *Darius the Great is Not OK* (Khorram, 2018), *If You Could Be Mine* (Farizan, 2013),[88] and *The Bridge Home* (Venkatraman, 2019), which are set in contemporary Iran and India respectively, can be used by teachers to begin to address this gap in the language arts classroom. Furthermore, future research should consider the experiences of racially diverse disabled children and adolescent characters, characters who are immigrants, as well as those whose narratives are set in non-Western locations, which increases the diversity of texts that receive scholarly attention. This would consequently provide education students and language arts teachers with more academic resources and texts that centre the experiences of racialized disabled characters, as well as disabled characters whose stories are set in non-Western locations, so that these texts can be taught in the language arts classroom.

The Absence of Disabled Gender and Sexual Minority Protagonists and Identities

The gender breakdown of the 12 disabled first-person protagonists in my study comprised eight boys and four girls, with there being no disabled gender or sexual minority protagonists

[88] Even though *If You Could Be Mine* (Farizan, 2013) does not contain disabled characters from a Western cultural perspective, the novel takes place in contemporary Iran where gender and sexual minority individuals and relationships are pathologized. Sex-reassignment surgery is used as a medical treatment for gender and sexual deviance. For a scholarly analysis of this novel from a language arts education perspective refer to (Blackburn & Deiri, 2018).

depicted. Moreover, there exists only a limited body of scholarship regarding disabled gender and sexual minority characters in young adult literature with the work of Browne (2020), Chrisman and Blackburn (2019), Duckels (2021a), Duckels (2021b), Jeffries et al., (2022), Markotić (2018), Meyer (2022), and Rumohr-Voskuil (2018) being the only studies that I could locate. Nonetheless, this small number of published studies does represent progress as Hazlett et al., (2011) were unable to locate any young adult novels that portray the experiences of disabled gender and sexual minority characters. They write, "Although exposure to such stories broadens acceptance, understanding, and inclusion between the disabled and nondisabled, it is difficult to ponder relationship issues of disabled non-LGBTQs and disabled LGBTQs when novels are nonexistent" (p. 210). Children's and young adult novels that include disabled gender and sexual minority characters have become more widely available, such as *The Many Half-Lived Lives of Sam Sylvester* (MacGregor, 2022), *The Trouble with Robots* (Mohrweis, 2022), *Forever is Now* (Lockington, 2023), and *Jude Saves the World* (Riley, 2023). Nonetheless, the experiences of disabled gender and sexual minority characters continue to be largely absent from academic studies in critical disability studies and education, as well as from the language arts classrooms in Ontario schools (Bates, 2017). As a corrective to the erasure of the experiences of disabled gender and sexual minority fiction in the language arts curriculum, future research can address this important but underrepresented intersection by developing ways in which teachers can include the experiences of disabled gender and sexual minority students in their language arts curriculum in a disability "culturally authentic" (Brown, 2020, p. 141) manner. Similarly, literary disability studies scholars can examine the ways that disabled gender and sexual minority characters are portrayed in children's and young adult literature from a "queercrip" (Kafer, 2013, p.14) perspective.

Disability and Straight Sexuality

Even though two of the disabled child protagonists in my study, Max in *Freak the Mighty* (Philbrick, 1993, p. 7) and Ambrose in *Word Nerd* (Nielson, 2010, pp. 42, 89, 193, 196, 235) expressed sexual desire, as do five of the seven disabled adolescent protagonists, Charlie in *Perks* (Chbosky, 1999, p. 20), Troy in *Fat Kid Rules the World* (Going, 2004, p. 98), Craig in *It's Kind of a Funny Story* (Vizzini, 2010, p. 90), Arnold in *True Diary* (Alexie, 2007, p. 25), and Hazel in *The Fault* (Green, 2012, p. 12). Three protagonists, Charlie, (Chbosky, 1999, p. 202), Craig (Vizzini, 2010, pp. 253, 310-311), and Hazel (Green, 2012, pp. 206-208) participate in intimate relationships. Even though this is a positive development in that it challenges the myth that disabled people are not interested in or capable of participating in romantic and/or sexual relationships (Barnes, 1992, p. 16) these texts communicate other problematic discourses regarding disabled sexuality as I have previously described. Moreover, to date, little scholarly attention has been paid to the portrayals of disabled sexuality in young adult literature, with the work of Ellman (2012) and Nykvist (2016) being two notable exceptions. Academic research does, however, reveal that disabled adolescents do participate in sexual relationships (Shandra & Chowdhury, 2012; Shandra et al., 2016; Kahn & Halpern, 2018) which challenges the assumed asexuality of disabled people that is widely portrayed in the media (Barnes, 1992, p. 16). Additionally, East and Orchard's (2014) work highlights the confusion regarding who should be responsible for the sex education of disabled adolescents in Ontario between parents, teachers, and health care providers. Thus, future scholarship in this area could examine how the romantic and sexual lives of disabled characters are depicted in disability-themed young adult literature as well as how these texts can be used as part of sexuality education in schools as a means of both

increasing the visibility of disability within the curriculum, while challenging "sexual ableism" (Gill, 2015, p. 3).

Sexual Violence and Mental Health Disability

A third important theme that I noted in my study was that two of the young adult protagonists, Melinda in *Speak* and Charlie in *Perks*, acquire mental health disabilities after experiencing sexual violence. Both novels have been examined by scholars of English literature (Monaghan, 2016; Snider, 2014; Tannert-Smith, 2010) and education (Alsup, 2003; Malo-Juvera, 2014; Matos, 2013), none of whom use a critical disability studies informed perspective. As such, these scholars do not make an explicit connection between surviving sexual violence and mental health disability. Consequently, future scholarship with regard to Chbosky's (1999) and Anderson's (2019) novels could examine the link between experiencing sexual violence and mental health disability from literary disability studies and disability studies in education perspectives. From a mental health disability perspective in academic research and secondary school language arts classrooms, examining the experiences of adolescent characters who experience sexual violence adds an important but under-researched aspect of the experiences of sexual assault survivors to classroom discussions of sexual violence in schools.

Socio-Economic Class and Disability

Throughout my study, socio-economic factors were an important aspect of the 12 disabled first-person protagonists' experiences which have received limited scholarly attention in education and critical disability studies. It is, however, notable that socio-economic factors impact each disabled character's identity and experiences, with Arnold in *True Diary*, Ambrose in *Word Nerd* and Hazel in *The Fault* living in economically disadvantaged households, August in *Wonder* growing up in an economically well-off family, and the remaining characters living in

middle-class families. In a first demonstration of how socio-economic class impacts the experiences of the disabled characters in my study, Hazel blames her cancer diagnosis for causing her family's worsening financial situation in *The Fault* (Green, 2012, p. 79). In a second example, Arnold has to rely on the low quality of medical care provided by the Indian Health Service in *True Diary* due to his family's economic situation, which negatively impacts his access to disability related medical care (Alexie, 2007, pp. 2-3). In a final example, August's family's wealth in *Wonder* not only allows his parents to provide him with the disability related medical care that he needs but also for his mother to home-school him (Palacio, 2012, p. 1). In preparation for writing this recommendation, I attempted to locate academic articles that examine the intersection of socio-economic class and disability in disability-themed children's and young adult literature but have not been able to find any academic studies regarding this topic. Thus, the intersection of socio-economic class and disability in disability-themed children's and young adult fiction is an important but under investigated area of inquiry based on the research that I have undertaken in my dissertation, which could be considered in future studies.

