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A Changing Disability-Intertext: Representation of Disability in Canadian Young Adult Fiction

by

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Abstract

This study examines the disability-intertext in contemporary Canadian young adult fiction and seeks to analyze new patterns in the representation of disability. The disability-intertext is explored using Michel Foucault’s theory of the “background-body” and Ato Quayson’s theory of “aesthetic nervousness.” The representation of disability in six contemporary Canadian young adult texts is analyzed through the categories of disability as normality, temporality, social context, textual landscape, genre, self-image, abuse, humour, and author’s notes. The intentionality of situating issues of disability in the young adult genre represents an important development in Canadian literature, where disability narratives in young adult fiction are critically reread so as to bring out deeper meanings for the contemporary audience.

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Introduction

One of my earliest memories of disability occurred at about age six. My aunt had obtained tickets to attend a performance of “Sharon, Lois and Bram,” a popular children performing group in the early 1990s. I was very excited to go on a “big girl” trip with my aunt, firstly, because I was going to see my favourite television stars in person, and secondly, because it was my very first concert at the Jubilee Auditorium in Edmonton. When we got to the auditorium I began to feel agitated. The auditorium was very dark and there were so many people and new faces. Before the concert began I also noticed that immediately behind us were three mentally handicapped teenagers in wheelchairs. I had never seen a person in a wheelchair so close before, and seeing three people in wheelchairs at once became overwhelming. My older siblings thought “Sharon, Lois and Bram” was for babies, and so I wondered, “what are teenagers doing here,” “why are their faces shaped funny,” and “why are they in wheelchairs?” Amidst all the confusion of the dimming lights, and parents and guardians rushing children to their seats, I now had to deal with the fact that directly behind me were three teenagers, with what I considered at that age to be oddly shaped faces and bodies in wheelchairs. These were individuals with whom I had never been in such close proximity before.

Recalling this memory is difficult for me, and I believe it must have been the first time that I had ever really seen someone severely disabled and in a wheelchair. My only point of reference at this time in my early life was the families at church who had mentally and physically disabled children. In particular, there was a girl in a wheelchair, who often moaned and groaned throughout Mass. Her family always sat at the very back of the church and consequently I had never really seen or sat near her, and I would only periodically hear her during the service. So, for my very first concert, my fear of the disabled youths was preventing me from enjoying “Sharon, Lois and Bram.” Looking back on the memory, I realize that at the time, my little body and mind could only compute that these people were different. I also believed that they were in pain because they were moaning. I became upset because I did not understand why someone did not do something to help them.

As the concert began I became more uncomfortable with where I was sitting and could not enjoy the concert. I wanted to change seats but I was too embarrassed and ashamed realizing that I feared the disabled teenagers behind me. The emotions of guilt and shame consumed me. The thought that I would enjoy my first concert was replaced by paralysing fear. Interestingly enough, now, after all my research in Disability Studies,[1] I still have chosen the word “paralyzed” to describe my experience. I was frozen in my seat, immobile out of fear that something unknown and different was going to happen to me. So, as Sharon, Lois and Bram ran about the stage and sang and danced, I, in contrast, sat motionless, scared that something menacing was about to take place in that dark corner. When my aunt realized that I was not singing and dancing she asked me what was wrong. I finally told her that I was upset and did not like my seat. We switched seats, and I remember immediate ease flooding over me. I could enjoy the concert now that my aunt had switched places with me. The fear that the people in the

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[1] Disability Studies will be defined and explained in Chapter 1 of this thesis.

wheelchairs would grab at me had dissipated. My aunt, who is a registered nurse, spoke with me after the concert and explained to my six-year-old self what was "wrong" with the kids, and why I should not be scared, and that everyone, enjoys concerts in their own way. Moaning and groaning can be considered singing, and not sounds of pain, she told me. I thought back to the girl in church who moaned and groaned. Perhaps she too was "singing"?

I think that this memory of my first concert combined with my encounter with the unknown body created an everlasting impression. The moment of fear I felt towards the "other" body, and the subsequent shame I felt afterwards, began my interest in how people read the disabled body. Many years later, I was introduced to Disability Studies in the second year of my Comparative Literature undergraduate studies at the University of Alberta in 2006. "Women in World Literature" was the title of the course, and one class was dedicated to Disability Studies, something I had never heard of before. Under the instruction of Dr. Asma Sayed, we spent one hour and a half reading and learning about Disability Studies, and of women who were writing about a disability that had either affected themselves or someone in their family. Coincidently, the "Women in World Literature" class corresponded with another class I was taking on Semiotics, where we were theorizing the concept of reading bodies like texts. A light bulb went off in my brain: if bodies are texts, what type of text is a disabled body? Are disabled-body-texts treated differently from able-body-texts? Do authors incorporate disabled bodies into their texts as primary characters? New words began to enter my vocabulary; extraordinary bodies, crip theory, ableism, freakery, subjectivity, the government of disability, absent citizens, cultural spectacles, body language...all very powerful new words and theories. More questions began circling in my mind: what are representations of disability like in literature, and is a disabled text fluid and intertextual? Of course, I also began to think about my own experiences with disability. I realized that growing up in Edmonton I have had many friends who have had siblings with intellectual[2] or physical disabilities. My childhood and upbringing was filled with these families as they wove in and out of my life, whether it be at sporting events, school functions or at work when their families came in to say hi. I interacted with these children and their siblings, and constantly recognized that they all loved their disabled siblings very much. My friends' siblings with disabilities were always included, always cheering on at sporting games, went on vacations with their families, and always, most importantly, were visible in the community. My childhood allowed me to be shown the value and importance of inclusion at a young age.

In my adult years I was able to take part in an Alberta Parks and Recreation initiative called "Push to Open." The "Push to Open Access Challenge" is an annual event that focuses on making Canada's National Parks

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[2] *Intellectual disability* is defined by the National Dissemination Center for Children with Disabilities. It is a term used when "a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child" (no page). Further, "children with intellectual disabilities (sometimes called *cognitive disabilities* or *mental retardation*) may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating" (no page). I have chosen to use the term intellectual disability in this thesis because it is not the same as a mental illness, psychological disability, learning disability, or psychiatric condition (*Best Buddies Canada*: *What is an Intellectual Disability?* no page). Some examples of intellectual disabilities include Autism, and Down Syndrome (*Best Buddies Canada*: *What is an Intellectual Disability?* no page).

more accessible for physically disabled individuals. The three-day event features adaptive equipment for kayaking, biking, hiking, and even over-night outdoor camping. Interestingly enough, the "Push to Open" slogan is "Everyone Belongs Outside." The slogan is important to consider, since the North American dichotomy of "insider" versus "outsider," often puts emphasis on the idea of outsider as negative and insider as positive. The idea that "Everyone Belongs Outside," takes the previous dichotomy of insider/outsider and reverses it, creating a new idea that being on the outside, on the periphery, is somewhere every single person, regardless of ability, belongs. The transformation of the inside/outside connotation demonstrates how important Disability Studies is to challenge preconceived notions not only about abilities, but, more importantly, about the power of language.

What I have realized in my own research about portrayals of disability in literature, and what I hope that this thesis will succeed in demonstrating, is that the disabled body really is meant to push the boundaries of what the story of any life has the capability to tell. I think the power to tell a story, and to tell something about the self, is the truest human desire, no matter what ability.

<u>Statement and Justification of Problem</u>. In this thesis, I have undertaken the challenge of examining how contemporary Canadian young adult fiction, engages intentionally with representations of disability in literature, creating a disability-intertext.[3] Issues concerning the representations of disabilities, both

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[3] The disability-intertext thread is represented through an author's intentional inclusion of characters with disability and this intertext is also in a dialogue with historical representations of disability. This inclusion of disability-intertext has aided in the creation of new patterns and new

physical and intellectual, are prominent in today's social and literary discourse, especially in young adult fiction. Notably, the educational researcher, Beverley Brenna, in her unpublished doctoral dissertation *Characters with Disabilities in Contemporary Children's Novels: Portraits of Three Authors in a Frame of Canadian Texts* (Spring 2010), found that in the period of 1995-2001 Canadian publishing houses published seven novels that contained characters with disabilities. This number more than tripled from 2002 to 2009 with the publication of forty-two new titles that contained characters with disabilities. Beverley Brenna's doctoral thesis completed at the University of Alberta in Elementary Education is a qualitative study exploring influences on three Canadian authors: Rachna Gilmore, Pamela Porter, and herself, who present characters with disabilities in children's fiction. Her methodology included portraiture, interviews with the authors, and Bakhtin's conceptualization of the literary chronotope. More specifically, her work was done in order to offer perspectives that impact critical literacy in the classroom. My project is different from Brenna's research because I offer an exploratory textual analysis through a sample of six young adult Canadian novels. Further, I suggest that the authors are engaging with patterns of a new disability-intertext and are creating characters with disabilities as examples of disability as normality.

Since Brenna's research, three new novels were published and shortlisted for the 2010 Governor General Awards: Lesley Fairfield's young adult graphic novel *Tyranny* (2009), Gina McMurchy-Barber's young adult historical novel

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methods to represent literary characters with disabilities. The disability-intertext will be explored in Chapter Three of this thesis as examples of disability as normality.

Free as a bird (2010), and Ian Brown's non-fiction work *The Boy in the Moon: A Father's Search for His Disabled Son* (2009). These three titles represent not only books that deal with mental and physical disabilities, but also possible answers to the questions of the nature of new patterns exploring contemporary trends depicting disability. These questions include, "how do we imagine disabled children as children?" and "what new patterns are emerging to explore contemporary trends that depict disability?"

The inclusion of disability within the young adult genre, as well as the addition of what Rosemarie Garland-Thomson calls "extraordinary bodies"[4] in fiction, is a conscious decision made on the part of the young adult writer. The young adult writer utilizes new patterns of representing disabilities to advance particular goals in articulating an intentional disability-intertext. The application of the author's intentional use of the disability-intertext becomes a strategic method "to make meaning out of inarticulate matter, to make silent material speak" (Rowe 300) and to "create work that reflects the individual and collective experience of being disabled" (Sutherland 79). Whether the intertextual nature of disability evokes feelings of shock, pity, embarrassment, or memories from childhood (or of a family member), disability in text is used to interpret one's thoughts, attitudes, and/or behaviours towards the multiple meanings of disability on a social scale. Further, "we must listen to what the texts have to tell us and gauge the applicability of Disability Studies" (Eyler 6) in young adult literature, as Disability Studies offers reading methods that open "new angles in well-

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[4] See Rosemarie Garland-Thomson's *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997) for discussions of the disabled figure as an "extraordinary body" in culture and literature.

trodden texts" (Eyler 2). In literature the disabled body serves as a "crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight" (Mitchell and Snyder 49). Through a phenomenon called "narrative prosthesis," when the use of "**dis**-ablity" occurs to "**en**-able" a story,[5] the inclusion of the disability-intertext has proven its worth in the cultural importance of storytelling. However, the idea of a disability-intertext is altered in order to fit within the fiction written by the author. Such alterations demonstrate the author's intentional inclusion and engagement with the disability-intertext. Through acts of borrowing, adjusting, and performing to current literary trends, the young adult genre has experienced its own modifications concerning the inclusion of characters with disabilities. Ato Quayson, a key researcher in Disability Studies scholarship today, has conceptualized these modifications of disability in literature as acts of "aesthetic nervousness" (19).[6]

The interest in the disability story, or story of disability, has been rising since 2002[7] with Canadian writers and publishing houses giving more attention to disability within young adult texts. The young adult genre may imply a certain type of simplicity, but disability stories are in fact more complex than they first appear to be. By framing disability as a children's discourse, situated within

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[5] In *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), David T. Mitchell and Sharon L. Snyder discuss disability in narrative which is seen as both excessively visible and conversely invisible.

[6] In his cross-cultural interdisciplinary study of representations of physical disability in *Aesthetic Nervousness: Disability and the Crisis of Representation* (2007) Ato Quayson primarily focuses on the works of Samuel Beckett, Toni Morrison, Wole Soyinka, and J. M. Coetzee. While my study focuses on the young adult literature of contemporary Canada, and new patterns emerging to develop characters with disabilities, Quayson's study puts forward a post-colonial analysis looking at how subliminal unease and moral panic (ie. aesthetic nervousness) is invoked within the reader by characters with disabilities, thus forcing the reader to take an ethical standpoint.

[7] I have used the year 2002 based from the findings of Beverley Brenna's doctoral research in *Characters with Disabilities in Contemporary Children's Novels: Portraits of Three Authors in a Frame of Canadian Texts* (Spring 2010).

mainstream literature (rather than the traditional placement with medical discourse), theorists can revise an oppressive narration, revealing a liberating one. It is my hope that, as listeners and readers of literature, we continue to engage with and construct meanings of texts, disabled or not. The concept of disability, which should be recognized and understood as a fundamental human experience, is still missing from our critical consciousness (S.L. Snyder, Brueggemann and Garland-Thomson, *Enabling* 3), and the texts examined demonstrate how we may imagine disabled children as children. The texts chosen for this study not only represent Canadian bilingual literariness, but also address the discovery of the marginalized disabled young adults' voice in literature. Arguably, "disability is not simply about diversity. It is also about commonality – not a commonality of embodied experiences but a commonality of purpose, in the struggle for a more inclusive society" (Preistly 240), where the disabled protagonists of the texts demonstrate shared aims in being accepted by the community.

The corpus of my thesis consists of the following works of fiction: the Canadian English texts, *Wild Orchid* (2005) by Beverley Brenna, *Waiting for Sarah* (2003) by Bruce McBay and James Heneghan, *Free as a bird* (2010) by Gina McMurchy-Barber, *The Space Between* (2007) by Don Aker, and the French Canadian texts, *Té malade toi!* (2004) by Line Gamache (translated by KerryAnn Cochrane as *Hello, me Pretty!* (2007)), and *La liberté? Connais pas*... (1998) by Charlotte Gingras (translated by Susan Ouriou as *Pieces of Me* (2009)). These texts, and the disability-intertext they represent, will be analyzed using Quayson's theory of aesthetic nervousness, for the purpose of exploring the journey of the new disabled protagonist.

These particular works of young adult Canadian fiction are included for a number of reasons. First, these are contemporary texts that feature disability in a protagonist; to include main characters with disabilities represents an important trend in today's young adult texts. Second, these texts are indicative of new patterns emerging in Canada to represent disability in literature. Finally, on the basis of representative English-Canadian and French-Canadian young adult texts, an examination of the patterns of disability representation in both traditions can be made.