Disability and CRRP

Building on my work in this study, future scholarship can develop ways that CRRP can be used to teach disability-themed content in the language arts classroom. From a theoretical perspective, future studies in this area could build on the foundational work of Waitoller and King Thorius (2023) whose scholarship takes an "asset-based pedagogies" (p. xv) approach to teaching about disability in schools. However, due to the theoretical nature of this work, applied scholarship is needed on how CRRP can be used to teach disability-themed content from a critical disability studies informed perspective in the language arts classroom.

Study Limitations

My research study is limited in numerous ways. First, my interpretations of the depictions of disabled characters in the novels being reviewed are based on my experience as a visually disabled person. This fact limits my ability to effectively communicate the experiences of the disabled characters whose impairments are different from mine. For example, since I do not have personal experience of mental health disabilities or developmental disabilities, my understanding of these forms of impairment are based on published academic research. Furthermore, I want to state that I am writing from my own standpoint and am not speaking for, or in place of, all disabled people or those whose impairments have been portrayed fictionally in the literary works that I have critiqued in my study. The second limitation of my project is that the books that I have included in this study are based on the previous scholarship of Bates (2017). In her study, Bates (2017) identified the texts that were being taught in grades 7-12 in Ontario schools, which geographically limits my project. A third limitation of my study is that the texts that Bates (2017) identified as being taught in grades 7-12 in Ontario schools need to be approved by school leadership, which limits teachers' ability to select the novels that they teach in their classrooms. A fourth imitation of my work is that since Bates' study was published in 2017, my dissertation is limited to analysing the disability-themed children's and young adult novels that were being taught in Ontario schools at the time of her study. A fifth, but related, limitation of my study is that the disability-themed children's and young adult novels that Bates (2017) reported were being taught in grades 7-12 in Ontario schools portrayed a limited range of disabled protagonists' identities and intersectionality. As a result of these limitations, my critical disability studies informed autoethnographic critical inquiry into the representations of disability in these novels was limited to the identities of the 12 disabled first-person protagonists whose characterizations

were depicted in the texts that Bates (2017) reported were being taught in grades 7-12 of Ontario schools. A final limitation of my study is that I have not been able to locate any academic literature regarding *Word Nerd* (Nielsen, 2010), which limited my analysis of the novel.

Final Thoughts: A Reflection on the Journey

The impetus for this study has its roots in my early childhood when my mother read me stories that contained disabled characters, most of which depicted disability in a derogatory manner. This pattern continued throughout my elementary and secondary schooling because my teachers taught disability-themed texts uncritically. As a young disabled person, I did not have the words to explain the literary ableism that I was experiencing, which negatively impacted how I thought about myself as a disabled person. It was only with my introduction to critical disability studies through independent reading in 2012 and later in graduate school in 2014 that I began to develop the vocabulary to describe my experience. By 2017 I had completed two master's degrees which have given me the tools to address one of the causes of the internalized ableism that I continue to experience; the source of which is the impact that demeaning representations of disability in cultural texts have had on my beliefs about myself as a disabled person. This has resulted in the critical disability studies informed autoethnographic critical inquiry that I conducted throughout my dissertation in order to answer the research questions with which I began this study: (1) How are disabled first-person protagonists depicted in the contemporary realistic children's and young adult literature that is being taught in grades 7 through 12 in Ontario schools? (2) How can "asset-based pedagogies" (Waitoller & King Thorius, 2023, p. xv) be used by teachers in the language arts classroom to teach disability-themed children's and young adult literature in a disability "culturally authentic" (Brown, 2020, p. 141) manner? Finally, I have provided teacher educators, classroom teachers, and school

librarians with tools to evaluate the portrayals of disability in classroom literature that were not available to me during my education. By doing so, my work in this dissertation has attempted to address the problem of the literary representation of disability in society in general and, more specifically, in language arts education that Garland-Thomson (1997) describes:

> If we accept the convention that fiction has some mimetic relation to life, we grant it power to further shape our perceptions of the world, especially regarding situations about which we have little direct knowledge. Because disability is so strongly stigmatized and is countered by so few mitigating narratives, the literary traffic in metaphors often misrepresents or flattens the experience real people have of their own or others' disabilities. (p. 10)

By identifying and challenging literary ableism in the disability-themed children's and young adult novels that contain disabled first-person protagonists which are being taught in grades 7-12 in Ontario schools (Bates, 2017), my dissertation serves as a starting point that I hope will be built upon by teacher educators and classroom teachers who share my desire to address the literary ableism that currently exists in the language arts classroom. As a result, through the literature that they encounter in the language arts classroom, students can be shown that being disabled is one of the numerous forms of human diversity that exist in our world.

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Appendix A: Categorical Scholarship Regarding the Representation of Disability in Literature and Other Media

Author	Criteria
(Andrews, 1998, pp. 420-426)	1. The most important and most often cited criterion when selecting inclusion literature is the accuracy of information. (related to the character's disability). 2. Teachers should also look for books that point out that characters with disabilities share the same kinds of life experiences, dreams, successes, and failures that the readers do – to do otherwise is to select works that portray characters with disabilities as one sided, as only disabled. 3. Other aspects related to disabilities that must be accurate include information given about and terminology used to discuss related issues such as medical treatments, rehabilitation efforts, and socialization issues. 4. Another aspect of correct terminology involves the use of people-first language. Language that puts the person first and the label second is most desired. Instead of using terms like "that Down's kid", books should use more progressive language such as "the child with Down's Syndrome". Books that fail to use people-first language can still be used to provide a format for discussion of labelling and its potential negative impact. 5. Rather than perpetuate negative and false stereotypes about disabilities, inclusion literature should present situations and characters that provide understanding of the thoughts and feelings of people with disabilities, not those that use disabilities as a tool to create unsolicited pity and sympathy. 6. Likewise, inclusion literature should not be parasitic; that is, it should not feed off or use the character with the disability as the catalyst for the positive growth of the "normal" characters simply because the two characters happen to interact. 7. The plot of the book should not focus solely on the disability; rather, aspects of the disability should naturally be revealed through the storyline.