Stories are the ways in which we tell of ourselves to each other.[8] Stories are connected "to peoples' lives through emotional links that produce resonance; such emotional linking is not simply a passive reflex; it is an active construction, a placement of one story to another" (Conle 307). In the words of Quayson, the story of disability and acts of aesthetic nervousness returns the reader to an "active ethical core" (19). These stories that feature disability are shaped by social, political, economic and medical forces. An absent theme in literature, philosophy and history has been the inclusion of people with disabilities. The discourse of Disability Studies is attempting to move from invisibility to visibility to legibility: to be read, understood and discussed. The relationship between Disability Studies and the humanities is an important one, as it takes the focus of

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[8] See Tomson Highway's lecture on *Comparing Mythologies* (2003) where John Moss writes the introduction stating "stories, to paraphrase Robert Kroetsch, make us real...if there is anything like truth accessible to us in the world, it must be through the way we tell of ourselves to each other" (9).

disability away from the arena of a medical discourse, and instead into a place of literary discussion. For the purposes of this study, it must be recognized that each disability has its own history, vocabulary, language and trajectory, and thus is distinct. The conclusions that will be made in this examination of the disabled individual in literature have implications for the way in which the disabled body is viewed in society today, and suggestions for ways that authors may develop new perspectives.

Methodology. In this explorative study of examining characters with disabilities in Canadian young adult fiction, I have used a comparative methodological approach to accentuate the very construction and inclusion of the intentional disability-intertext. Further, I employ the language and methodology of Disability Studies as my argument is created. The disability-intertext is explored using Michael Foucault's theory of the background-body. My inquiry uses Ato Quayson's theory of aesthetic nervousness to identify the landscapes where narratives about characters with disabilities reside. Representation of disability in Canadian young adult texts will be analyzed as examples of disability as normality. The characters with disabilities will be looked at in terms of the disability-intertext which includes the categories of temporality, social context, textual landscape, genre, self-image, abuse, humour and an analysis of the author's notes left within the novels.

Chapter Outline. In Chapter 1, I will begin with an exploration of the literary traditions of disability. First, a working definition of disability is suggested. Next, I will outline the evolution of the disability-intertext from antiquity to present day. Images of disability in media are also explored to demonstrate the way in which the disability-intertext can operate. Representations of disability have grown and changed over the centuries and this will be discussed in relation to the disability-intertext. The disability-intertext, or perhaps, the tale of disability, has the ability to adopt and adapt to its present society's trends and literary movements, further indicating how individuals find continual relevance within the stories.

In Chapter 2, I will explore Michel Foucault's conceptualization of the "abnormal body" and relate his theory to Quayson's theory of aesthetic nervousness. Through this analysis, I will argue that disability in the young adult genre provides a space for writers to negotiate new frameworks and borders of the literary treatment of disability. For example, I will analyze Heidi Janz's historical young adult novel *Sparrows on Wheels* (2004) to demonstrate how the theoretical framework of the "intentional fallacy"[9] and aesthetic nervousness function in the midst of the "intentional disability."[10] This analysis will foreground the instances of disability-intertext in the young adult genre that I will look at in the subsequent chapter.

In Chapter 3, I will apply the theories of Chapter 1 and 2 to contemporary young adult fiction as I investigate the intentional disability-intertext present in the texts. The use of the disability-intertext creates a place of intertextual meaning directed towards Canadian literature as a whole. Further, by asking what the new

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[9] See William K. Wimsatt Jr. and Monroe C. Beardsley's *The Intentional Fallacy* (2001).

[10] I will argue that the "intentional disability" occurs when an author intentionally includes a character with a disability within his/her work, and that by leaving an author's note to indicate his/her own experience and relationship with disability, s/he are engaging with the disability-intertext.

patterns of disability representations are advocating and promoting, I will analyze the major implications of the intentional disability and suggest methods for future researchers to look towards when exploring the journey of the new disabled protagonist in the young adult genre.

The re-imagining and creation of new patterns of disability representations in relation to the disability-intertext will be revisited again in my conclusion. Here, I will discuss how new voices and new forms of identity have developed and are irrevocably linked to the process of storytelling. The intertextual nature of the intentional disability in literature allows authors to utilize the idea of otherness. Further, attempts at “perfected” representations of disability are being constructed in the young adult genre, and as a result these texts are more complex than they first appear to be.

Chapter 1. Theorizing the Intentional Disability

Towards a Working Definition of Disability

Disability is far from an absolute term, and does not define the person. To create a working definition of the word "disability" in this work, I have adapted ideas from Disability Studies scholars Rosemarie Garland-Thomson, and Lennard J. Davis. Garland-Thomson contends in *Extraordinary Bodies* that "the disabled are produced by ways legal, medical, political, cultural, and literary narratives that comprise an exclusionary discourse by becoming a repository for social anxieties about such troubling concerns as vulnerability, control and identity" (6). Lennard J. Davis suggests in "The Need for Disability Studies," that people working in the field of disability must "place disability in a political, social, and cultural context, and discuss disability in similarly complex ways to the way race, class, and gender have been theorized" (3). *The Oxford English Dictionary* defines "disability" as "lack of ability (to discharge any office or function); inability, incapacity; weakness." Further, in my analysis of the disability-intertext the attempt to eliminate ableist language and ableist metaphors from this thesis has occurred.[11] Any ableist metaphors that do occur in this thesis will appear in quotations or titles, and ultimately demonstrate our society's "need to develop a cognitive awareness of a 'lack of understanding'" (May and Ferri 118). Recognizing the limitations and complexities outlined above, if there can ever be a correct consideration of the word disability, perhaps it will only come from

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[11] Ableism is defined as "discrimination in favour of the able-bodied" (Linton 161) which "includes the idea that person's abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to nondisabled people" (Linton 161).

those who view themselves as disabled. Those who conceptualize themselves as disabled can give meaning to the term because of their own life experiences.

Firstly, it must be stated that disability cannot be generalized as there is no single figure or example of a disabled individual. In my analysis of representations of characters with disabilities I realized that seeking to provide an analysis covering all dimensions of every disabled person's experience is not a useful or attainable concept because disability is personal and varies from bodies to bodies, and texts to texts. Further, "disability cannot be reduced to a singular identity: it is a multiplicity, a plurality" (Gabel and Peters 588); it is "simultaneously a very personal, and intensely social experience" (Sherry, *Reading ME* 164) where "disabled people have been spoken about, and spoken for, but rarely listened to" (Sherry, *Reading ME* 165). What is important to bear in mind is that disabled bodies encompass a vast assortment of readings and re-readings for the many different types and circumstances concerning every disabled body. Within literature, there appears to be a disability-intertext, where although each disability is inherently different, the language used functions in a way to "perfect" how the disabled body is being represented.

Disability Studies has developed as a field for academic research over the past decades. Disability Studies is regarded as a "field of inquiry that brings together the humanities and social sciences to explore the complex relationship between disability and the socio-cultural forces that shape it" (Eyler 1). Historically, disability in literature of antiquity and the medieval period was constructed to be linked inherently with sickness, sin and illness (Quayson 7). The stereotype of disability as caused by unknown evil forces is a dominant notion in ancient and medieval societies as well as prevalent in belief systems of some cultures today. From the eighteenth century onwards, the perception of disability was dominated by a medical model where disability is seen as a “problem” that must be “cured.” Reaction and criticism towards the medical representations of disability has been developed by contributions of scholars in Disability Studies through constructionist models. Constructionist models of disability have further been separated into a social and a cultural model. For the purposes of this study, I have taken the cultural model approach. The cultural model does away with distinctions between impairment[12] and disability, using “the term ‘disability’ to include both the reality of corporeal differences as well as the effects of social stigmatization” (Eyler 4). Further, the cultural model approach acknowledges the entire continuum of experiences and representations of people with disabilities and does not limit its focus to any one constructed perception of disability.

As Disability Studies scholars have continuously reiterated, disability is both an extremely personal and enormously social experience. Disability in its most basic conception can be viewed as the ultimate oppositional category to normality. Further, the language surrounding disability has been commonly negative. The negative language can be seen in examples of the use of the words “invalid,” “no good,” or “useless” to equate and/or describe a disabled figure. These negative readings function to perpetuate an idea of a negative body, and a negative reading of disability from the perspective of the able-bodied. Society’s

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[12] The term “impairment” is usually associated with an abnormality of structure or function at the organ level. In contrast, “disability” is the functional consequence of such impairment (Gilman, *Obesity and Disability* 271)

idealization of the human body promotes what is positive. The positive body then acts as a constant reminder of what is a negative body. The disabled voice becomes a voice of alterity, the voice of an “other,” promoting the questions of what it means to be other, and what constitutes the “otherness” of disability. Further, questions asked in Disability Studies are “what body constructs what body,” “what is the disabled point of view,” and “what does it mean to stare, or to be stared at?” Ultimately, it appears that it is the threat of disability entering at any time into every single person’s life that disability scholars often ground their theories in. At one point, every single one of us will age, or become victim of an accident that may affect and inhibit us from a daily routine. If one can imagine that every single person is situated on a continuum of ability, then it might be plausible to imagine ourselves situated on the imaginary line of ability. On this line of ability imagine that at any one moment, the line may curve, and one will possibly have disability enter one’s life, creating a new line, one that should not be thought of as better or worse, but simply as different.

Disability allows for alternative interpreters and interpretations, where the intention of the author, an intentional fallacy,[13] can be upset by the author’s intentional use to include a character with a disability in a story. When writing about disability it must be asked “what are the demands of texts that contain characters with disability” and further, do the texts “demonstrate new, expressive means that have shifted away from previous models?” What I have found is that the texts that contain characters with disabilities in this thesis are necessary in

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[13] See *The Intentional Fallacy* (2001) by William K. Wimsatt Jr. and Monroe C. Beardsley. These two literary critics that set out to pursue why the “design or intention of the author is neither available nor desirable as a standard for judging the success of a work of literary art” (1374-75).

reflecting a range of lived and potential experience. Canadian writers are moving away from former patterns of representations of disability. Characters are not miraculously healed, nor do the young adult novels end in death. Canadian writers, unlike the Disability Studies scholars, do not seem to concern themselves with the notion that "one day we will all become disabled." The dichotomy of the "disabled" versus "able-bodied" is one of the many complex levels of the disability-intertext challenged in the young adult literature as new patterns have emerged in the way disability is represented. Abandoning the "take up thy bed and walk" [14] attitude Canadian young adult fiction writers instead intentionally strive to present disability as "normal," but with an effort to make it believable and different from the "norm."

Ideas previously concerning the vulnerability of the disabled were constructed through social conditions of segregation, rejection, isolation and loneliness. If we are to grow accustomed to the idea of the disabled presences as "normal" and positive, the characters must be interacted with, and believed by the reader as plausible additions to the stories. Further, the disabled texts must feature stylized repetition of acts of disability so as to be recognized as believable. The act of applying somewhat formulaic means for making disability in literature believable contradicts the unique nature of a disability, and a desire to get away from the historic treatment of disability as inherently different. The question then becomes, can we move away from the binary concept of disabled (them-us) versus able-bodied (us-them) in literature?

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[14] See Lois Keith's *Take up, Thy Bed & Walk: Death, Disability and Cure in Classic Fiction for Girls* (2001) for further analysis on the surprising tenacity of the temptations of writers to cure or kill disabled characters.

In Canada there are programs and initiatives, at both the Provincial and Federal levels of government that advocate for the disabled.[15] Disability Studies scholar Paul Drake argues that "despite social change, the archetypal and stereotypical persist" (97), and according to Simi Linton, "a premise of most literature in Disability Studies is that *disability* is best understood as a marker of identity" (162). The disability-intertext is becoming a "more capacious category, incorporating people with a range of physical, emotional, sensory and cognitive conditions" (Linton 162), of which I am exploring the positive implications in this thesis. Stories and the context in which these stories are provided can demonstrate important mediums for change, drawing disability to the forefront of social consciousness alongside other aspects of human diversity. Stiker (1997) notes that disability scholarship highlights repeated features from the general social treatment of the disabled. Exposures to new views on disability instead of stereotypical representations become necessary for advancements in literature. The inclusion of characters with disabilities in texts is beneficial and constructive not only for young adult fiction as a genre, but for the disability story. For the authors, the heroes/heroines successfully depict images of disability which are free from stereotypes. The disabled protagonists in the texts examined are situated in the traditional position of storyteller so that they may negotiate their "dis/abilities." Finally, the presentation of characters with disabilities in recent

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[15] The *Disability-Related Policy in Canada* website aims to "build the capacity of the disability community to engage with federal and provincial/territorial governments in policy discussion and development related to disability supports, and to strengthen capacity of the community and governments to more effectively draw on the knowledge base of the disability community about disability supports needs, issues, best practice and policy options. These goals were expressed by disability organizations at meetings hosted by the Council of Canadians with Disabilities (CCD) and the Canadian Association for Community Living (CACL) in March 2004" (no page).

Canadian young adult fiction has emphasized the importance of the topic of disability for critical studies.

An Introduction to the Evolving Field and Discourse of Disability Studies

Disability Studies is still a relatively new and emerging field within the humanities. The critical discourse on the evolution and growth of disability representation in text can be traced in North American literature from the 1950s and onwards. Perspectives on disability and the representations of disability in literature have radically changed over the last thirty years.[16] More specifically, images of disability in the news and texts concerning disability, whether it be an academic article or study, a government policy, a work of fiction, or autobiography have increased rapidly since the 1980s. Disability Studies, however, was not formalized as an academic discipline until the 1980s with the works of theorists such as Rosemarie Garland-Thomson, Lennard J. Davis, Michael Bérubé, Mark Sherry, and many more. Critiqued originally for its "whiteness" and "bourgeois attitudes," thirty years later contemporary Disability Studies theorists have created a niche within the humanities with an extensive body of literature including a Disability Studies Reader,[17] which has a second edition, special issues of the journal of the Modern Language Association of America (PMLA), and numerous articles and academic books. Moving away from

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[16] For further analyses and timelines regarding the history of Disability Studies I would recommend the *Disability Studies Reader*, edition I (1997) and II (2006), edited by Lennard J. Davis, *Disability Studies: Enabling the Humanities* (2002), edited by Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland-Thomson, as well as *Extraordinary Bodies* (1997), by Rosemarie Garland-Thomson.

[17] *Disability Studies Reader* (1997) was the first major publication to present important and thought-provoking writings to date about disability and the politics of "normalcy."

disability being explored solely within a medical context, disability is currently being discussed as a social construct, where the representation of disabilities in texts is being constantly challenged.

In the Canadian young adult literary scene, a unique situation is occurring in the publishing houses in that an increasing number of texts that feature characters with disabilities and their stories are being published. As mentioned previously, the very act of storytelling is perhaps the only way any type of truth is ever accessible in this world. The act of telling "your" story is conveyed in the way in which we tell of ourselves to one another. The Canadian young adult fiction to be analyzed offers new exposures to different "disabled" perspectives and points for further research. These points for further research include asking how the authors portray the characters with disabilities in Canadian young adult fiction, how the characters convey themselves, how the characters have their voices heard, and how their stories are interpreted by the community.

Disability, like gender, is often read visually. The visual source of the disabled body functions as a reminder to the able-bodied that human bodies are fragile. In "Seeing Disability," W.J.T. Mitchell states that for the most part the disabled do "not want sympathy or concern" (393), arguing that Disability Studies will have to "challenge the very notion of what it means to look at other people or see things from their point of view" (393), that is, the disabled point of view. Through my analyses of young adult literature, I will argue that the disabled point of view that the author creates offers insight into intentional attempts at inclusion. By consistently presenting a disabled protagonist in the young adult texts I will suggest that perhaps the authors are taking unintentional or intentional aims to "perfect" how disability is being represented. When such a concept like disability refuses to be "perfected," the result is seemingly an attempt at a formula for inclusion in literature.

Scott Lunsford argues in "Seeking a Rhetoric of Dis/Abilities" that "we often do not see that our ability constructs disability" (330) and that society ignores "individual identity by labelling people collectively but also maintain[ing] the person is the disability itself" (331). Conversely, disability can define ability, as under the premise that "no able-bodied person can be sure that she will continue to be able-bodied through her later years, and there is no guarantee that any of us will escape disabling encounters with the world" (Breckenridge 356). When reading texts, a reader's eye will "move along the verbal surface of a text...gain[ing] access to a space that is multi-dimensional" (Hoffman 395), illustrating that the ability and disability are inherently involved and constructed by one another. As disability enters a text, it "invites the reader to inquire into the body" (Hoffman 408), and begins to share in scenarios of bodily experience which may displace the outer world. Hughes writes in "A Critique of the Disabled Body" that "impairment is the fate of each and every one of us and, therefore, it is important to recognise that able bodied status is essentially temporary" (401), demonstrating that there is a vulnerability and frailty involved in portraying characters in texts that include disability.

Since disability has historically negative connotations within global contexts and social structures, it becomes all the more threatening to the able-bodied. Disability becomes a threat to the able-body because the disabled body has been placed in a social context of negativity, given that "many disabled bodies can appear defective" (Mollow 277). Fear of a disabled body functions as a negative reminder that one day the able-bodied may become disabled.

Disability Studies is caught up in the politics of spectacle, staring and body language. Stereotypical images of disability include "heroic, tragic *and* freakish" (Millett-Gallant 21), where "disabled bodies are only accepted when attached to a 'worthy message'" (Millett-Gallant 68). Historically, as Margrit Shildrick discusses in *Dangerous Discourses of Disability, Subjectivity and Sexuality* (2009):

> the received history of the disabled body is deeply problematized by a genealogy that disrupts the notion of a continuous development of ideas and images, and shifts the focus to competing, fractured, and discontinuous discourses culturally embedded in particular historical periods. (10-11)

Representations of the disabled individual have also included ideas and images of the wondrous, spectacular or even divinely heroic (Shildrick 11). In contrast, pessimistic ideas towards disability cause the advancement of views to be trapped by long lasting negative stereotypes. Three stock responses towards disabled people include the following: "they (or their ancestors) have been punished; they have been pitied; or through faith in God or self, they have been encouraged to 'overcome' what is usually seen as a burden of sorrow" (Keith 15). As a child, if you hear your parents sternly telling you "Don't Stare!" such an admonishment instantly commands both a looking at and simultaneously a looking away. Further, the disabled body disrupts the social body “because it remains undecidable, neither self nor other” (Shildrick 46). Visual consumption in society is supplied by disability as “the desire to witness body-based spectacles and a desire to know an object empirically as an after effect of viewing” (Chivers and Markotic 180). Inherent in the visual consumption of disability is a tragedy model of disability, which encompasses many “perceptions of disabled people, which are nearly always negative. These include notions of inferiority, inadequacy, pity, sadness, evil and disgust” (Swain and French 8). The tragedy model “assumes that impairment and disability are about loss (with no possibility of gain) and that disabled people, without exception, want to be other than they are” (Swain and French 9-10). In his text *Abnormal* (1974-75), Foucault claims that “the monstrous is constituted not by the otherness of morphological abnormality as such, but by the offence it offers to the law in transgressing the established customs and regulations that set out what is proper” (Shildrick 13), where circulations of power and difference are equally constructed and regulated. In contrast, a critique of the Foucauldian body would argue that:

> the bodies that appear in Foucault’s world do not enjoy a prolonged visibility as corporeal entities. Bodies are produced but their own powers of production, where they have any, are limited to those invested in them by discourse. As such the body is dissolved as casual phenomenon into the determining power of discourse and it becomes

> extremely difficult to conceive of the body as a material component of social action. (Hughes, *Foucauldian Analysis* 85)

Arguably, “the security of binary differences is constantly undermined by the irreducible *difference* – the refusal of the self/other relation – of the disabled body” (Shildrick 40), and the disabled individual in the texts of this study demonstrate a new continuum and new model for representations of difference.

The tragedy model, as well as stereotypes of disability is challenged in the young adult texts to be analyzed. Further, these texts create new patterns of representations of disability in literature. The way disability is represented textually and the way the representation is projected onto the reader are both central aspects of the experience itself. When we read disability, the “*representation* of disability does not exist separate from disability itself” (Chivers and Markotic 4), and the disability-intertext causes the reader to participate in disability discourse.

In the ground breaking *Extraordinary Bodies,* Rosemarie Garland-Thomson argues that:

> disabled people seldom consider themselves a group. Little somatic commonality exists among people with different kinds of disabilities because needs and situations are so diverse. A blind person, an epileptic, a paraplegic, a deaf person, and an amputee, for example, have no shared cultural heritage, traditional activities, or common physical experience. Only the shared *experience of stigmatization created commonality*. (14-15, my emphasis)

The "shared experience of stigmatization" is represented in the selected texts chosen for this thesis. The shared experience of stigmatization that the characters with disabilities display creates not only a "commonality," but also an interaction with the disability-intertext. While each disability is distinctively unique in the texts, "there are disagreements about what it is that unites disabled people and whether disabled people should have control over the naming of their experience" (Linton 162). Relevant themes of identity and the role of the body in society and art are represented by the very presence of disability, creating a disability-intertext. The disability-intertext is intentionally being used, reproduced, and re-presented by the authors in the young adult fiction. Allan Sutherland argues in "Disability Arts and Collective Identity" that the movement described as "disability arts:"

> has developed over the last three decades, as disabled people have rejected negative assumptions about their lives, defined their own identities, expressed pride in a common disabled identity and worked together to create a work that reflects the individual and collective experience of being disabled. (79)

An example of disability within the arts is demonstrated through societal trends to focus on success stories when a person may overcome their disability, or to "pass" as "normal." These issues include:

> ideas imbedded in the *overcoming* rhetoric [that] are of personal triumph over a personal condition. The idea that someone can

> *overcome* a disability has not been generated within the community; it is a wish fulfillment generated from the outside.” (Linton 165)

Further, “disability pervades literary narrative, first, as a stock feature of characterization and, second, as an opportunistic metaphorical device” (Linton 205), which raises important issues about the complexity of text creations that include characters with disabilities. The politics involved for writers to push at boundaries, by including disability in their works for instance, continues to represent a vast assortment of perspectives and experiences to the discourse of Disability Studies.

Images of Disability in Media

Throughout my research I had to often ask myself, “why do we like seeing disability be ‘overcome’”? Even in the media the belief system is reiterated. For example on November 9, 2010, a man in a wheelchair, Larry Skopnik, wrestled a potential thief to the ground after a Vancouver convenience store clerk was threatened. The action of Skopnik was caught on camera and became a *YouTube*[18] sensation, with over 258, 800 views as of April 18, 2011. Skopnik even told *CTV News*, “Just because I’m in a chair doesn’t mean I can’t stand up and do what’s right” (no page). Disability in the news is often portrayed to be a triumphant story, and not representative of the day-to-day lives of people living with disability. This is not to say that effort to change this firmly entrenched mind set of overcoming

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[18] *YouTube* ©2011 (http://www.youtube.com) is an online community hosting website wherein users develop personal profiles and interact in a multimedia capacity (video, photography, text) with other users via private and/or public message boards.

disability is not occurring, but the literature to be discussed in this thesis challenges any preconceived notions of disability and of overcoming it.

The disabled voice in the young adult texts mentioned in this thesis offers examples of alternative voices in critical discourse. Disability in a text is important to note because the physically and mentally disabled individual inherently lends itself to a representation of many meanings and insights into the complexities of being human. Arguably, as the visibility of the disabled body in texts grows the increased amount of legibility concerning disability is also occurring. The visibility and legibility of disability can also be seen in current media. Television shows like "Glee," or "Family Guy," and reality television series like "Big Brother," "Survivor" and "Dancing with the Stars" have included physically disabled competitors, demonstrating that the visibility of a disabled body in North America is apparent onscreen. Further, on stage, plays deal with disability and characters with disabilities. For instance, the 2010 University of Alberta Lee Playwright-In-Residence, Kevin Kerr, wrote *Spine* which featured ten wheelchairs on stage at one time.[19] *Spine* represents the second play for the *RealWheels* production team which advocates productions that deepen an audience's understanding of the disability experience (*RealWheels*, no page).

With the tale of disability as something for the character with a disability to either overcome and be cured of, or, conversely, die from (firmly established and incorporated in the formal education of children by teachers and librarians in the twentieth century), the discourse of Disability Studies has transformed through

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[19] *Spine* (2010), by Kevin Kerr was created in part through collaboration with the University of Alberta, and the commission of a play for the BFA acting class of 2010. The play centres on the idea of "cure chasing," which is the idea that a cure must be found for a disability at any cost.

acts of inclusion and story-telling in films, music videos, and reality television. Most recently, Lady Gaga's music video "Paparazzi" (2010) places her in a diamond studded wheelchair,[20] and the success of the television series "Glee" included a story line where a young male in a wheelchair begins dating the head cheerleader and eventually loses his virginity to her. A final example that I think best indicates the instances of intentional uses of disability in media was illustrated in an episode of "Modern Family" entitled "Unplugged." Cameron and his same-sex partner Mitchell are desperate to get their adopted Asian daughter, Lily, into a high-end preschool. Told by the interviewer that they are a shoo-in for the pre-school because they are such a diverse family, they are quickly outdone by (as Cameron states), the "disabled inter-racial lesbians" who are also looking to get their child into the preschool ("Unplugged" no page). The comedic image of two gay males being bested by two lesbians, one of whom is in a wheelchair, with an African-American baby, all in the hopes to get a child into pre-school demonstrates new levels of social commentary and a heightened comedic awareness towards images of diversity.

Related to the question "why do we like to see disability overcome," is the issue of "why do we like to stare?" Rosemarie Garland-Thomson, in her work *Staring* (2009) states that:

> we stare when ordinary seeing fails, when we want to know more. So staring is an interrogative gesture that asks what's going on and demands *the story*. The eyes hang on, working to recognize what

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[20] For further research on the glamorization of the disabled body see Helmut Newton's photography. Lady Gaga quoted Newton's work as her inspiration for the video "Paparazzi" in an interview she gave for *Vanity Fair* magazine (August 2010).

> seems illegible, order what seems unruly, know what seems strange. (3, my emphasis)

Any one of us can be a *starer* or be *stared at*, but people with visible disabilities often trigger the sight of someone who is unlike them. Garland-Thomson explains that “staring has a history sedimented over time and across space that is specific to each culture, which in turn shapes its meaning and practice” (*Staring* 13), where staring is an urgent effort to make an unknown known. The sight of an individual with a physical disability, or as Garland-Thomson succinctly puts it, “the sight of an unexpected body – that is to say, a body that does not conform to our expectations for an ordinary body” (*Staring* 37) becomes compelling to the eye. Unusual or unexpected bodies disorder a viewer’s or a reader’s expectations. Further, in regards to aesthetic nervousness, the abnormal body returns the *starer*, or the reader, to an ethical core, since we “suffer self-consciousness about looking or not looking” (Garland-Thomson, *Staring* 37). The bodies that are stared at (in attempt to make sense out of the unexpected) can be imagined through literature and on television. When reading a book that contains a character with a disability, the reader can continuously read the passage of the description over and over, not worrying about the shameful experience of staring. Similarly, in the media of television, film, and the internet, the viewer is able to view disability for as long as he/she wants in order to make sense and make connections. By staring, “traditional ways of reading the body are inherently open to a process of rethinking” (Shildrick 39), so the eyes can be given an opportunity to understand.

As mentioned above, “visibility results in legibility” and the concept of “perfecting” how disability is represented and understood is taking place in Canadian young adult literature. Recognizing the limitations and complexities of representing the new disabled protagonist, the authors, by engaging with a disability-intertext to make disability believable as normality, contradict the unique nature of a disability. Further, the creation of a text is a complicated process and currently the drive of publishing houses is to encourage writers to “push at boundaries and rewrite genres that more clearly represent a multitude of experiences and perspectives” (Luce-Kapler 16). Perfecting the way disability is represented is a problematic and contradictory premise, one that foregrounds my theory of the intentional disability, and the idea of an intentional disability-intertext.

Disability in text: Disability-Intertext

As the tradition of characters with disabilities in literature has been passed down, the customs, beliefs, rituals and stereotypes concerning disability were simultaneously preserved. Although the disability tale, and the intertextual relationship of disability, remained largely unaltered during the Middle Ages, a more effective form of dissemination occurred with the invention of the printing press. Saxby (1997) indicates that “children’s books, as with other forms of literature, mirror the outlook, philosophies and values of the society that produces them” (77). Depictions of disability in classical literary representations are “almost invariably marked by the grossly stereotypical attributes of sin and evil and weakness" (Liachowitz 7), where characters with disabilities were ultimately produced and marketed as "damned and to be pitied" (Kriegel 32). Further, the folktale, for instance, manifested "the disabled body...[as]...almost always a freakish spectacle presented by the mediating narrative voice" (Garland-Thomson, *Freakery* 10), where physical differences were used as metaphors for a character's inner qualities (Dyches and Prater 2005).

Through history, people with disabilities were viewed, treated and regarded very differently from current perceptions. For instance John Locke writes in *An Essay concerning Human Understanding* that:

> perhaps the outward shape is as necessary to be taken into our complex idea, signified by the word man...for it is the shape, as the leading quality, that seems more to determine that species, than a faculty of reasoning, which appears not at first, and in some never. And if this be not allowed to be so**,** *I do not know how they can be excused from murder who kill monstrous births, (as we call them), because of an unordinary shape, without knowing whether they have a rational soul or not*; which can be no more discerned in a well-formed than ill-shaped infant, as soon as born. And who is it has informed us that a rational soul can inhabit no tenement, unless it has just such a sort of frontispiece; or can join itself to, and inform no sort of body, but one that is just of such an outward structure? (428, my emphasis)

While Locke is ultimately concerned about deciphering rational souls, he does make an important point regarding the infanticide of "monstrous births" because of "unordinary shapes," demonstrating that the disability-intertext is at work here. Further by recalling Locke's sentiments, we can "liken history to the structure of language, where signifiers are infinitely reinterpretable, and the signified changes constantly with reiteration, such that there can be no question of recovering a pure origin" (Shildrick 45), or, of what the original disabled body is.