	8. Books that include sensitive issues, such as cruelty to persons with disabilities, should not be discounted because of the unpleasantness of the issue, but rather should be selected for the realistic portrayal of the situation and certainly should not encourage or approve of the inappropriate behavior. 9. An additional question to be asked regarding the plot is whether or not the conflict is resolved in a reasonable, believable manner. Teachers should look for inclusion literature that depicts characters who learn to accept their disability and focus their efforts on their abilities, or simply learn how to live with and in spite of their disability. Inclusion literature with overly simplistic cures or fairy-tale endings is highly unbelievable. Good inclusion literature skillfully incorporates an adequate amount of accurate information into a compelling storyline. Literature that is preachy or attempts to indoctrinate the reader into believing a certain way about a disability should be avoided. 10. Another area to consider when selecting inclusion literature is the realistic portrayal of parents. All too often, parents, if included at all, are presented as strong and virtuous, just as unbelievable and unacceptable as the stereotypical pathetic or heroic character with disabilities. (Andrews, 1998, pp. 422-424)
(Barnes, 1992, pp. 1-29)	1. The Disabled Person as Pitiable and Pathetic. 2. The Disabled Person as an Object of Violence. 3. The Disabled Person as Sinister and Evil. 4. The Disabled Person as Atmosphere or Curio. 5. The Disabled Person as Super Cripple. 6. The Disabled Person as an Object of Ridicule. 7. The Disabled Person as Their Own Worst and Only Enemy. 8. The Disabled Person as Burden. 9. The Disabled Person as Sexually Abnormal. 10. The Disabled Person as Incapable of Participating Fully in Community Life. 11. The Disabled Person as Normal. (Barnes, 1992, pp. 7-19)

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(Biklen & Bogdan, 1977, pp. 4-9)	1. The disabled person as pitiable and pathetic. 2. The disabled person as object of violence. 3. The disabled person as sinister and/or evil. 4. The disabled person as "atmosphere." 5. The disabled person as "Super Crip." 6. The disabled person as laughable. 7. The disabled person as his/her own worst and only enemy. 8. The disabled person as burden. 9. The disabled person as non-sexual. 10. The disabled person as incapable of fully participating in everyday life. (Biklen & Bogdan, 1977, pp. 6-9)
(Carroll & Rosenblum, 2000, pp. 620-630)	1. Does the book have characters with congenital and adventitious sight loss? Does it have both characters with low vision and characters who are blind? If it does not, readers may erroneously believe that all of those who have impairments have acquired them after having sight, at least for some time. 2. Does the book have a character with low vision? If not, student readers may mistakenly believe that all people with visual impairments are functionally blind. 3. Does the book have characters who attend public school and have contemporary teenage experiences (e.g., with dating and sexual pressure, family problems, drugs and alcohol, violence, poverty)? Since 90% of children and adolescents with visual impairment are in public schools (Corn, Bina, & DePriest, 1995), it is important for these characters to have experiences that typical adolescents face. 4. Does the book have characters who are facing issues specific to teenagers with visual impairment in the 21st century, such as being non-drivers in a society where driving symbolizes independence and entrance to adulthood? Adolescents with visual impairment need realistic role models with whom they can identify, even in literature. 5. Does the story resolution involve a cure for the visual impairment, with the implication that in

	order to be normal, happy, and independent, one must be sighted? If it does, the book may lead a student reader to develop the belief that one cannot be normal unless a visual impairment is cured. 6. Do the families and peers of the character with visual impairment act realistically toward that character? Occasional fear, anger, and questioning are normal not only for the character who has a disability, but for the others in that character's life. 7. Do the families and teachers expect the character with visual impairment to be a successful independent person? Of people with visual impairments, 70% are unemployed. Student readers need to meet characters with visual impairment who are successful and independent as adolescents. They need to believe that these characters will become successful adults. (Carroll & Rosenblum, 2000, p. 626)
(Connor, 2017, pp. 199-218)	In his chapter, Connor (2017) cites Safran's (1998) 9 "Disability Archetypes" which include: 1. Villain. 2. Monster. 3. Seeker of Revenge. 4. Bitter or Nasty. 5. Object of Pity. 6. Perpetually Infantilised. 7. In Possession of Special Powers. 8. Suicidal. 9. Inspirational. To which Connor (2017) adds 10. "The Everyday and Therefore No Big Deal Portrayal of Disability" (Connor, 2017, p. 205)
(Dolmage, 2014, pp. 41-61)	1. Disability as Pathology. 2. Kill-or-Cure. 3. Overcoming or Compensation. 4. Disability as Object of Pity and/or Charity. 5. Physical Deformity as Sign of Internal Flaw.

	6. Disability as Isolating and Individuated. 7. Disability as Sign of Social Ill. 8. Disability Is a Sign from Above. 9. Disability as Symptom of Human Abuse of Nature. 10. Disability Drift and the Disability Hierarchy. 11. Disability Drop. (Dolmage, 2014, pp. 43-45)
(Dyches et al., 2009, pp. 304-317)	**Personal Portrayal** 1. Portrays characteristics of DD accurately. 2. Describes the character(s) with DD as realistic. 3. Character(s) with DD are fully developed. 4. Does not portray only disabilities of the character(s), but portrays abilities, interests, and strengths of the character(s). 5. Emphasizes similarities, rather than differences, between characters with and without DD. 6. Uses nondiscriminatory language that avoids stereotypic portrayals. **Social Interactions** 1. Depicts character(s) with DD engaging in socially and emotionally reciprocal relationships. 2. Depicts acceptance of the character(s) with DD. 3. Promotes empathy, not pity for the character(s) with DD. 4. Portrays positive social contributions of person(s) with DD. 5. Promotes respect for the character(s) with DD. **Exemplary Practices** 1. Depicts character(s) with DD having full citizenship opportunities in integrated settings and/or activities. 2. Depicts character(s) with DD receiving services appropriate for their age, skill level, and interests. 3. Depicts valued occupations for character(s) with DD (if appropriate). 4. Promotes self-determination. **Sibling Relationships** (if applicable) 1. Sibling(s) of the character(s) with DD experience a wide range of emotions.

	2. Sibling(s) of the character(s) with DD have opportunities for growth that are not typical for siblings of children without DD. 3. The sibling relationship is reciprocal. 4. The sibling(s) are not given unusually burdensome household and family duties. 5. The sibling(s) appear aware of the nature of the disability and its effects on the character with DD. (Dyches et al., 2009, p. 307)
(Hayden & Prince, 2020, pp. 1-26)	**Strength-based** 1. Character accepts his/her disability and focuses on his/her abilities. 2. Character is not portrayed as a stereotyped case (violent, laughable, a burden, pitiable, victimized, dependent, lesson in perseverance, exists only to initiate development of an able-bodied character etc.). 3. Character with a disability grows and changes throughout story. 4. Plot shows character with a disability having similar life experiences as peers without disabilities (similar conflicts, goals, likes etc.). 5. Character with a disability is well developed. 6. Setting allows character with a disability to be included in society (school, work, recreation). 7. Theme rectifies a stereotype/myth about people with disabilities. **Illustrations** 1. Format is appealing for children; relatively simple instead of overly sophisticated. 2. Illustrations and images are realistic, appropriate. 3. Illustrations and images show distinctive personality of character with a disability. They do not appear stereotypically alike, as if all people with disabilities look the same. 4. Illustrations and images show character with a disability actively involved in the environment. **Narrative Appeal, Effectiveness, Flow** 1. Language/vocabulary is appropriate for children/clear style/appropriate vocabulary.

	2. Narrative and dialogue portraying characters with disabilities is appropriate for age of reader. 3. Descriptions provide colourful imagery without being lengthy. 4. Dialogue among characters is genuine. 5. Catches interest within first 3-5 pages. 6. Interesting plot throughout story. 7. Plot progresses in a chronological order. 8. Theme is familiar and appealing to children (making friends, sibling conflicts, school issues). (Hayden & Prince, 2020, p.12)
(Kleekamp & Zapata, 2018, pp. 589-597)	1. How is the life of the character with a disability presented as multidimensional? 2. Whose voice is represented and emphasized in the telling of this story? 3. How are readers positioned to think and feel about the character with a disability? 4. What steps has the author taken to create and present authentic relationships? (Kleekamp & Zapata, 2019, p. 591)
(Landrum, 2001, pp. 252-258)	**Plot** 1. The events are realistic and reasonable, rather than unrealistic and contrived. 2. The disabled characters are active participants in the plot and its various conflicts; they initiate action, rather than exist outside of it. 3. The unfolding of the plot focuses on what the characters with disabilities can do rather than what they cannot do. 4. A superhero theme does not appear in the story. 5. For the most part, the same narrative could exist without a disabled character; it is not a didactic theme for a cause. 6. The disabled character faces conflicts similar to those of his or her peer group. 7. Although both the climax and the ending may include the disability of one of the characters, they do not focus on it. 8. A cure for the disability is not the solution to the disabled characters' problems or conflicts. Nor will a cure give them a normal life. Similarly, attitude will not prevent or create a cure.