A social "disabling" process appeared during industrialization with the concept of "normal" and the bell curve (Davis, *Constructing Normalcy* 4). This "disabling" process, replaced the concept of the "ideal," which had its roots cemented in the seventeenth century thought. Through industrialization, the goal of the "ideal" was agreed as unattainable, and the word and goal of "normal" was highlighted instead. Inadvertently, the word "normal" emphasized binary concepts of what it means to be "good" or "bad," or the idea that there can only be "normal" if there is "abnormal."[21]

The literary disability tale gradually takes on its own conventions in contemporary Canadian young adult fiction. The powerful intertextual nature for disability to amuse, entertain, fulfill wishes, and preserve cultural heritage still remains seen within the literary disability-intertext. Rather than dismissing traditional literature for its stereotypical renderings of characters with disabilities, it is important to acknowledge the iterations of past discourse in modern literary texts, such as Lousia May Alcotts' *Little Women* (1868-69), Johanna Spyri's *Heidi* (1880), or Frances Hodgson Burnett's *Secret Garden* (1911).

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[21] In *Abnormal* (2003), Michel Foucault claims that the monstrous is constituted not by the otherness of morphological abnormality, but by the offence it offers to the law in transgressing the established customs and regulations that set out what is proper.

Regarding classic folktales, Garland-Thomson (*Freakery* 1997) suggests that “the disabled body is almost always a freakish spectacle presented by the mediating narrative voice” (10), manifesting that physical difference appears as metaphors for a character’s inner qualities. Over time though, the presentation of characters with disabilities has evolved (Dyches and Prater 2005) from this narrow conception. Keith (2001) argues that authors of characters in the nineteenth and twentieth century novels tended to “kill or cure their disabled characters with worrying ease” (5). Further Keith argues that the following ideologies were pervasive:

> (1) There is nothing good about being disabled;
> (2) Disabled people have to learn the same qualities of submissive behaviour that women have always had to learn: patience, cheerfulness, and making the best of things;
> (3) Impairment can be a punishment for bad behaviour, for evil thoughts or for not being a good enough person;
> (4) Although disabled people should be pitied rather than punished, they can never be accepted;
> (5) The impairment is curable. If you want to enough, if you love yourself enough (but not more than you love others), if you believe in God enough, you will be cured. (7)

Similarly, Garland-Thomson argues in *Extraordinary Bodies* that assumptions made by society regarding disability influence the interpretation of characters with disability. Garland-Thomson states that:

> disabled literary characters usually remain on the margins of fiction as uncomplicated figures or exotic aliens whose bodily configurations operate as spectacles, eliciting responses from other characters or producing rhetorical effects that depend on disability's cultural resonance. (*Extraordinary Bodies* 9)

Garland-Thomson further states that "when literary critics looks at disabled characters they often interpret them metaphorically or aesthetically, reading them without political awareness as conventional elements...of traditions" (*Extraordinary Bodies* 9-10). In this thesis a metaphorical reading, such as disability as epiphany, is seen as a previous pattern of the disability-intertext to analyze disabled characters. In order to analyze the disability-intertext characters with disabilities have been read as examples of disability as normality in context of Quayson's theory of aesthetic nervousness.

The journey of the disabled character as a viable protagonist has emerged in the young adult literary scene. The tale of disability is no longer the negative story associated with "cure" or "kill" endings it was once accredited with, when the stories were meant to inspire few and scare many. Rather, the disability-intertext thread's transformation indicates that there are new representations of characters with disabilities occurring in literature. The authors' manipulation of the disability-intertext demonstrates an ability of the authors to adopt and adapt to present society's trends and literary movements. The disability tale and disability-intertext have a strong impact on readers' self-realization and self-discovery towards the characters with disabilities. It will be through the medium of storytelling, that tales of disability will be told and understood further indicating how individuals find continual relevance within the stories of disability.

Chapter 2: The abnormal, the grotesque, the disabled – "Why can't these people just be people"?

Foucault's theory of the background-body

The concept of abnormal individuals is discussed in great length by Michel Foucault in *Abnormal: Lectures at the Collège de France 1974-1975*. Foucault argues that the "body" can be used as a site for literary discussion and seen as a discourse. Further, Foucault's theories regarding the body and the abnormal body provide a basis for understanding of the social conception of disability and previous models of the disability-intertext. The historical trajectory of disabling images over time provides analysis of the way power systems have represented the disabled body and created a disability-intertext. Since Foucault's lectures, the disability-intertext has evolved from the notion of monstrosity to the concept of disability as heroic, and finally, an attempt at portraying disability as normality.

Foucault begins his lectures by delving into "grotesque texts" and proposing that "by virtue of their status, a discourse or an individual can have the effects of power that their intrinsic qualities should disqualify them from having" (11). Further, the grotesque figure is "someone who is effectively discredited" (Foucault 13) by systems in power. Reviewing Foucault reminds us that historically, throughout literature, the grotesque figure like the disabled character is "disqualified" and "discredited."

The foundation for Foucault's argument of the body is situated primarily on the physical attributes and the aesthetic nature of an abnormal individual. On first viewing the abnormal individual, Foucault writes, the "individual resembles his crime" (19) and yet, "the subject is responsible for everything and nothing" (21). In contrast, there is a fear that the abnormal individual will internalize the abnormality. In this context, the disabled individual or the abnormal individual (who inherently resembles his crime due to physical difference and intellect) is at once blamed for being different, yet, still for nothing. The contradiction that an abnormal individual is at once responsible for being different yet responsible for nothing creates a moment of uncertainty and unease in a reader. Encounters with an abnormal individual demonstrate instances where disability-intertext, ethics, and aesthetic nervousness can enter Foucault's text.

For Foucault, when an abnormality appears, stereotypical questions and thoughts arise regarding the so-called abnormal individual. Foucault's questions include: "is the individual dangerous," "can he/she be cured," and "can he/she be reformed." These questions imply the "emergence of the power of normalization" (Foucault 26), and demonstrate past patterns of the disability-intertext. For instance, Foucault theorizes that "madness cannot be crime, just as crime cannot be, in itself, an act rooted in madness" (32). Foucault suggests that the "institutional system is aimed at the dangerous individual, that is to say, at the individual, who is not exactly ill and who is not strictly speaking criminal" (34). What can be inferred from Foucault's lectures is the emergence of a government that is engaged in disseminating fear towards the "other."

Functioning through a government monitored by fear and moralization, Foucault believes that his government's methodology is to detect danger in the "other" and to counter the abnormal individual. For example, Foucault calls on the role and treatment of Lepers during the Biblical Period into the Middle Ages as examples of exclusion and “social practice[s] that included...a distancing, a rule of no contact [...] it involved casting these individuals out into a vague, external world beyond the town’s walls, beyond the limits of the community” (43). These practices of exclusion, or, perhaps, acts of modern day marginalization, can be seen in previous patterns of the disability-intertext. Arguably, the previous practices of “casting out” have been woven into the new emerging patterns of representations of disability. For instance, a contemporary “casting out” can be compared to the act of institutionalizing a person with a disability. The previous disability-intertext that included themes of disqualification, exile, rejection, deprivation, and refusal still exists in the texts studied in this thesis, but it has been tweaked for the contemporary audience, so as to transform the literature of disability.

The literature of disability has originally always appeared in moments of fear and confusion. These moments have hidden themselves in a literary dream, where disability has often been viewed as monstrous. Questions of eradicating the “other” and producing a “healthy population” remained at the forefront of “normalization” in the eighteenth century and later on. Similarly to Lennard Davis’ argument regarding the creation of the bell curve (reviewed in Chapter One of this thesis) and the inception of the “norm,” Foucault states that:

> the norm is not at all defined as a natural law but rather by exacting a coercive role it can perform in the domains in which it is applied. The norm is not simply, and not even a principle of intelligibility, it is an

> element on the basis of which certain exercise of power is founded and legitimized. (50)

Foucault suggests the norm brings principles of qualification, correction, intervention and transformation. In contrast to the norm, the monster (outside of the norm) combines the impossible and the forbidden (Foucault 50). For example, in a first reading of a text, the monster (or what appears to be "monstrous") has a power in "its capacity to create anxiety...due to the fact that it violates the law while leaving it with nothing to say" (Foucault 56). The reader views the abnormal individual as "essentially an everyday monster, a monster that has become commonplace" (57). In contrast to the monster, the disabled individual exists and interacts within a family environment, and would exercise relationships within the community. Verging precisely on undecidability, the individual with a disability surpasses the monstrous and is at once "normalized." Interestingly enough, even if the person with a disability is "normalized," he/she is still instantaneously viewed as an everyday phenomenon and as an "unexpected body" (Garland-Thomson, *Staring* 37) due to acts of staring.

The concept of the monster is one that relies on the "transgression of natural limits, the transgression of classification" (Foucault 63), and "the difference between disability and monstrosity is revealed at the *meeting point* of friction" (Foucault 63, my emphasis). I wonder often about this "meeting point" of friction and suggest that it is really a meeting point for the reader between anxiety and acceptance when disability enters a text. When reading about characters with disabilities it would be interesting to consider in future research if there is a readers' threshold to decipher between an imagined monster and an individual with a physical or intellectual disability? Foucault argues that that "disability may well be something that upsets the natural order, but disability is not monstrosity because it has a place in civil or canon law. The disabled person may not conform to nature, but the law in some ways provides for him" (64) an ethical situation. Foucault does not see the disabled as monstrous because the government provides for a disabled person. This is interesting to note considering previous analysis of scholars indicated that the disabled were historically always linked to monstrosity.[22] Perhaps through increasing government efforts the disabled individual rose out of the realm of the metaphysical and into the realm of "person."

An essential description (concerning the disability-intertext) is illustrated in the relationships of the family when disability becomes a day-to-day factor. Textually, the disability-intertext provides a "perfect collaboration between medicine, justice, family, and the sick person – the patient is consenting, the family is concerned, the court official is vigilant, and the doctor is scientific" (Foucault 144), yet these patterns exist in a perfect, imagined world. Foucault argues that:

> there is not illness intrinsic to instinct. Rather, there is a sort of functional imbalance of the whole, a sort of bad setup in the structures that ensures that the instinct, or a certain number of them, is made to function "normally" in terms of their own regime, but "abnormally" in

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[22] For a full examination of the disabled individual as historically monstrous I would suggest Rosemarie Garland-Thomson's *Freakery: Cultural Spectacles of the Extraordinary Body* (1996).

> the sense that this regime is not controlled by levels whose function is precisely to take charge of the instincts, put them in their place, and delimit their actions. Labels still exist though, and the degenerate may be viewed as an individual who suffers from a condition, who has a condition, is not a normal individual. (312)

Asking "what is a condition," Foucault introduces his theory of the background-body. The background-body is presented by Foucault as the "original" body from which the abnormal body came. Foucault states that:

> a condition is not exactly an illness with a starting point, causes, and processes; indeed it is not an illness at all. The condition is a sort of permanent causal background on the basis of which illness may develop in a number of processes and episodes...the condition is the abnormal basis upon which illnesses become possible. (311-12)

Further, the background-body is intrinsically linked to familial issues. These familial ties are connected and layered by those who represent normality. Bodies, texts, and works devoted to disability are products of the "parents' body, the ancestors' body, the body of the family, the body of heredity" (Foucault 313). It is the background-body, disabled or not, that gives meaning to the stories for families to tell. The background-body is also illustrated in the authors' notes that the writers provide when including characters with disabilities in their works.

The disability-intertext is a type of background-body. The background-body is what authors look to for past representations of disability. Further, the authors both in academic discussion and fictional works rely on the background-body as the discussion of disability will appear in the introductions to their scholarly works, or, in the form of an author's note in the young adult novels. Often, if not always, the authors or the academics will take the time to leave an author's note to discuss their own personal relationship with disability. As is the case in my own thesis introduction I had to step back and ask myself "why did I feel the need to disclose my own background-body?" I could not find any research done in this area and would like to suggest that it be a place for further research in the disability-intertext. Upon reflection, I think it is because when one begins to talk about disability (as mentioned previously in Chapter One), one realizes that disability is very much a personal and yet extremely social process. The process is one in which you inherently begin talking about your own "disabling" experiences, your own background-body, and your personal relation to disability.

Aesthetic Nervousness Examined

One work that is critical in my overall analysis of characters with disabilities in Canadian young adult literature and the disability-intertext is Ato Quayson's *Aesthetic Nervousness: Disability and the Crisis of Representation* (2007). In his study, Ato Quayson explores a literary phenomenon that he coins "aesthetic nervousness" (15). Aesthetic nervousness is seen when "protocols of representation within literary text are short circuited in relation to disability" (15), where "aesthetic nervousness overlaps social attitudes to disability that themselves often remain unexamined in their prejudices and biases" (15). Quayson's theory of aesthetic nervousness is useful for identifying the landscape on which books about characters with disability reside. Disability, both physical and mental, seems to elicit language and narrative. Quayson argues that disability as it appears in texts often “cancels out other qualities, reducing the complex person to a single attribute” (16), their disability. My inquiry into the intentional use of disability by the Canadian authors uses Ato Quayson’s theory of aesthetic nervousness to analyze the ways in which disability as normality is being presented in the young adult literature.

Quayson argues that when an author actively chooses to include a disabled character in his/her text, the disability in the text will trigger aesthetic nervousness. This trigger is started “by the implicit disruption of the frames within which the disabled are located as subject of symbolic notions of wholeness and normativity” (19). Disability in a text returns not only “the aesthetic domain to an active ethical core that serves to disrupt the surface of representation” (19), but is also caught up in the theory that “literary representations of disability somewhat subtends real-life treatment of disabled people in a variety of ways” (Quayson 30). Just as “literature does not merely reflect any already socially interpreted reality, but adds another tier of interpretation that is comprehensible within the terms set by the literary aesthetic domain” (Quayson 14), the author’s intent (illustrated through an author’s note) provides another tier of analysis that the disability-intertext operates in. The author’s intent in a work does not reflect the overall intent of the text, but instead is an addition to the interpretation of the work.