	9. Even though the book is fiction, all the data pertaining to the disability is accurate. **Character development** 1. The disabled characters are portrayed as strong and independent, rather than passive, atypically naive, child-like, or dependent. 2. The disabled characters are competent individuals who speak for themselves. 3. The prominent traits of the characters with disabilities are what they can do, as opposed to what they cannot do. 4. The disabled characters portray a full range of emotions: anger, sadness, joy, love, pride, shame, and so forth. 5. The disabled characters' temperament is not dramatically different than the other characters. An extraordinary positive or negative temperament may imply that the disability was caused by attitude or vice versa. 6. The disabled characters may or may not be coming to terms with their sexuality, typical of readers of intermediate and adolescent fiction; however, they are not represented as asexual. 7. The disabled characters are not portrayed as outsiders or rejected by their peers because they are disabled; they have friends, families, etc. 8. The disabled characters are developed as multidimensional and rounded; they are not flat or stock characters. 9. The disabled characters are not portrayed artificially as heroes or victims. **Tone** 1. The text does not use words such as retarded, handicapped, lame, crippled, or special. 2. The tone fits the theme, rather than being overly saccharine or simplistic. 3. Whenever emotionally or sexually charged scenes appear, they are critical to the plot and theme, not to manipulate the reader's emotions. 4. If the story is a tragedy or leaves a feeling of hopelessness, it is due to the human condition in general, not a character's disability.

	(Landrum, 2001, p. 254)
(Menchetti et al., 2011, pp. 56-66)	**Physical Appearance of Book** 1. Format is appealing for young adults; sophisticated instead of childish. 2. Illustrations and images are realistic and/or appropriate. 3. Illustrations and images show the distinctive personality of the character with a disability. (They do not appear stereotypically alike, as if all people with disabilities look the same.) 4. Illustrations and images show the character with a disability actively involved in the environment. **Characterization** 1. Focuses on common traits of all people while showing human qualities of people with disabilities. 2. The character with the disability possesses dynamic qualities and is not only defined by his/her disability. 3. Character accepts his/her own disability and focuses on his/her abilities. 4. Characters with and without disabilities use correct terminology when referring to the disability itself. 5. Meaningful interactions exist among characters with and without disabilities. 6. The character is not presented as a stereotyped case (e.g. violent, laughable, asexual, a burden, pitiable, etc.). 7. A positive portrayal of character's strengths exists. 8. Character is portrayed as confident and able to make own decisions. 9. Character is accepted by peers. 10. A balance of roles exists between the character with a disability and characters without a disability. **Literary Style** 1. Person-first language is used appropriately (e.g. "a boy with mental retardation" instead of "the mentally retarded boy"). 2. Terms used to describe characters and settings are appropriate.

	3. Language/vocabulary is appropriate for adolescents/clear style/appropriate vocabulary. 4. The narrative and dialogue portraying characters with disabilities is appropriate for age of reader. 5. Descriptions provide colorful imagery without being lengthy. 6. Dialogue among characters is genuine. 7. Catches interest within first 10 pages. **Plot** 1. The character with the disability plays a major role in the plot. 2. The character's disability is naturally revealed throughout the plot. 3. The plot highlights the abilities of the character (not just disabilities). 4. Plot is realistic/believable (e.g., character with a disability is not portrayed as a superhero, the character is not cured, parents are not saints, etc.). 5. The plot shows the character with a disability having similar life experiences as peers without disabilities (e.g., similar conflicts, similar goals, similar likes, etc.). 6. Accurate information regarding the disability is provided throughout the plot. 7. All characters are well developed. 8. Interesting plot throughout story. 9. Dialogue and action are used to develop the plot. 10. Uses humor appropriately. 11. Plot progresses in a chronological order. **Setting** 1. The setting allows the character with the disability to be included in society (school, work, recreation). 2. Portrays up-to-date practices regarding living with disabilities. 3. Accurate historical/current perspective of people with disabilities living within society. **Theme** 1. The theme teaches a valuable lesson about interacting with people with disabilities.

	2. The theme rectifies a stereotype/myth about people with disabilities. 3. The theme is familiar and appealing to young adults (making friends, parental conflicts, sibling conflicts, dating, school issues, etc.). **Point of View** 1. Written from the perspective of the character with a disability. (Menchetti et al., 2011, pp. 60-61)
(Monaghan, 2016, pp. 32-42)	1. The protagonist/narrator accurately reflects the knowledge of someone his age under the circumstances in which he finds himself. 2. The protagonist's/narrator's illness experiences allow the reader to draw parallels between her life and experiences and those represented in the narrative. 3. The protagonist's/narrator's story rings true: if Point A is connected to Point B, it does so according to the logic of the narrative. 4. Somewhere in the narrative, the illness or condition is explicitly articulated. (Monaghan, 2016, p. 39)
(Quayson, 2007, pp. 32-53)	1. Disability as null set and/or moral test. 2. Disability as the interface with otherness (race, class, sexuality, and social identity). 3. Disability as articulation of disjuncture between thematic and narrative vectors. 4. Disability as bearer of moral deficit/evil. 5. Disability as epiphany. 6. Disability as signifier of ritual insight. 7. Disability as inarticulable and enigmatic tragic insight. 8. Disability as hermeneutical impasse. 9. Disability as normality. (Quayson, 2007, p. 52)

Appendix B: The 39 Children's and Young Adult Novels that Contain Disabled Characters in Bates (2017)

1. Aker, D. (2003). *The First Stone*. New York, NY: HarperCollins.
2. Alexie, S. (2007). *The Absolutely True Diary of a Part-Time Indian*. Boston, MA: Little, Brown.
3. Anderson, L. H. (2019). *Speak.* New York, NY: Farrar, Straus, and Giroux.
4. Anderson, L H. (2014). *Wintergirls*. London, UK: Marion Lloyd.
5. Asher, J. (2007). *Thirteen Reasons Why*. New York, NY: Penguin.
6. Barrie, J. M. (2015). *Peter Pan.* London, UK: HarperCollins.
7. Chbosky, S. (1999). *The Perks of Being a Wallflower*. New York, NY: MTV Books.
8. Collins, S. (2009). *Catching Fire*. New York, NY: Scholastic.
9. Collins, S. (2008). *The Hunger Games*. New York, NY: Scholastic.
10. Coy, J. (2010). *Crackback*. New York, NY: Scholastic.
11. De Vries, M. (2014). *Rabbit Ears*. Toronto, ON: HarperCollins.
12. Draper, S. M. (2010). *Out of My Mind*. New York, NY: Simon and Schuster.
13. Draper, S. M. (1994). *Tears of a Tiger*. New York, NY: Simon Pulse.
14. Ellis, D. (2011). *The Breadwinner*. Toronto, ON: Groundwood Books.
15. Flake, S. (1998). *The Skin I'm In.* New York, NY: Disney Book Group.
16. Going, K. L. (2004). *Fat Kid Rules the World*. New York, NY: Penguin Young Readers Group.
17. Green, J. (2012). *The Fault in Our Stars*. New York, NY: Dutton Books.
18. Haddon, M. (2004). *The Curious Incident of the Dog in the Night-time*. Toronto, ON: Anchor.

19. Hesse, K. (2002). *Out of the Dust*. New York, NY: Scholastic.

20. Holubitsky, K. (2008). *Tweaked*. Victoria, BC: Orca Book Publishers.

21. Hopkins, E. (2013). *Crank*. New York, NY: Margaret K. McElderry Books.

22. Hunt, L. M. (2015). *Fish in a Tree*. New York, NY: Penguin.

23. Lowry, L. (2000). *Gathering Blue*. Boston, MA: Houghton Mifflin Harcourt.

24. Lowry, L. (1993). *The Giver*. Boston, MA: Houghton Mifflin Harcourt.

25. Martin, A. M. (2004). *A Corner of the Universe*. New York, NY: Scholastic.

26. McCormick, P. (2011). *Cut*. New York, NY: Scholastic.

27. McGovern, C. (2016). *Just My Luck*. New York, NY: HarperCollins.

28. Nielsen, S. (2010). *Word Nerd*. Toronto, ON: Tundra Books.

29. O'Neill, H. (2006). *Lullabies for Little Criminals*. New York, NY: HarperCollins Publishers.

30. Palacio, R. J. (2012). *Wonder*. New York, NY: Alfred A. Knopf.

31. Philbrick, R. (1993). *Freak the Mighty*. New York, NY: Scholastic.

32. Riggs, R. (2011). *Miss Peregrine's Home for Peculiar Children*. Philadelphia, PA: Quirk Books.

33. Riordan, R. (2005). *Percy Jackson and the Lightning Thief*. New York, NY: Disney Hyperion.

34. Stevenson, R. L. (2017). *Treasure Island*. Brookfield, MO: James Hart Publishers.

35. Taylor, T. (2011). *The Cay*. New York, NY: Random House.

36. Vizzini, N. (2010). *It's Kind of a Funny Story*. New York, NY: Hyperion.

37. Walters, E. (2006). *Shattered*. Toronto, ON: Penguin.

38. Wood, J. R. (1992). *The Man Who Loved Clowns*. New York, NY: Penguin.

39. Wynne-Jones, T. (2014). *The Boy in the Burning House*. Toronto, ON: Groundwood Books Ltd.

Appendix C: The 12 Novels that I Analyse in my Dissertation

1. Alexie, S. (2007). *The Absolutely True Diary of a Part-Time Indian*. Boston, MA: Little, Brown.
2. Anderson, L. H. (2019). *Speak*. New York, NY: Farrar, Straus, and Giroux.
3. Chbosky, S. (1999). *The Perks of Being a Wallflower*. New York, NY: MTV Books.
4. Draper, S. M. (2010). *Out of My Mind*. New York, NY: Simon and Schuster.
5. Going, K. L. (2004). *Fat Kid Rules the World*. New York, NY: Penguin Young Readers Group.
6. Green, J. (2012). *The Fault in Our Stars*. New York, NY: Dutton Books.
7. Haddon, M. (2004). *The Curious Incident of the Dog in the Night-Time*. Toronto, ON: Anchor.
8. Hunt, L. M. (2015). *Fish in a Tree*. New York, NY: Penguin.
9. Nielsen, S. (2010) *Word Nerd*. Toronto, ON: Tundra Books.
10. Palacio, R. J. (2012). *Wonder*. New York, NY: Alfred A. Knopf.
11. Philbrick, R. (1993). *Freak the Mighty*. New York, NY: Scholastic.
12. Vizzini, N. (2010). *It's Kind of a Funny Story*. New York, NY: Hyperion.

Appendix D: Novel Summaries Chapter 5 (Children's Literature)

In *Freak the Mighty* (Philbrick, 1993) readers are introduced to Maxwell (Max) Kane who lives with his grandparents because his father is in prison for murdering his mother. Max experiences social stigma due to his large size as well as his physical resemblance to his father. Max does poorly in school because of his learning or developmental disability. [The novel supports both categorizations of Max's disability (Carico & Stanley, 1999; Meyer, 2013)]. Prior to Kevin moving in next door, Max is socially isolated and does not have any friends. However, as a result of his friendship with Kevin, Max begins to go on adventures in his neighbourhood. Late in the novel readers learn that Kevin has a terminal illness and that after Kevin's death, Max has written the text of the novel that we have been reading.

In *Word Nerd* (Nielsen, 2010) readers meet Ambrose Bukowski, the only child of his single mother. Ambrose has chosen to socially isolate himself owing to the bullying that he experiences at school. Ambrose's mother is overly protective of him because of his peanut allergy and her fear of losing him after the death of her husband. Because of his mother's over-protectiveness, Ambrose has to lie about having friends and forges his mother's signature so he can join the Scrabble Club and participate in the tournament.

In *Out of My Mind* (Draper, 2010) readers learn about the life and experiences of Melody Brooks, a non-verbal wheelchair user with cerebral palsy. Until the fifth grade, Melody is educated in a segregated special education classroom but when her mother visits her class unexpectedly and learns that the students are not receiving access to grade- and age-appropriate curriculum she advocates for Melody to be placed in an inclusive classroom with paraprofessional support. Afterwards, with the help of her family, Mrs. V. (a neighbour), and Catherine (her paraprofessional) Melody earns a place on her school's Whiz Kids team and helps

them win their local tournament but when a snowstorm changes the team's flight plans, Melody is deliberately left behind.

In *Wonder* (Palacio, 2012) readers are introduced to August (Auggie) Pullman who has been homeschooled until the fifth grade because of his frequent surgeries. Throughout the narrative, August experiences both bullying and friendship as readers learn about his first year attending Beecher Prep. Additionally, readers discover what other people think about August through their first-person narrations, including his sister Via and his friends, Jack, and Summer.

In *Fish in a Tree* (Hunt, 2015) readers meet Ally Nickerson who struggles in school as she is living with an undiagnosed learning disability. Ally lives with her parents and older brother Travis. However, during the novel her father is deployed overseas. Throughout the text, Ally experiences both bullying and friendship, and develops literacy skills with the help of her new teacher, Mr. Daniels. Ally also gains the support of her classmates and becomes class president by the conclusion of the novel.

Appendix E: Novel Summaries Chapter 6 (Young Adult Literature)

In *Speak* (Anderson, 2019) readers are introduced to Melinda Sordino, who is friendless during her ninth-grade year because she called the police while attending a party the previous summer. However, it is not revealed until two-thirds of the way through the novel that Melinda was raped at the party, which has negatively impacted her mental health. However, when the truth is revealed near the end of the book Melinda's reputation is restored.