The role that an author should be given in a critical analysis of a text is problematized by Quayson as he states that the “final dimension of aesthetic nervousness is that between the reader and the text" (15). The inclusion of disability in a text can be read in nine different methods that Quayson proposes in his provisional typology of disability representations. The reading methods include but are not limited to:

> (1) Disability as null set and/or moral test
> (2) Disability as the interface with otherness (race, class, 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. (52)

Combinations of any of these categories in a text that contains characters with disabilities will produce many different interpretations. These groupings of representation function as dominant paradigms for readings and interpretations of intentional uses of disability in literature. Further, what Quayson argues to be aesthetic nervousness,

> may also be misread as a codification of a particular form of aesthetic ordering, rather than the collapse and discomposition of the putative textual order around the figure of disability as such. It is only an

> attentive close reading that would allow us to identify the precise nature of aesthetic nervousness that is focalized through and around the disabled character. (35)

This suggests that close readings of the text will allow for analysis in the way aesthetic nervousness is functioning. In the case of the young adult texts in this study, the disability intertext is primarily conveyed as disability as normality. Quayson also states that:

> the literary-aesthetic domain does indeed remind us of reality, but in such a way as to interrupt our memory or recognition of it in order to place different emphases on what might be taken for granted. Because disability in the real world already incites interpretation, literary representations of disability are not merely reflecting disability; they are refractions of that reality, with varying emphases of both an aesthetic and ethical kind. (36)

It is these reading methods put forth by Quayson that will be explored in the texts to be analyzed as I argue that the intentional disability is occurring. The refractions and reflections demonstrate that aesthetic nervousness is focalized through and around the disabled character (Quayson 35). The thread of the disability-intertext for disability as normality is only realized through close reading. Through a close reading of disability in Canadian young adult literature it is revealed “that the place assigned to characters with disability is not necessarily singular” (Quayson 34), and the characters can carry contradictory meanings. Often the physical impairment will be correlated to cognitive or mental condition, even if the text is building up to a second or third dimension of the disability. It is only "literature more than anything else that helps refracts these multivalent attitudes toward disability" (Quayson 36), especially through the disability-intertext. Within the disability-intertext is it important to identify if the attitudes towards a disability are being refracted or reflected? When pondering refraction and reflection, Quayson writes that "the literary aesthetic domain does indeed remind us of reality, but in such a way as to interrupt our memory or recognition of it in order to place different emphases on what might be taken for granted" (36), and that "because disability in the real world already incites interpretation, literary representations of disability are not merely reflecting disability; they are refractions of that reality, with varying emphases of both an aesthetic and ethical kind" (Quayson 36). What I have found in this thesis by applying aesthetic nervousness to analyze the texts, is that disability must be accounted for as part of the totality of textual representation. This especially occurs when reading the texts as examples of disability as normality.

Quayson's ninth category in his provisional methods (the final category) is disability as normality. Disability as normality is defined by Quayson as "one in which the disabled characters are completely normalized and exist within the full range of human emotions, contradictions, hopes, fears, and vague ideas, just like any other characters" (51), and provides the most compelling argument for the disability-intertext in the young adult texts. What has occurred in the Canadian young adult texts is disability as normality, seen through the new patterns of disability in the character's self-image, use of humour, the temporality of the novels, and also the inclusion of author’s notes. It is interesting to note that the texts would be unable to function if the disability was separated and removed from the text, suggesting that work still needs to be done by the authors in order to fully demonstrate that the disability of the characters should not be contingent on all the action in the text. Quayson is also quick to point out (like many other scholars in Disability Studies), that “the life writing of disabled people themselves has ensured an increasing number of such accounts, but such complex accountings are not solely from the pens of persons with disabilities” (51). What I have found in my study indicates that authors who have disabilities will indicate their relationship to disability in an author’s notes section. It is important to bear in mind that there are also additional categories to place authors who have included disability in their writings. These categories to be considered are writers with disabilities and writers who have siblings with disabilities (or have experienced instances of disability in their own unique way and are writing to make sense of the experience). Further, the young adult texts that include disability are being written with a full sense of the complexity of responses that attend disability. The disabilities in the texts are not presented as stereotypical or as conditions that can be easily assimilated to an essentialzed category.

The characters with disabilities (represented in the literary writings in contemporary Canadian fiction) demonstrate a changing pattern in the way a disabled individual is represented in the arts. The transformation of disability has been noted by many Disability Studies scholars, including the fact that disability stereotypes have altered. For instance, disability has ceased being a representation of the metaphysical realm or a signal of danger to the purity of a nation. In contradiction to this positive premise, Quayson argues that "certain present-day responses to disability even among people presumably sharing an enlightened mode of thinking still hark back to unexamined sentiments of a bygone era" (Quayson 13). Unlike Quayson, I argue that the unacknowledged social attitude towards persons with disabilities is changing, and inclusion efforts are taking place, specifically in Canadian young adult literature. These efforts can be traced through the many levels of reading disability in text. For instance, there can be the disabled and non disabled character interaction. Further, the categories for analysis include disability as normality, self-image, social context, temporality, textual landscape, genre, humour, abuse, and the inclusion of author's notes of the novels. This interaction can be seen through an interplay with other levels of the text, including symbols, motifs, narrative perspective, and plot structure. Secondly, a dimension of reading disability in text is that between the reader and the text. Quayson states that:

> the reader's status within a given text is a function of the several interacting elements such as the identification with the vicissitudes of the life of a particular character, or the alignment between the reader and the shifting positions of the narrator, or the necessary reformulations of the reader's perspective enjoined by the modulations of various plot elements and so on. (15)

The reader can be both a non-disabled reader and a disabled reader. Further, first-time encounters between the non-disabled and people with disabilities are examples of aesthetic nervousness. This first-time encounter can usually be seen through the ways in which impairments are interpreted. Thoughts on interpretation are effectively argued by Rosemarie Garland-Thomson (*Extraordinary Bodies* 1997), who builds upon Erving Goffman's (1959) insights about stigma. Garland-Thomson argues that:

> in a first encounter with another person, a tremendous amount of information must be organized and interpreted simultaneously: each participant probes the explicit for the implicit, determines what is significant for particular purposes, and prepares a response that is guided by many cues, both subtle and obvious. When one person has a visible disability, however, it almost always dominates and skews the normate's process of sorting out perceptions and forming a reaction. The interaction is usually strained because the nondisabled person may feel fear, pity fascination, repulsion, or merely surprise, none of which is expressible according to social protocol. Besides the discomforting dissonance between experienced and expressed reaction, a nondisabled person often does not know how to act toward a disabled person: how or whether to offer assistance; whether to acknowledge the disability; what words, gestures, or expectations to use or avoid. Perhaps most destructive to the potential for continuing relations is the normate's frequent assumption that a disability cancels out other qualities, reducing the complex person to a single attribute. (Garland-Thomson, *Extraordinary Bodies* 12)

Reducing the complex person to a single attribute, their disability, is the easy way to categorize an individual. In fact, “moral panic has been normalized and unquestioned through numerous repetitions historically through social encounters between disabled and nondisabled people” (Quayson 32-33). What is important to bear in mind is that “every/body is subject to change and contingent events” (Quayson 17). Further, through positive repetitions of social encounters between disabled and non-disabled people, seen specifically in Canadian young adult literature, inclusion will be normalized and unquestioned.

An overview of Quayson’s theory of disability as normality in terms of aesthetic nervousness provides grounds for my argument of the disability-intertext. Aesthetic nervousness, as defined before, is conveyed in a text when the “dominant protocols of representation within the literary text are short-circuited in relation to disability” (Quayson 14). Quayson argues that when disability enters a text it triggers a “disruption of the frames within which the disabled are located as subjects of symbolic notions of wholeness and normativity” (19). When the disruption occurs, “disability returns the aesthetic domain to an active ethical core that serves to disrupt the surface of representation” (Quayson 19), and this “active ethical core becomes manifest because the disability representation is seen as having a direct effect on social views of people with disability in a way that representations of other literary details, tropes, and motifs do not offer” (Quayson 19). To put it simply, the representation of disability in text, and the presence of disability in text, ultimately transcends any literary domain, and cannot be assimilated into one. Disability in text is able to transcend the literary domain because the disabled are represented as always having an ethical dimension. The ethical dimension that the disability in the text produces is able to bridge a space between representation and ethics. This bridge allows insight into what disability in the real world reveals. Through close readings the parameters of aesthetic nervousness and disability-intertext demonstrate a new wave of representations of disability in text. Ultimately, Quayson argues that his theory of aesthetic nervousness should be used so that disability can be "read as a fulcrum or pivot out of which various discursive details emerge, gain salience, and ultimately undergo transformation with the literary-aesthetic field" (Quayson 34). The transformation of disability in the literary-aesthetic field can be attempted and revealed through practices of close reading, and new patterns will continue to emerge.

Writing about Disability: The Intentional Disability

The background-body in relation to the inclusion of an author's note for young adult works that contain characters with disability suggests that writing about disability is a complex process. The authors of the texts discussed in Chapter Three, as well as many scholars of Disability Studies, often include in their texts author's notes. These notes provide insight into why the authors included disability in their works and/or chose to write about disability. Upon first noticing this trend I wondered why authors feel the need to demonstrate that they have a "right" to write about disability. As my project gained momentum, I felt like an outsider to the issues explored in Disability Studies since I do not have a disability and often I considered what my background-body might be to this thesis. Reflecting on my own experiences with disabilities with family, friends and classmates I realized that it was "okay" for me to want to write on the subject of disability and analyze characters with disabilities in texts. Through my analysis I realized the important role families play in the portrayals and representations of disability occurring in Canadian young adult literature today. The importance of an author's relation with disability became apparent when I found articles written by authors discussing their experiences of writing about disability.

In the March 2011 instalment of *Quill and Quire* Annabel Lyon (author of *The Golden Mean*, 2009) notes in her article "My Brother's Keeper: Creating characters with Down's syndrome forced Annabel Lyon to reckon with some very personal joys and pains" that she had "been struggling since [her] teens to create a mentally handicapped character who honoured [her] brother without being didactic, who was realistic but not patronizing" (42). Lyon's brother, Mark, "had a snarl in his genetic code" (42), one that made her "ashamed: because it was him and not [her], because he would never get better, because [she] pitied him and was afraid for him, of what the world would do to someone like him if people like me didn't take care of him" (42). Lyon poses the question that she struggled with in her youth "wonder[ing], can't the world of literature have a mentally handicapped character who is neither a joke nor a horror, neither a metaphor nor a tragedy? *Why can't these people just be people?*" (42, my emphasis). Lyon's personal struggle about creating characters with disabilities is representative of what the other writers in this study demonstrate in their author's notes. Lyon concludes that "fiction gives [her] the opportunity," "the opportunity to sing that love" (42) she feels towards her brother. Lyon states that:

> growing up, I can't remember ever reading a book that featured a character with Down's, let alone a character dealing with the conflicting emotions of having a sibling with the condition: the love, the guilt, the confusion about how to be cool with such a person in your life, and what 'cool' really meant." (42)

Lyon's internal battle while growing up is echoed in the struggles identified in the authors' notes section of this thesis. What is occurring in the young adult fiction is that while the authors are creating new, respectful patterns of representing disability they are indirectly "perfecting" the way in which disability is represented. As a result, new positive patterns have emerged to represent the disability-intertext.

There has been a move away from the conventionality of the disabled character being a metaphor (or signifier to the spiritual world), where instead, disability is attempted to be portrayed as normality. A point of contention in Disability Studies is the premise for disability as normality to occur effectively and persuasively in a text. Representations of disability and the portrayal of disability as normality in literature allow readers to ask themselves how they react to difference. First, if there is a "believable" disabled protagonist there can be two reactions from a reader. Non-disabled readers would gain insight into disability and an opportunity to explore their own belief and feelings towards the "other." Disabled readers may gather a new perspective on what life is like for others living with a disability. Reflections on Lyon's question "why can't these people just be people" are valuable to consider when discussing writing about disability and the inclusion of an author's note into a work. Perhaps, as more of the stories of disability begin to appear in mainstream media, literature and the arts, "these people" will be seen as just "people," and writers will not feel the need to include their background-body or their author's note.

The idea of the intentional disability occurred after research on William K. Wimsatt Jr. and Monroe C. Beardsley's theory of the "intentional fallacy." Wimsatt and Beardsley contend that trying to gleam truths about texts from an author is a fallacy and that the meaning or value of a work cannot be judged or defined in terms of the writers' intention.[23] That being said, I found that disability, as it occurs in literature, upsets the intentional fallacy. The intentional fallacy is upset by the intentional disability when the author him/herself is disabled or leaves an author's note, as is the case in many of the young adult Canadian children's texts. It is also plausible that the authors that are including disabled characters intentionally within their works are perhaps doing so to meet the demands of inclusion that Canadian people and government are asking for. It is important for these stories that feature disability so predominantly to be written and published, but the authors should be aware that they might get caught up in a program of "perfecting" the way disability is being represented in order to demonstrate disability as normality.

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[23] Wimsatt and Beardsley are New Critics and are adhering to the goals set out by New Criticism. New Criticism sets out to "establish rigorous and objective methods of formal interpretation, paying particular attention to structural coherence achieved through the use of irony, paradox, and ambiguity" (*OED*).

What I found in my analysis of the young adult novels was that each novel that was representative of disability as normality came in contact thematically with other types of signifiers in Quayson's provisional model. So while disability as normality may remain at the forefront of the young adult texts, it is sometimes subtended to a relationship with previous models specifically disability as a signifier for epiphany. Perhaps this is why the attempt at describing the full complexity of living with a disability often comes back to another age-old-question: "why does society enjoy seeing a disability overcome?" This question is representative of the intertextual relationship of disability. The young adult texts are indicative of a new model that transitions from disability being "overcome" to someone with a disability succeeding in life. The authors of these young adult Canadian novels are attempting to present disability as normality, and indirectly "perfecting" how disability is being represented.

While the disability-intertext is evolving, the nervousness that an author may feel (one who has a Down's brother for instance, like Annabel Lyon), still exists. The hesitation involved in writing about disability is difficult because there is no "perfect" way of representing disability. There is no all encompassing effective figure of disability to turn to as a writer looking for inspiration. There could not be a "perfect" figure of disability, as disability is inherently not "perfect." A writer (as Lyon suggested previously in her article on her brother), through the power of fiction and autobiography, is allowed to write about disability and not feel like she is doing a family member or a friend an injustice by telling a story. For instance, Lyon's faith in writing is indicative of the power of language and the importance for the stories of disability to be told.