In *The Perks of Being a Wallflower* (Chbosky, 1999) readers learn about Charlie (no last name given) as the novel chronicles his experiences during his first year of high school. At the beginning of the book, Charlie does not have any friends because his only friend committed suicide the previous spring. However, early in the narrative, Charlie befriends Sam and Patrick through whom he is introduced to many teenage experiences. Throughout the book, Charlie experiences symptoms that are associated with depression and anxiety for which he is seeing a therapist and taking medication. Near the end of the novel readers discover that Charlie's favourite person, and now deceased Aunt Helen, repeatedly sexually abused him as a young child, and that this abuse is the underlying cause of his mental health disability.

In *Fat Kid Rules the World* (Going, 2004) readers meet Troy Billings, who is friendless, overweight, believes that he is a disappointment to his father, and is contemplating committing suicide. However, when Troy meets Curt, a homeless high school guitar prodigy, Curt invites him to become the drummer of his band. Through their musical collaboration Troy gains self-confidence and his beliefs about himself begin to change.

In *The Curious Incident of the Dog in the Night-Time* (Haddon, 2004) readers are introduced to Christopher Boone who is coded as being autistic, although not identified as such in the novel. Christopher lives with his father after being told that his mother died, but he later

discovers is living with another man in London. When his father prohibits Christopher from continuing his investigation into the death of Mrs. Shear's dog Wellington, Christopher discovers that his father committed the crime. This revelation leads Christopher to travel to London in search of his mother.

In *The Absolutely True Diary of a Part-Time Indian* (Alexie, 2007) readers meet Arnold Spirit Jr. who is Indigenous and lives on the Spokane Reservation. The novel opens with Arnold describing in detail his numerous disabilities, as well as the bullying that he experiences as a result. With the encouragement of his teacher, Arnold transfers from his Reservation's high school to one in the adjacent community of Reardan where he succeeds academically and athletically on the basketball court.

In *It's Kind of a Funny Story* (Vizzini, 2010) readers are introduced to Craig Gilner, who is living with clinical depression. When the pressure of his academically rigorous high school causes him to contemplate suicide, Craig admits himself to a hospital in which the majority of the novel is set. During his stay in the hospital, Craig describes his relationships with the other patients and staff at the facility, including his potential new girlfriend, Noelle.

In *The Fault in Our Stars* (Green, 2012) readers learn about Hazel Grace Lancaster who is living with terminal cancer. While attending a cancer support group, Hazel meets Augustus, and they quickly begin dating. During their trip to Amsterdam to meet her favourite author (Peter Van Houten) Augustus tells her that his cancer, which had been in remission, has returned and that it is now terminal. Shortly after they return home Augustus dies.

Appendix F: Key Textual Information Based on Bates (2017)

No.	Author	Title	Year of First Publication	Ranking on (Bates, 2017) List of Books Taught in Ontario Schools	Number of Ontario Schools in Which the Novel is Taught	First-Person Protagonist	Types of Disabilities	Other Disabled Characters	Types of Disabilities	Representations of Disability
1	Sherman Alexie	*The Absolutely True Diary of a Part-Time Indian*	2007	11	27	Arnold Spirit Jr.	Hydrocephalus, Visual Disability, Epilepsy and Speech Impairment	None	None	"Overcoming or compensation" "disability drop" (Dolmage, 2014, pp. 44-45). "*Disability as the interface with otherness* (*race, class, sexuality, and social identity*)" (Quayson, 2007, p. 39).[89] "The Disabled Person as an Object of Violence" (Barnes, 1992, p. 10), "Evil or Sinister" (Connor, 2017, p. 206).
2	Rodman Philbrick	*Freak the Mighty*	1993	30	14	Maxwell Kane (Max)	Learning Disability or Developmental Disability (the text supports both interpretations).	Kevin, or Freak	Unidentified Terminal Illness	"Disability as pathology" "Disability drift", "Disability as Isolating and Individuated" "Overcoming or Compensation" "kill or cure" (Dolmage, 2014, pp. 43-45) "Disability as bearer of moral deficit/evil" (Quayson, 2007, pp. 38-39) "Villain", "Monster", "Inspirational" (Connor, 2017, p. 205). The moralizing dying child trope (Keith, 2001).
3	Mark Haddon	*The Curious Incident of the Dog in*	2003	38	9	Christopher Boone	Autism	Steve (only mentioned	Unknown	"Disability as Isolating and Individuated" "Overcoming or

[89] The italics are in the original.

		the Night-Time					Not identified or diagnosed in the text.	once in the novel)		compensation" (Dolmage, 2014, p. 44), "evil or sinister" (Connor, 2017, p. 206) "*Disability as the interface with otherness* (*race, class, sexuality, and social identity*)" (Quayson, 2007, p. 39),[90] "The disabled person as an object of ridicule" (Barnes, 1992, p. 13), "Disabled person as burden" (Barnes, 1992, p.15).
4	R. J. Palacio	*Wonder*	2012	41	9	August Pullman (Auggie)	Numerous physical disabilities including Facial Disfigurement, and Hard-of-Hearing.	None	None	"*Disability as the interface with otherness* (*race, class, sexuality, and social identity*)" (Quayson, 2007, p. 39),[91] "Disability as Isolating and Individuated" "Overcoming or Compensation" "Disability as pathology "Disability as (an) object of pity and /or charity" "Kill or cure" (Dolmage, 2014, pp. 43-45), "The disabled person as an object of ridicule" (Barnes, 1992, p. 13), "The Disabled Person as an Object of Violence" (Barnes, 1992, p. 10), "Disability as contagion myth (Park et al., 2003). "Monster", "The inspirational disabled character" (Connor, 2017, p. 205).
5	Laurie Halse Anderson	*Speak*	1999	46	8	Melinda Sordino	PTSD Not diagnosed or self-identified in the text.	None	None	"Disability as Isolating and Individuated" (Dolmage, 2014, p. 44), "*Disability as epiphany*" (Quayson, 2007, p. 45), "The Everyday and Therefore No Big Deal Portrayal of

[90] The italics are in the original.
[91] The italics are in the original.

										Disability" (Connor, 2017, p. 205).
6	Lynda Mullaly Hunt	*Fish in a Tree*	2015	75	5	Ally Nickerson	Dyslexia Not identified or diagnosed in the text but was going to be tested at the end of the novel.	Travis Nickerson	Dyslexia (Not identified or diagnosed in the text).	"Disability as Isolating and Individuated" "Overcoming or Compensation" (Dolmage, 2014, p. 44), "Inspirational" (Connor, 2017, p. 205), "The Disabled Person as an Object of Violence" (Barnes, 1992, p. 10)."
7	Stephen Chbosky	*The Perks of Being a Wallflower*	1999	91	4	Charlie (no last name given)	PTSD, Anxiety, Depression Not formally diagnosed but describes seeing a therapist throughout the novel and spends several months in a mental health facility at the end of the text.	None	None	"Disability as Isolating and Individuated" (Dolmage, 2014, p. 44), "*Disability as epiphany*" (Quayson, 2007, p. 45), "The Everyday and Therefore No Big Deal Portrayal of Disability" (Connor, 2017, p. 205).
8	Susin Nielsen	*Word Nerd*	2008	162	2	Ambrose Bukowski	Life-Threatening Peanut Allergy	None	None	"Disability as Isolating and Individuated" (Dolmage, 2014, p. 44), "The Disabled Person as an Object of Violence" (Barnes, 1992, p. 10).
9	Sharon M. Draper	*Out of My Mind*	2010	208	2	Melody Brooks	Cerebral Palsy and Synesthesia	Ashely Carl Maria Gloria Willy Williams Jill	Physical Disability Physical Disability Down Syndrome Autism Cerebral Palsy Physical Disability	"*Disability as the interface with otherness* (*race, class, sexuality, and social identity*)" (Quayson, 2007, p. 39),[92] "Disability drift" "Disability as pathology" "Disability as Isolating and Individuated" "Overcoming or Compensation" (Dolmage, 2014, pp. 43-45), "Disabled person as burden" (Barnes, 1992, p. 15), "The inspirational disabled character" (Connor, 2017, p. 205).

[92] The italics are in the original.

10	K. L Going	*Fat Kid Rules the World*	2003	537	1	Troy Billings	Obesity and associated Mental Health Disability. No formal medical diagnoses are given in the text.	Curt MacCrae	Addiction	"Kill or Cure". "Disability as Isolating and Individuated" "Disability as Pathology" "Overcoming or Compensation" (Dolmage, 2014, pp. 43-44), "*Disability as the interface with otherness* (r*ace, class, sexuality, and social identity*)" (Quayson, 2007, p. 39),[93] "The Disabled Person as an Object of Violence" (Barnes, 1992, p. 10), "The Disabled Person [is] Their Own Worst and Only Enemy" (Barnes, 1992, p. 14), "The Disabled Person as Sexually Abnormal" Barnes, 1992, p. 16), "Suicidal" (Connor, 2017, p. 205).
11	John Green	*The Fault in Our Stars*	2012	544	1	Hazel Grace Lancaster	Cancer	Augustus Waters Isaac Other minor characters	Cancer and Amputee Cancer and Visual Disability Cancer	"Disability as Isolating and Individuated" "Disability as pathology" "Kill or cure" "Overcoming or Compensation" "Disability as an object of pity and /or charity" (Dolmage, 2014, pp. 43-44), Disabled person as "burden" (Barnes, 1992, p. 15), "*Disability as epiphany*" (Quayson, 2007, p. 45), "Inspirational" (Connor, 2017, p. 205). The moralizing dying child trope (Keith, 2001)
12	Ned Vizzini	*It's Kind of a Funny Story*	2006	673	1	Craig Gilner	Depression	Numerous other characters	Mental Health Disabilities	"The Disabled Person as Sexually Abnormal" Barnes, 1992, p. 16), "The Everyday and Therefore No Big Deal Portrayal of Disability" (Connor, 2017, p. 205)

[93] The italics are in the original.

Appendix G: Recommended Disability-themed Children's Novels[94]

1. Allen, S. (2021). *Breathing Underwater*. New York, NY: Farrar Straus & Giroux.*
2. Arlow, J. M. (2023). *The Year My Life Went Down the Toilet*. New York, NY: Penguin.*&
3. Baldwin, C. (2023). *No Matter the Distance*. New York, NY: Quill Tree Books.*
4. Cartaya, P. (2019). *Each Tiny Spark.* New York, NY: Penguin.#
5. Carter, C. (2021). *The Fifty-Four Things Wrong with Gwendolyn Rogers*. New York, NY: Quill Tree Press.*
6. Comrie. C. (2022). *Rain Rising*. New York, NY: HarperCollins.*#
7. Cujec, C. & Goddard, P. (2020). *Real.* Melrose Park, IL: Shadow Mountain.*
8. Draper, S. M. (2021). *Out Of My Heart*. New York, NY: Atheneum Books for Young Readers.
9. Hart, M. (2022). *Daisy Woodworm Changes the World*. Mendota Heights, MN: Jolly Fish Press.
10. Lucas, C. (2021). *Thanks a Lot, Universe.* New York, NY: Amulet Books.*&
11. Lucas, C. (2023). *You Owe Me One Universe*. New York, NY: Amulet Books.*&
12. McDunn, G. (2022). *Honestly, Elliott*. New York, NY: Bloomsbury.
13. McNicoll, E. (2020). *A Kind of Spark*. New York, NY: Crown Books For Young Readers.*
14. Melleby, N. (2022). *The Science of Angry*. Chapel Hill, NC: Algonquin Young Readers.&
15. Mendez, J. (2023). *Aniana Del Mal Jumps In*. New York, NY: Del Books for Young Readers.*#

[94] Novels that have been written by self-identified disabled authors are marked with an *, novels containing gender or sexual minority protagonists are marked with an &, and novels that examine the intersection of race and disability are marked with an #.

16. Mohrweis, M. (2023). *The Problem with Gravity*. Atlanta, GA: Peachtree Publishing Company.*&

17. Mohrweis, M. (2022). *The Trouble with Robots*. Atlanta, GA: Peachtree Publishing Company.*&

18. Reynolds, J. (2017). *As Brave as You.* New York, NY: Atheneum Books for Young Readers.#

19. Riley, R. (2023). *Jude Saves the World*. New York, NY: Scholastic. &

20. Roe, M. (2022). *Air*. New York, NY: Farrar, Straus, & Giroux.

21. Venkatraman, P. (2019). *The Bridge Home*. New York, NY: Nancy Paulsen Books.*

Appendix H: Recommended Disability-themed Young Adult Novels[95]

1. Blake, A. H. (2018). *Girl Made of Stars.* New York, NY: Houghton Mifflin Harcourt.&
2. Bulla, M. G. (2023). *If I Can Give You That*. New York, NY: Quill Tee Press.*&
3. Day, C. (2021). *The Sea in Winter*. New York, NY: HarperCollins.#
4. Garrett, C. (2019). *Full Disclosure*. New York, NY: Random House Children's Books.&#
5. Girard, M. E. (2023). *Then Everything Happens at Once.* New York, NY: HarperTeen.&
6. Gregorio. I. W. (2020). *This Is My Brain in Love*. New York, NY: Little Brown and Company.*#
7. Jacobus, A. (2023). *The Coldest Winter I Ever Spent.* Minneapolis, MN: Carolrhoda Lab.
8. Khorram, A. (2018). *Darius the Great Is Not Okay.* New York, NY: Penguin Young Readers Group.*&#
9. Lockington, M. J. (2023). *Forever is Now*. New York, NY: Farrar Straus Giroux.*&#
10. MacGregor, M. (2022). *The Many Half-Lived Lives of Sam Sylvester*. New York, NY: Astra Publishing House.*&
11. Oshiro, M. (2018). *Anger is a Gift*. New York, NY: Tom Doherty Associates.*&#
12. Reyes. S. (2023). *The Luis Ortega Survival Club.* New York, NY: Balzer + Bray.*&#
13. Rodriguez, C. L. (2015). *When Reason Breaks*. London, UK: Bloomsbury Publishing.*#
14. Silverstein, K. R. (2019). *Cursed*. New York, NY: Charlesbridge.*
15. Smith, A. (2016). *The Way I Used to Be*. New York, NY: Simon & Schuster.
16. Smith, A. (2023). *The Way I Am Now*. New York, NY: Margaret K. McElderry Books.

[95] Novels that have been written by self-identified disabled authors are marked with an *, novels containing gender or sexual minority protagonists are marked with an &, and novels that examine the intersection of race and disability are marked with an #.