In context of Lyon's belief in the power of the written word in representing and talking about disability, Quayson states that:

> from at least the 1980's, the main interest of scholars in this field [Disability Studies] has been to shift the discussion of disability away from the medical discourse that had dominated such discussion previously and to see disability as woven out of a range of problems connected to the architectural environment, the public-transport system, and most important, to the often ill-concealed social attitudes that attend people with disabilities. (2)

In this regard, the term disability is no longer taken as referencing the notion of a reduced ability deriving from an impairment, but speaks to the built and social environments that generate difficulties for the disabled person's capacity to live a full and fulfilled life (Corker and Shakespeare 2002). Once viewed from this angle, disability can no longer be seen as the product of tragic circumstances and thus be understood simply as the presumed sad fate of the individual (Oliver 1990). The shift away from the medical model and medical discourse (that for so long dominated previous discussion of disability) is occurring especially in the examples of young adult fiction. The main focus in Disability Studies literature has been on the social attitudes that appear when discussing people with disabilities. People with disabilities, as Nancy Mairs (1996) suggests should be allowed to live life. Not better or as worse as someone else's, but a life nonetheless, one that should be recognized as having the capacity to be lived to fulfillment (Mairs 1996). The medical model pushes for the strenuous effort toward improvement and creates a dichotomy of wanting to get well, versus the obligation to get well. In contrast to the medical model Disability Studies can move past the idea of disability being a product of tragic circumstance, and can be more than a presumed sad fate of an individual.

Case study: Heidi Janz's *Sparrows on Wheels*: Intentional Fallacy upset by the Intentional Disability

Similar to what the intentional fallacy advocates, critics must read and analyze text as the primary source. However, when disability enters the text, the theory of the intentional fallacy is disrupted, especially when the author is disabled. It becomes difficult for a critic to separate, for example, the author's intent as a disabled female academic from the disability in the text itself, as is the case in Heidi Janz' historical young adult novel *Sparrows on Wheels* (2004). Janz's novel follows a young girl with severe cerebral palsy, Tallia, growing up during an educational integration period in Alberta. Interestingly enough, Janz offers an author's note as to why she wrote what she wrote in *Sparrows on Wheels* for the sole purpose to state that the disability in her text is intentional and meant to be read semi-autobiographically and historically.

In *Sparrows on Wheels* the central character, Tallia, has cerebral palsy, and is determined to go to university and to become a writer. Inspiring her to write, are her late friends who have died due to complications with their muscular dystrophy. Tallia must cope with the loss of her friends, as well as her own opposition towards the increasing push for the integration of able-bodied and disabled students in school. By applying Ato Quayson's theory of reading disabled characters as initiators of aesthetic nervousness, *Sparrows on Wheels* can be read as "disability as normality" (Quayson 52), one of Quayson's provisional typologies of disability representations.

Disability as normality occurs in texts when "disabled characters are completely normalized and exist within the full range of human emotions, contradictions, hopes, fears and vague ideas, just like any other character" (Quayson 52). Interestingly enough, Quayson suggests that "if a writer does not declare him or herself to carry an impairment, it becomes almost impossible to detect signs of their disability from their writing" (52), and Janz declares her own impairment in the author's note. With aesthetic nervousness in mind, if disability is read as normality in Janz's text, "the key distinction to be drawn would have to be that between texts of a biographical or autobiographical kind and those that are plainly fictions" (Quayson 52). If the author is writing from a biographical or autobiographical framework, the author's intent can then be gleaned from the work. *Sparrows on Wheels* is a concrete example of disability as normality since Heidi Janz has cerebral palsy like her main character Tallia. For Quayson, an example like *Sparrows on Wheels* demonstrates that "the book...becomes a simultaneous documentary of [her] own subjective attitudes to [her] disability and the responses of the world around [her]" (Quayson 52).

In *The Intentional Fallacy*, Wimsatt and Beardsley define authorial "intention" as the "design or plan in the author's mind" (1375), and assert that the work upon completion is solely "about the human being, an object of public knowledge" (1376). The author's intention should not be used as a criterion to critique if a work is artistically successful or not. Instead, as critics, "we ought to impute the thoughts and attitudes of the poem immediately to the dramatic speaker, and if to the author at all, only by a biographical act of inference" (1376). Further, Wimsatt and Beardsley write:

> there is an intermediate kind of evidence about the character of the author or about private or semi-private meanings attached to words or topics by an author or by a coterie of which he is a member. The meaning of words is the history of words, and the biography of an author, his use of a word, and the associations which the word had for him, are part of the word's history and meaning. (1381)

The "biographical act of inference" is something that I will pay particular attention to when discussing *Sparrows on Wheels* due to Janz's author's note.

Within literary criticism the intentional fallacy places the author in an unavailable category and only the text can be analyzed. *Sparrows on Wheels* is a text that historicizes disability from a disabled character's point of view. While Wimsatt and Beardsley contend that "the text itself remains to be dealt with, the analyzable vehicle of a complicated metaphor" (1383), Janz's novel creates tension within the theory of the intentional fallacy through the inclusion of the author's note. Presupposing that the reader will misread her work, Janz begins her novel with a note that states the context that *Sparrows on Wheels* should be read in. If Janz is mis-read herself on a daily basis because of her own disability, it would seem probable that she would feel the need to protect and explain her own interpretation. In light of the intentional fallacy, though, the author's aim should not be relied on when analyzing a text. Janz writes in her note:

> Originally written as a Master's thesis, Sparrows on Wheels is, in a sense, a historical novel, in addition to being semi-autobiographical. It's a story that offers readers, those who have disabilities and those who don't, glimpses of what life was like for those of us who grew up in the pre-integration era and hence were educated primarily in so-called special school. (no page)

With the inclusion of Janz's author's note, can *Sparrows on Wheels* be measured against something outside the author? It would seem that Janz, who is disabled, cannot be separated from her work. Janz has asked to be separated from the work, but at the same time she has requested that the reader not read in a certain way, and thus has demonstrated her authorial intent. However, one should ask if there is a threat of mis-reading a text because of the disability in the author, or is there something inextricably disabled contained within the text itself that problematizes the intentional fallacy? Is the intentional fallacy subverted by the use of intentional disability within the text, such as *Sparrows on Wheels*? Ultimately, the success and message of a work cannot simply depend on the intention of the author. As a reader, if one acknowledges an author's intention, s/he has one way of accessing meaning of a text. Relying solely on the author's intention is not the precise way to access the text, but it is necessary to take intention into account as one of the many layers of meaning, especially when considering the use and patterns of disability-intertext at work.

Consulting the author provides insight into the autobiographical realm of *Sparrows on Wheels*. After Janz's novel came out she wrote an article analyzing and defending her work. In "Crip-Academic, Disabled-Writer, Sparrow on Wheels and other Split-Identities: Reflections on the Oxymoronic Aspects of Writing and Auto/Biographical Novel about Disability" Janz states:

> I wanted to give readers a sense of the actual day-to-day realities experienced by those of us crips who grew up in the pre-integration era, and who, consequently, had most, if not all, of our primary and secondary education in so-called "special" schools for students with disabilities. I soon realized that, in order to do this effectively, I would have to draw heavily on my own experiences and memories of that time, and that would mean running the risk that what I intended to be a fictionalized work of disability history would be read as straight out autobiography. The academic in me recoiled at the prospect of opening up my personal history to such mis-reading; I feared that, at worst, if I went through with this project, my Master's Thesis could end up being viewed as little more than an exercise in creative narcissism. Nevertheless, I had a strong conviction that this book project had the potential to be a significant contribution to the preservation of disability history and, by extension, disability culture.

> In my view, these potential educational and cultural benefits for the disability community far outweighed any potential risk of mis-readings and/or damage to my credibility as a "serious" academic or creative writer. Consequently, I decided to move forward with writing the novel as my Master's Thesis. (Para 2)

The intentional fallacy, when applied to Disability Studies and history, provides for some interesting analysis. Janz's article demonstrates the concern she had that *Sparrows on Wheels* ultimately would be misread as biography. Janz believed that her "preservation of disability history" was more meaningful than "any potential misreading." Interestingly enough, she then wrote an article on what *Sparrows on Wheels* is about. The author's interpretation of disability is closely linked to intent of her project, demonstrating that the intentional fallacy is upset by the intentional inclusion of disability.

The re-imagining and creation of new patterns of disability representations in relation to the disability-intertext is a complex process for the author. The demands of texts that contain characters with disabilities prompt a critic to analyze how the authors of the texts are demonstrating new and expressive means to represent previous models of a disability-intertext. Further, the attitudes of a changing disability-intertext that the Canadian young adult fiction writers are engaging in will be explored in the next chapter. The intentional inclusion of primary characters with disabilities in young adult texts continues to suggest that efforts have been taken by the authors to present disability as normality.

Chapter 3: Representation of disability in six contemporary Canadian young adult texts

New Patterns and Emerging Trends

The exploration into Canadian young adult fiction brought me to a variety of texts that included characters with disabilities.[24] Since Beverley Brenna's research in *Characters with Disabilities in Contemporary Children's Novels: Portraits of Three Authors in a Frame of Canadian Texts* (Spring 2010) new titles have emerged to be analyzed in this thesis. Brenna's dissertation is a qualitative study exploring influences on three Canadian authors: Rachna Gilmore, Pamela Porter, and herself, who present characters with disabilities in children's fiction. Her methodology included portraiture, interviews with the authors, and Bakhtin's conceptualization of the literary chronotype. More specifically, her work was done in order to offer perspectives that impact critical literacy in the classroom. Differing from Brenna, my research is an exploratory textual analysis comparing six young adult Canadian novels and their disabled protagonists. Further, I suggest that the authors are engaging with patterns of a new disability-intertext thread and are creating characters with disabilities as examples of disability as normality. I was also able to find French Canadian young adult literature, which Brenna did not include in her dissertation. More specifically, in my study of the disability-intertext the texts I have chosen to analyze are: the Canadian English texts, *Wild Orchid* (2005) by Beverley Brenna, *Waiting for Sarah* (2003) by

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[24] For an extensive list of Junior Fiction (ages eight and up), Intermediate Fiction (ages eleven and up) and Young Adult Fiction (ages fourteen and up), and a detailed annotated bibliography of Contemporary Children's Novels (1995-2009), I would suggest Beverley Brenna's doctoral thesis, *Characters with Disabilities in Contemporary Children's Novels: Portraits of Three Authors in a Frame of Canadian Texts* which can be found on her website, www.beverelybrenna.com.

Bruce McBay and James Heneghan, *Free as a bird* (2010) by Gina McMurchy-Barber, *The Space Between* (2007) by Don Aker, and the French Canadian texts, *Té malade toi!* (2004) by Line Gamache (translated by KerryAnn Cochrane as *Hello, me Pretty!* (2007)), and *La liberté? Connais pas...* (1998) by Charlotte Gingras (translated by Susan Ouriou as *Pieces of Me* (2009)). Within these texts I was able to analyze the characters with disabilities in relationship to Quayson's theory of aesthetic nervousness as primary examples of disability as normality. Also, it was found that some of the characters within the young adult novels were seen as engaging within previous models of a disability-intertext thread such as disability as epiphany. My analysis follows a similar model and method used by Brenna in her doctoral research, specifically in the categorization of the young adult novels in terms of time, social context and place. These categories were particularly helpful in establishing points of comparison between and among the Canadian young adult fictions, indicating disability-intertext at work.

Currently in Canada, the publishing houses like "Harper Collins," "Orca Reader," "Dundurn Press" and "Tundra Books" are some of the "big names" taking an "intentional" look at including, backing, and producing children and young adult fiction that features protagonist children who are disabled intellectually and/or physically. The publishing companies all share mottos that advocate diversity, innovation, and the idea of defining Canadian identity.[25] More importantly though, for the purposes and goals of this thesis, I have considered the question "what do the books have in common" in order to provide an exploratory study. What I found was that the intentional disability-intertext thread can be

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[25] See specific internet publishing home pages about their specific goals and target audiences

compared throughout the texts by looking at categories that include but are not limited to temporality, social context, textual landscape, genre, abuse, humour and the addition of author's notes. It is through these categories that a new disability-intertext is functioning and can be analyzed.

Taylor, Mike, Ruby Jean, Lucas and Jace, Mirabelle and Paule, and Josée: An introduction to characters with disabilities in Canadian young adult literature

A comparison of the Canadian English texts, *Wild Orchid* (2005) by Beverley Brenna, *Waiting for Sarah* (2003) by Bruce McBay and James Heneghan, *Free as a bird* (2010) by Gina McMurchy-Barber, *The Space Between* (2007) by Don Aker, and the French texts, *Té malade toi!* (2004) by Line Gamache (translated by KerryAnn Cochrane as *Hello, me Pretty!* (2007)), and *La liberté? Connais pas*... (1998) by Charlotte Gingras (translated by Susan Ouriou as *Pieces of Me* (2009)), offers six distinctly different renditions of characters with disabilities. Further, the disability-intertext that the characters are engaged in includes (but is not limited to), the transition for the characters with disabilities to move towards some sort of independence, and self-actualization. Such an examination of the concept of aesthetic nervousness also offers an in-depth look at the characters' unique paths and patterns of the disability-intertext as disability as normality.

Taylor

I have calmed myself down from our recent discussion. I counted to a hundred, seven times, and found that to be very soothing. I know that when I'm angry, my

IQ goes down sixty points, and I try not to let this happen. It is frightening to be stupid when I am not accustomed to it. (Brenna 7)

Taylor Jane Simon is an eighteen-year-old autistic girl and protagonist to Beverley Brenna's *Wild Orchid*. Taylor has Asperger's Syndrome, and although eighteen, cannot stay home on her own, so she spends the summer with her mother in Prince Albert, Saskatchewan, National Park. Taylor is on the search for a boyfriend, friends, and independence from her mother. Writing in her journal helps Taylor deal with new experiences and eventually Taylor is able to find her courage and independence by the conclusion of the book.

Mike

he missed his strong legs and it was like he was hollowed out and empty because so much of his life had been stolen from him. (Mcbay and Heneghan 75)

In Bruce McBay and James Heneghan's *Waiting for Sarah*, Mike Scott is the lone survivor after a horrific car accident takes the life of his parents and younger sister as they drove home from an Abbottsford Air Show. Mike's legs, crushed in the crash, are amputated before he wakes up. Depressed, angry and distant to his new caregiver (an estranged aunt), Mike must learn how to navigate himself back into his final year of high school. Mike's disability for most of the story isolates him from everyone, but soon he meets Sarah while working on a special project; a commemorative edition of the school's yearbook to be published in celebration of Carleton High School's fiftieth anniversary. Sarah becomes Mike's friend and helps him emotionally recover from the accident. As the novel progresses, Mike begins to realize that no one else in the school seems to know

Sarah. He never sees Sarah anywhere else in the school, and eventually Mike finds out there is a link between Sarah's history and Carleton's High School's as well.

Ruby Jean

My name's Ruby Jean Sharp an I growed up in Woodlands School. That wasn't a nice place for a liddle kid – nope, not a nice place a'tall. (McMuchy-Barber 9)

Free as a bird by Gina McMurchy-Barber follows the moving story of Ruby Jean Sharp as she recounts her life from the time she spent at Woodlands School for developmentally disabled people, and the life she started after she left. Ruby Jean has Down's syndrome, and her story takes place against the backdrop of the historical Provincial Lunatic Asylum that opened in 1878 in New Westminster, British Columbia and closed in 1996. After her beloved grandmother passes away and she is abandoned by her mother, Ruby Jean is faced with physical and sexual abuse by her appointed caregivers in the institution. Eventually finding herself on the streets in the east side of Vancouver, Ruby Jean is able to survive against isolation, boredom and abuse, and makes her way home to a new family that accepts her for who she is.

Jace and Lucas

next to the window, sits Lucas, his eyes focused on some point in front of his face. To see him like that, you'd think he was mesmerized by the movie that's playing on the monitor in front of him, but I know he isn't seeing it, isn't hearing the dialogue on the earbuds plugged into his seat. He's gone again, disappeared *inside his nine-year-old head, listening to sounds or non-sounds only he can hear. (Aker 3)*

Jace and Lucas are two brothers in Don Aker's *The Space Between*. Jace and Lucas are travelling with their mother and aunt from Nova Scotia to Mexico for a vacation. In reality, the family is travelling to get away from a horrible sadness. The oldest brother Stefan had committed suicide after coming out as a homosexual and the family is left with a great loss of a beloved son and brother. Jace, almost eighteen, is preoccupied with losing his virginity, and his mission is sidetracked by his care of nine-year-old Lucas, who is autistic. Further issues explored include suicide, homosexuality, and family dynamics in the context of the communal raising of a sibling with a disability. These all become spaces for Jace to navigate, while remaining true to himself and to his younger brother.

Mirabelle and Paule

On ne peut quand même pas refuser son aide à une aveugle. Je lui prends le bras et nous traversons lentement le boulevard. J'ai peur qu'elle trebuchet. Je décide de lui donner des explications supplémentaires. Ça peut toujours server si jamais elle revient. (Gingras 28)[26]

Mirabelle, a talented fifteen-year-old artist with no friends and a mentally unstable mother, finds herself losing her own mental battle in Charlotte Gingras' *La liberté? Connais pas...* or *Pieces of Me*. Mirabelle eventually meets Catherine, the new girl to the school who becomes Mirabelle's first friend and introduces her to colour and happiness. Eventually a depression resulting from her mother's own

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[26] "It's not like you can refuse to help a blind woman when you've been asked. I take her arm and we cross the boulevard slowly. I'm afraid she'll stumble. I decide to give her some explanations. They might help if she ever has to come back this way" (Ouriou 26).

mental health and the death of her estranged father overcomes Mirabelle's life. Mirabelle is sent to meet with Paule, the school counsellor who is blind. These two individuals form a new relationship, one which helps Mirabelle realize that her life is falling into pieces, pieces that she must put back together.

Josée

Elle était differente dans un monde où la differénce faisait peur! Parce que les gens ne la comprennent pas de la comprendre. (Gamache 18)[27]

The graphic novel *Té malade toi!* translated as *Hello, me Pretty!* follows author Line Gamache's firsthand account of growing up with an intellectually disabled younger sister outside of Montreal in rural Quebec during Expo'67 and the FLQ crisis as the historical backdrop. Josée is the inspiration for this tale, and Josée is portrayed as someone whose family loves her unconditionally. Josée emerges at the end of the graphic novel as a vibrant twenty-seven year old woman with an exceptional personality. Raising a child with an intellectual disability may resonate and leaves a distinct impression on the reader as Gamache's story could be anyone's story, anyone's family. People's intolerance and lack of understanding towards Josée allow readers to come away from the novel with the unforced message of tolerance and the value of difference.

The Disability-Intertext in the Sample Texts

Disability as normality. With the methodology of aesthetic nervousness in mind, I then examined the narratives of each text with respect to each individual

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[27] Josée is different, in a world where differences frighten people. Because people don't understand her and don't even try to (Cochrane 18).

character. According to Quayson’s categories of aesthetic nervousness, I found that disability as normality remained at the forefront of all of the texts analyzed with specific texts also engaging with disability as epiphany. Many of the characters’ journeys are circuitous in the manner in which they move forward, and then backward. The characters at times struggle with feelings of self-loathing because of their circumstance, yet the authors manage to prompt in the readers a look at the richness to be explored within the context of disability. I focused on whether or not the character was presented from a first-person or third-person point of view as well as took into consideration the range of the age group of the intended audience of each book. What I found was that the age range of each book is for young adults’ ages fourteen and up. *The Space Between*, and *Waiting for Sarah* represent third-person point of views, and *Free as a bird*, *Wild Orchid*, *Té malade toi!* and *La liberté? Connais pas...* represent first-person point of views. When the characters were presented in their own first-person narrative, he/she appeared as a character very much in control of his/her own destiny, making decisions that allowed for him/her to change and grow. Each text was examined in relation to see if the characters being represented with disabilities were conveyed in their own voice, through the voice of another character, or through the voice of a narrator. Through close reading I was able to delve into the disability-intertext as I analysed if the characters with disabilities occupied main or secondary roles. The position of the characters with disabilities was analyzed in each novel, and in all six texts, each character with a disability was seen as a main character.

Temporality. Exploring the temporality of the books to discuss the disability-intertext (in terms of aesthetic nervousness) produced some interesting results. In this analysis of the temporality of the disability-intertext, I examined a number of elements related to the characters with disabilities through close readings. This examination included the time period in which their stories take place, the time span addressed through the novels, and the tenses of narration within the novels. The characters with disabilities were given enough space and time in the novels to navigate the textual landscape. This freedom is something that was not previously given to characters with disabilities in past disability-intertexts, indicating disability as normality occurring in the texts.

In Brenna's *Wild Orchid*, Taylor's story has the time span limited to the summer months of vacation from school in Saskatchewan. Taylor describes her summer adventures in a first person account. To demonstrate insight into Taylor's autism, Brenna conveys that Taylor has a peculiar interest with numbers. For example, Taylor's autism becomes more apparent to a reader through a conversation she shares with her mother as they begin their journey to Waskesiu.

> "You're not going to start that counting thing again, are you?" Mom asked when I got back into the car...
>
> "Start that counting thing again?" I said to Mom, pretending not to know what she was talking about...
>
> "You know what I am talking about," Mom said.
>
> "You know what I am talking about," I repeated. "Seven words."
>
> "Don't you dare start," she said.

> I have this feeling that the number 7 is lucky, and if I do things 7 times, I feel safe...The fact that her words came out in sevens it was just a lucky event. (Brenna 15)

Taylor’s autism becomes more apparent in the text when she becomes stressed. For instance, after her mother tells Taylor that “*Someone’s* starting to talk back” (Brenna 15) Taylor becomes mad. She writes in her diary:

> What made me mad in this situation is that I have this thing about names. It seems to me that a name really defines the person or thing it describes. Names are important. If I get called by something other than my actual name, such as ‘someone,’ I start feeling light-headed and anonymous. I’ve told my mother not to do it, but sometimes she forgets. (Brenna 15)

Taylor’s issues regarding control and repetition are clearly indicated throughout the book, suggesting the role that Taylor’s autism plays in not only her day-to-day life, but also in her interactions and expectations of others.

In *Waiting for Sarah*, Mike’s journey transpires over a time span of two years and is set against the backdrop of British Columbia. These two years of struggle are chronicled through a third-person narration. The narrative starts from the moment of Mike’s accident, his missing a year of school due to recovery time, the reintegration back into his final year of high school, and finally, the moment that Mike decides to walk with the assistance of mechanical legs and crutches. As Mike is recovering from the accident that took his family and legs, he becomes distant from the world. For example,

> he learned how to move from his bed to a wheelchair and from his wheelchair to his bed, how to wheel himself about, how to take care of himself. But he still kept the world at a distance, growling at everyone, patients, staff and visitors alike, and only occasionally reverting to episodes of anger and self-pity whenever frustrated by his own weakness and physical limitations. (McBay and Heneghan 5-6)

When Mike reluctantly returns to high school his negative attitude persists. For instance, as Mike pushes his wheelchair towards the main entrance of the Carleton High for his first day back he is faced with a new challenge:

> The building was old and lacking ramps. He looked at the steps again. There was no way he could get his chair up to the entrance. Annoyance turned to anger. Damned school! Was there a way around the back? (McBay and Heneghan 24)

Mike's friends Robbie and Ben appear and carry Mike unwillingly up the stairs. Eventually Mike realizes that an entrance with a ramp has been made for him and that it is around the back of the school near the music room. Instances of Mike's frustration towards his disability and the way he believes others are treating him are found throughout the text. For example, even within the classroom Mike's frustration towards his peers is demonstrated:

> Desks were moved; space was made for him. If anyone stared he glared back at them, and they turned away, withered by his hate. Even Carleton's new, cute and over-excited eighth graders, all with two strong legs, all with mothers and fathers and brothers and sisters, all

> with proper homes and families. He despised them all. (McBay and Heneghan 25)

Mike is evidently dealing with extreme anger issues regarding the accident but soon he is challenged even further when the mysterious Sarah enters his life and forces him to answer some difficult questions about what it means to be a friend. When Mike first meets Sarah in the library, she blatantly asks him why he is in a wheelchair, which catches Mike off guard:

> "Hasn't anyone ever told you not to sneak up on people?" he yelled angrily.
>
> The girl flinched at the force of his anger.
>
> His heartbeat steadied.
>
> Damned kid!
>
> The anger went out of him. He felt weak, drained. He said quietly, "I didn't hear you come in."
>
> She said, "What happened to your legs?"
>
> "Did you hear what I said?"
>
> Instead of answering she came closer to the wheelchair, examining him boldly. "What happened to your legs?" she asked again.
>
> Wasn't the answer obvious? Stupid kid! "I don't *have* any damn legs." (McBay and Heneghan 49-50)

But Sarah steadies herself and becomes unfazed by Mike's angry tone and continues to ask him questions about his physical disability:

> She probed for details. Would he always be in a wheelchair? Couldn’t he get artificial legs? Was it hard to get out of the chair when it was time to go to bed? How did he manage to go to the bathroom? What was it like looking up at people all the time? (McBay and Heneghan 51)

Through Sarah’s questions, Mike begins to open up about the tragedy that took his family. Mike begins to question why he discloses to Sarah so much about himself wondering “Why was he telling this to a kid? Because sometimes Sarah didn’t seems like a kid, that’s why; sometimes she seemed quite grown up” (McBay and Heneghan 64). Sarah asks Mike the tough questions that everyone else is avoiding talking to Mike about, and their friendship begins Mike’s emotional healing process.

Ruby Jean’s story in *Free as a bird* is a bit different from the other young adult novels chosen for this study sample. *Free as a bird* is told as a memoir and covers many years, oscillating between Ruby Jean’s past and present memories in her first-person account. Ruby Jean tells her story with a distinctive voice, and many of Ruby Jean’s spelling mistakes and poor enunciation of words are indicative throughout the text. For example, when Ruby Jean recounts her experience to a tape recorder, she is filled with dread upon the memory of being physically and psychologically tortured by the “uniforms” in the Institution. Ruby Jean states that:

> I dint have no say over my own body no more. Had to stand naked in front of the others, had to sit on a toilet with em uniforms watchin, an

> if I dint go they poured hot water on my privates to make me go – that hurt...a lot. Nother thing I dint like...I never gotta say bout what I wanted to wear. (McMurchy-Barber 14-15)

What is interesting about this passage is the agency Ruby Jean demonstrates in the telling of her story. Ruby Jean is fully aware that from the time before she went into the institution to the time she entered the institution she lost a part of herself, especially when she says "I dint have no say over my own body no more." What Ruby Jean does have power over, though, is her voice. After entering the institution Ruby Jean makes herself a vow of silence. The wards decide she is a mute and dumb. By the end of the novel, sixteen years since Ruby Jean left the institution, she has made the decision to start speaking again. With a strong determined voice Ruby Jean's voice and memories come spilling out.

> I told Mr. Turner he could turn on his recorder. I dint wanna be eight again, dint wanna walk through all em locked doors in my head – down bare hallways or into the bad kid room or the cold showers – but I knowed I had to. Yup, had to say something for all those ones who dint never get a chance. (McMurchy-Barber 158)

Ruby Jean's story then becomes the story for all the people who never received a chance to live a life outside of the institution.

In *The Space Between,* Jace and Lucas' story is told only in a few weeks of vacation time in Mexico. Further *The Space Between* is narrated in Jace's first-person account. Occasionally Jace incorporates flashback sequences to Nova Scotia and the suicide of his brother Stefan that occurred in the family garage.

Jace has many internal issues that he deals with throughout the course of the novel. Jace's emotions are particularly heightened whenever he thinks of his younger brother Lucas. Lucas has childhood disintegrative disorder (CDD). Jace explains in his diary that:

> Lucas basically won the anti-lottery, because fewer than five kids in ten thousand get childhood disintegrative disorder. In fact, according to a weird statistics website that Rob found, you're seventeen times more likely to board a plane with a drunk pilot than to be diagnosed with CDD. Which, if you think about it, really isn't all that comforting. (Aker 27)

Through the use of his diary Jace also reflects upon how Lucas has dealt with Stefan's suicide. Jace reflects that:

> for the first time I envied my younger brother the world he was lost in, a world that now made perfect sense if it filled that silence with distraction. I longed for my own distraction, something that could help me forget what I'd found in the garage. (Aker 119)

Jace found his brother Stefan in the garage with a fatal shotgun wound to the head. What is interesting to note in this passage is how much Jace is jealous of Lucas' "ability" to appear and continue to function as though a family member is not missing.

In *La liberté? Connais pas...* Mirabelle and Paule's story takes place over one year of high school, and is told in Mirabelle's first-person account. After meeting Paule for the first time and helping her across the street Mirabelle reflects:

> Quelque chose me tracasse. Comment peut-elle se fier à n'importe qui pour traverse les rues et tout? Et cette école, c'est un vrai labyrinth. C'est pour ça que j'ose lui demander: Pourquoi vous n'avez pas un chien-guide? Les chiens, c'est mieux que les humains. (Gingras 29)[28]

Mirabelle's reaction to Paule's blindness is representative of an inquisitive young woman. Mirabelle often thinks about how Paule would manage to find her way around the busy school. When Mirabelle is sent to meet a guidance counsellor, she is surprised to find out that it is Paule, the woman she helped previously across the street.