17. Soloman, R. L. (2018). *You'll Miss Me When I'm Gone.* New York, NY: Simon & Schuster.

18. Steiger, A. J. (2018). *When My Heart Joins the Thousand*. New York, NY: HarperTeen.*

19. Sylvester, N. (2022). *Breathe and Count Back from Ten*. New York, NY: Clarion Books.*#

20. Watson, R., & Hagan E. (2019). *Watch Us Rise*. New York, NY: Bloomsbury.*#

Appendix I: A DSE and CRRP Informed Novel Study Unit: *A Kind of Spark* (McNicoll, 2020)

Lesson No.	Lesson Title	Theme	Critical Questions	Text Chapters	Assignments
1	Who are Disabled People?	Disability identity, the models of disability, and the concept of ableism.	1. How do you define yourself and what identities or labels have been given to you by others? 2. In what ways does your culture and lived experience impact how you identify yourself and the identities that others have given to you? 3. In what ways does your race, class, gender, immigration status, religion, disability etc., impact your chosen and given identities?		
2	Disability Language	Historical and contemporary overview of the language used to discuss disability and disabled people.	1. How does the language that we use impact our beliefs about ourselves and others? 2. In what ways can others' beliefs about us impact our rights and the laws that are created by society? 3. What if these laws and policies discriminate against you or other members of your community? How should we respond to these forms of injustice as individuals, and as a community?		

3	Introduction to disability as a personal and cultural identity.	Deficit-based and disability affirming depictions of disability in cultural texts.	1. In what ways do positive and or negative messages about cultural communities impact the beliefs and attitudes of community and non-community members of a cultural group? 2. Do the media have a responsibility to portray the members of non-dominant communities in a realistic manner? Or are stereotypical representations of minority groups protected under freedom of speech? Does this apply to fiction authors, the news media, and advertisers also? Why or why not?		
4	Disability representations in literature and other media.		1. What are the differences between cultural texts created by and for the members of a cultural group and those written about them by others? 2. How does this impact the representation of the community being portrayed, and how do these portrayals impact the readers/viewers of cultural texts? Think about and respond to this question in relation to art,		

			literature, film, plays, music, and other cultural texts? 3. What role do cultural texts have regarding the rights that society gives to or withholds from cultural groups? 4. How do activists use the media and other cultural texts to challenge society's beliefs about and attitudes towards the members of their communities?		
5	The Relationship Between Disability Identity, Disability Language, and Disability Representation in Cultural Texts	Synthesis of the first 4 lessons.	1. Do disabled people have a culture? 2. In what ways do the media and other culture producers depict the lives and experiences of disabled people, and disability culture? 3. How does the language used by the media to describe disabled people impact the way that abled and disabled people think about disability and those who have them? 4. What impact does this have on the rights of disabled people? 5. How do these laws and policies impact the lives of disabled people?		Quiz
6	Introduction to *A Kind of Spark*				

7	*A Kind of Spark* 1		1. How does Addie identify herself in the first section of the novel? How is she described by others such as her teachers, parents, siblings, classmates, and other community members? 2. What impact do others' beliefs about Addie have on her identity? 3. In addition to being Addie's older sister, Keedie is described as being "loud and proud" (p.13) regarding her autistic identity. What aspects of the neurodiverse community do Keedie and Addie share and demonstrate in this section of the novel?	Chapters 1-5	
8	*A Kind of Spark* 2		1. In Chapter 6, what do readers learn about ableism and social media? How does this incident impact Nina, Keedie, and Addie individually and collectively as sisters? 2. In Chapter 7 what do readers learn about the historical treatment of disabled people? How do Addie and the other characters respond to this? 3. In Chapter 8 readers discover that autistic people continue to be denied equal rights in	Chapters 6-10	Reading Response Assignment 1 question. In what ways does history impact your personal identity, and the identity[ies] that others have given you? Explain.

			the form of institutionalization. In what ways have society's beliefs about and attitudes towards disabled people changed overtime? What role do language, the media, and disability rights activism have on society's beliefs about and responses to disability today?		
9	*A Kind of Spark* 3		1. In what ways does Audrey show that she is a good friend to Addie? Does this also make her a good ally of the neurodiverse community? Explain. 2. What do readers learn about Emily in this section of the novel, and what do her words and actions teach readers about bullies and ableism? 3. How should Addie have responded to the bullying and ableism that she experiences in this section of the novel? 4. In Chapter 14 Miriam, Audrey, and Addie discuss whether "being nice and being good are the same thing" (p.115) do you think that there is a difference between them? Which one do you think is better in	Chapters 11-15	

			the context of the novel and in other areas of life?		
10	*A Kind of Spark* 4		1. In what ways do Nina and Keedie support Addie in the aftermath of the incident in Chapter 15? How should parents and students respond to ableist teachers and other adults in our schools and communities? 2. After having read *A Kind of Spark* (2020) would you consider Addie to be a disability rights activist? What actions does she take to advocate for herself and for other disabled people's rights throughout the novel? 3. In what ways are other characters supportive allies to Addie throughout the novel? In what ways can you be an activist for or an ally to disabled people in your daily life? Explain. 4. In Chapter 17, Nina apologizes for making the video about Addie. What can abled siblings of disabled people learn from their relationship? In what ways can abled siblings be supportive of their disabled siblings?	Chapters 16-21	Reading Response 2. What does it mean to you to be an ally, and how do you demonstrate your allyship and advocate for communities to which you may or may not belong? Explain.

11	Disability Identity, Rights and Culture Project Work 1	Students work on their group presentations on an aspect of disability Identity Rights and Culture			
12	Disability Identity, Rights and Culture Project Work 2	Students work on their group presentations on an aspect of disability Identity Rights and Culture			
13	Disability Identity, Rights and Culture Project Work 3	Students work on their group presentations on an aspect of disability Identity Rights and Culture			
14	Disability Identity, Rights and Culture Project Work 4	Students work on their group presentations on an aspect of disability Identity Rights and Culture			
15	Disability Identity, Rights and Culture Project Work 5	Students work on their group presentations on an aspect of disability Identity			

		Rights and Culture			
16	Disability Identity, Rights and Culture Project Presentations				
17	Disability Identity, Rights and Culture Project Presentations				
18	Disability Identity, Rights and Culture Project Presentations				
19	Disability Identity, Rights and Culture Project Presentations				
20	Disability Identity, Rights and Culture Project Presentations				

Appendix J: *A Kind of Spark* (2020) Final Assignment Guidelines

For this assignment students will be placed in small groups of 3-4 to conduct library, newspaper, legal, historical, documentary based, and interview-based research regarding a topic of contemporary importance to disabled people and disability rights activists. Some examples of topics may include, but are not limited to, accessible transportation, housing, access to higher education, employment, legal rights, etc. Based on their research each group will prepare a detailed written report pertaining to their chosen topic that highlights the historical and contemporary experiences of disabled people with your chosen sociopolitical issue and the current state of disability activism and societal change initiatives regarding it. Moreover, students' written reports will provide recommendations for changes to public policy, legislation, or other systems of power that could if implemented increase the social, political, cultural, or other forms of access being advocated for by disabled people. After each group has written their report, they will give a brief 10–15-minute oral presentation based on their research to their classmates. The written report should be 8-10 double spaced typed pages in addition to any charts, tables, graphs, as well as the title page and references.