> À côté d'elle, appuyée sur le bras de son fauteuil, une canne blanche.
> Je balbutie: "Mais...mais c'est vous?"
> Tu m'as croisée dans les couloirs, peut-être? Avec ma canne blanche, on doit me voir venir de loin.... (Gingras 118) [29]

Paule's blindness is an example of an invisible disability. When Mirabelle notices Paule's white cane, she is caught off guard. Mirabelle has misread Paule and now realizes that Paule is the blind woman she helped across the street. Mirabelle's second encounter with Paule causes Mirabelle to wonder how blind people remember. Mirabelle remembers Paule visually from their first encounter at the

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[28] "Something's bothering me. How can she trust just anyone to help her cross the street or do whatever? Not to mention the fact that our school's a real maze. That's what gives me the courage to ask, "Why don't you have a guide dog? Dogs are better than humans" (Ouriou 26-27).

[29] Propped up against the arm of her chair is a white cane. I stammer, "But...but it's you?" "You've seen me in the hallways, then? I must be visible from quite some distance with my white cane..." (Ouriou 110)

crosswalk and thinks to herself “je me demande comment ils font, les aveugles, sans images, sans couleurs, pour se souvenit” (Gingras 118). [30]

Mirabelle’s inquisitive nature into Paule’s disability demonstrates new ways characters with disabilities are being viewed, and the characters with disabilities are able to respond and give voice to the story of their disability. For instance, Paule sternly tells Mirabelle during one of their counselling meetings that:

> On ne peut pas changer de parents, Mira. Sa voix est rêche en disant ça. Puis je sens que ses yeux deviennent tristes, derrière ses lunettes teintées. Moi, vois-tu, ma mère m’a donné en héritage des cheveux roux. Je ne peux pas les voir. C’est difficile, pour un aveugle, di’imaginer les couleurs. J’en ai beaucoup de peine. (Gingras 148)[31]

This is an example of disability as epiphany functioning in the text. Paule is aware of her disability and by discussing her blindness, Mirabelle is told that she must learn to understand difference in new ways.

Finally, in *Té malade, toi!* Line Gamache has created a biography of her younger sister Josée. Twenty-seven years of Josée’s life is explained by her older sister (and author) Line Gamache in a first-person account. Gamache remembers her mother’s initial efforts to teach Josée speech stating “ma mere s’acharne à lui enseigner les rudiments de la parole, malgré le peu de volonté ou de capacité à

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[30] “I wonder how blind people remember without any pictures or colors to help them” (Ouriou 118)

[31] “we can’t change our parents, Mira.” Her voice is harsh. Then I sense her eyes growing sad behind her tinted glasses. “you know, my mother gave me her red hair. I can’t see it though. It’s not easy for a blind person to imagine colors, which makes me sad” (Ouriou 137)

vouloir apprendre de Josée! (Gamache 16).[32] Josée is represented by Gamache in a very positive way throughout the text and Gamache intentionally makes the reader question Josée's own agency. For instance, while Josée's mother is attempting to teach Josée speech, we are left as readers to decide if Josée is unable to learn speech because of her disability, or if she simply is choosing not to learn speech.

What I found while analyzing the six texts in terms of their respective temporality, was that the characters with disabilities storylines varied from a period of weeks, months and even years. This concurs with Brenna's findings that the time span of the novels, "allows the characters time to initiate and sustain the kind of growth and development often denied characters with disabilities in past texts" (Brenna 114). The characters with disabilities are given enough time in the novel to have their presence known to the reader, and are able to grow page by page, and year by year within the narratives functioning as examples of disability as normality.

<u>Social Context</u>. The social context surrounding the characters with disabilities was also explored when comparing the six texts. Like Brenna (2010), the analysis of the social context included assessing the number of characters with disabilities represented in each text, the gender of the characters with disabilities, and identifying if a particular ethnic culture or religious difference of the characters with disabilities was mentioned. In respect to previous models of disability-intertext, I took into consideration if the character with the disability

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[32] My mom went to great lengths to try and teach Josée to talk, even though Josée didn't seem to want to learn or else wasn't able to" (Cochrane16).

was “cured” during the course of the text, or if the character died. Aiding in the classification of the six novels’ social contexts was also the examination of the characters’ family situations. The examination included taking into account if the character with a disability came from a one- or two-parent home, as well as the gender of the one-parent home. The social context analysis ultimately suggested plausible trends and patterns that the authors had intentionally or unintentionally followed when creating the new disability-intertext and representations.

In *Wild Orchid*, there are two characters with disabilities, Taylor, who has Asperger’s Syndrome, and the wife of Taylor’s friend Paul, June, who has muscular dystrophy and is in a wheelchair. Taylor also lives solely with her mother, but often thinks of her dad, who has moved away, stating:

> I think Dad left because of my problems. For sure they didn’t suddenly appear once he was gone – they just changed in degree with added stress. I think him leaving really sucked. Being a good parent is helping your kids when they have problems, not disappearing. (Brenna 14)

Taylor’s dad leaving her and her mother remains a tough issue for Taylor to think about throughout the novel. As the novel progresses Taylor makes contact with her estranged father, who has asked her to come and visit him for Thanksgiving. Taylor remains sceptical of her father and even at the conclusion of Taylor’s summer Taylor begins to count her friends on her fingers, stating:

> If I count my friends on my fingers – Rose, Julie, Paul and Shauna – it makes four. Mom makes five, and even though sometimes she’s a

> pathological liar, she can also be a friend. I'll also count my dad. He is sort of borderline, but it's possible that Thanksgiving will work out. That makes six. Six friends. One day soon, I'm going to get a new gerbil. That will make seven. And seven is my lucky number. (Brenna 156)

Taylor's relationship with her mother is at times very intense as well, because Taylor takes everything her mother says quite literally. Taylor's mom will often say one thing and mean another, but Taylor struggles with sarcasm. Taylor's mother also often tells her "you have to learn the scripts for social situations and then expect that the responses might be different than what you would predict" (Brenna 16). "Scripts for social situations" results in many arguments flaring up between Taylor and her mother throughout *Wild Orchid*, and this is why Taylor often calls her mother a "pathological liar."

In *Waiting for Sarah*, Mike is left in the care of his aunt Norma after his parents and sister die in the car crash that takes Mike's legs. There are also two other characters with disabilities in *Waiting for Sarah*: Mike's adult mentor Chris as well as another youth David. At the end of the novel Mike is able to resolve his previous issues associated with his loss of legs and now focuses on helping David through the transition. Similar to how Mike first reacted to his disability, David often uses sarcasm to deal with his grief and considers himself the "well-behaved crippled robot in his wheelchair" (McBay and Heneghan 159). David's word choice and language when speaking to Mike, demonstrates a shared negative attitude towards disability that Mike originally had. When Mike begins to work with David, David begins to think of his own disability in a new light. After Mike gets fitted with a prosthesis, he stands in front of David and states, “I used to be a runner. I was on the track team. But that was then and this is now. I got over it. How do you like my new tin legs? Pretty good, huh?” (McBay and Heneghan 159).

As the novel progresses, it is apparent that Mike’s disability presents a formidable barrier to his future happiness, but when he receives his metal and plastic legs he remarks that “it feels good to stand” (McBay and Heneghan 168). This is the only novel out of the six texts in this study sample that provided a solution to the disability, and can possible be read as a modern day “cure” ending for the character with a disability.

Lucas is the only character with a disability in *The Space Between*. Also, Lucas and Jace both come from a two-parent heterosexual home. The family dynamic is upset by Stefan’s suicide, and Lucas and Jace’s parents are both taking time to be separate from one another as they grieve. While Jace’s mother focuses on Lucas, their father decides to tear down the garage in which Stefan killed himself. Jace realizes that his parents are just as lost as he is, and after his father tears down the garage he phones Jace and asks him:

> “Do you think it was the right thing, Jace? Tearing it down?”
>
> My father was asking what I thought. Was asking <u>me</u> what was right. I couldn’t speak, could only hang on to the phone and that moment.
>
> “Jace?”
>
> “Yeah, Pop,” I finally managed to say. “It was the right thing to do.”

> "Your mother –" he began.
>
> "I'll handle it," I told him. (Aker 245-46)

This example of is representative of Jace being the barrier between his parents as well as acting as their confidant.

In *Free as a bird*, during her time in the institution, Ruby Jean is surrounded by many intellectually disabled youth. When Ruby Jean first enters the institution she "had to share [her] room with seven other kids an every night one of em was mad or sad bout something" (McMurchy-Barber 14). Ruby Jean bounces from one caregiver to the next, only to find a very nice couple, Nan and Pop, who take her in. After a misunderstanding when Pop goes away in the ambulance, Ruby Jean runs away and spends a month on the street in East Vancouver. Eventually Ruby Jean returns home safely to her foster home and is reunited with Nan and a healthy Pop.

In *La liberté? Connais pas...* the characters with intellectual and physical disabilities are represented by Mirabelle; who suffers from depression, her mother; who is mentally unstable, and Paule; who is blind. Mirabelle comes from a divorced home. Being raised solely by her mother Mirabelle also has periodic visits by her father. When her father dies, Mirabelle spins into a great depression. With great efforts, it takes Paule to help Mirabelle put her life back together. Since Paule is blind, it is with great meaning that she tells Mirabelle "et si... si c'était à mon tour de te guider, là où tu perdu tes repères..." (Gingras 119).[33]

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[33] "maybe...maybe it's my turn to help you see where you've lost your way..." (Ouriou 110).

Here, blindness functions symbolically in the text. It takes Paule, who is blind, to "show" Mirabelle where she has lost her way. This example of metaphorical blindness harkens back to previous disability-intertexts or the model of disability as epiphany.

Finally, in *Té malade toi!*, the only central disabled character is Josée. Raised in a two-parent home, her mother unfortunately succumbs to cancer. Her father is unable to take care of her by himself, and Josée is placed in a group home. After her father cannot take care of Josée anymore Gamache states, "malgré la mort de ma mere...mon père continua à aller cher-cher Josée à toutes les fins de semaine, et ce, son plus grand bonheur à elle" (Gamache 52).[34] *Té malade toi!* is the only text in this study sample that contains a single male parent raising a disabled child. It is interesting to note that the father in this story is unable to raise his child alone and must rely on additional support. Further research is needed in this area of single men raising disabled children to see if there are other family depictions of characters with disabilities demonstrated in a different way.

In the six texts there were points for further research. For example, no mention of ethnicity was mentioned except for *The Space Between*, were the Greek heritage is periodically stated. Also, religion does not make an appearance in the texts except for *Té malade toi!* where young Josée is baptized. What can be inferred is that these texts primarily contain Caucasian characters, with no mention of any religion. These findings suggest room for advancements for future

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[34] After my mom's death...my dad continued to bring Josée home on weekends, which made her very happy (Cochrane 52).

writers to engage with the disability-intertext in new ways. With regards to social context, as mentioned previously, the family dynamic in all five novels was quite different. Although the traditional two-parent home was the most common setting the family situation was altered throughout the six novels. The character with the disability was eventually raised in a single parent home (representative of each gender) in *Wild Orchid*, *La liberté? Connais Pas..., Té malade, toi!),* or of an estranged relative in *Waiting for Sarah*, and in one instance, the character with a disability moves from being raised by a family, to a medical community, to finally, foster parents in *Free as a bird*. Only *The Space Between* maintained a traditional two-parent home.

Textual Landscape and Genre. Important to this thesis' findings on the disability-intertext was the textual landscape that the Canadian authors situated the characters with disabilities within. It was noteworthy that often the protagonist "traversed a strange geographical landscape away from home" (Quayson 38), and that the textual landscapes all made mention of a Canadian urban setting. These settings ranged from British Columbia in *Waiting for Sarah*, and *Free as a bird*, to Saskatchewan in *Wild Orchid*, and Quebec in *Té malade, toi!*, and *La liberte?Connais Pas...*. One novel, *The Space Between*, was an exception to the Canadian landscape but it did feature Canadians vacationing in Mexico. *The Space Between* also had many flashbacks to Nova Scotia.

The identification of the genre of the young adult novels was examined. Specifically, the novels were linked to realistic fiction seen in *Wild Orchid*, *The Space Between*, *La liberté? Connais pas...*, historical fiction seen in *Free as a bird* and *Té malade toi!* and mystery in *Waiting for Sarah*. It is interesting to note that none of the novels had futuristic or fantasy elements. Instead, concurring with Brenna (2010), I found that historical and realistic fictions were the dominant genres present in the novels of the study sample. This suggests that there is room for development in the disability-intertext and that perhaps future novels that feature disability in a main character can be set in a futuristic setting.

The previous patterns of disability-intertext that have included a prevalence of polio and blindness to populate texts (especially in the later half of the twentieth century), was not found in my analysis, except for one novel in the study. *La liberté? Connais pas...* had a secondary character Paule, who is blind. What I found was that the disabilities mentioned in the current texts range across the categories of what a disability may be, including examples of severe learning disabilities; *Té malade toi!*, *Free as a bird*, and *The Space Between,* cognitive disabilities; *Wild Orchid*, mental illness; *La liberté? Connais pas...* and orthopaedic handicaps; *Waiting for Sarah*. Further, previous models of disability-intertext often indicated that the author could not imagine a “happy future” or outcome for a character with a disability. The disability-intertext has evolved radically and the conception of a “happy future” has changed. Throughout all five novels, death is not the “popular option” or even an option, as it once may have been for characters with disabilities. Also, the “miracle cure” that is often seen in classical texts as a traditional ending is not particularly prominent. In only one of the five texts, *Waiting for Sarah*, Mike, a character that had lost his legs, is given mechanical legs to walk with, if he chooses, with the use of crutches. This option for Mike adheres to medical advancements that exist today. Interestingly, Mike is hesitant towards the legs as “he continued to use his wheelchair: it would be a long time yet before he would be ready to walk in public” (148-9). This implies that there is much more mentally to understand than an instantaneous previous model of a “miracle cure” would suggest. Mike has to be emotionally ready to accept the idea that he has the capability to walk again, and the legs he has been given is not an instantaneous cure.

Self-Image. Throughout the journey for the characters with disabilities, there was always an obstacle for the characters to face. This obstacle was primarily situated so that the characters overcame a negative self-image of themselves to internalize a positive outlook on their disability.

For Mike, an example of his negative self-image is demonstrated when he speaks with his doctor. The doctor is concerned about Mike’s negative moods stating “you still have your mind. And your arms and shoulders. There are many worse off than you” to which Mike screams, “worse off! You mean like no arms as well as no legs and no family? Hah!” (McBay and Heneghan 22).

In *Free as a bird*, Ruby Jean recounts that she had negative self-image stating that:

> sometimes the uniforms was happy with me that’s how come they called me Sharp-as-a-Tac. But there were other times when they wasn’t happy – that’s cause I’d scratch or bite or wet my pants. Uniforms said I did that cause I was a bad kid...said I had a behaviour problem. (McMurchy-Barber 9)

Similarly, Mirabelle describes her negative self-image to Paule, the school counsellor. Mirabelle's experience in therapy is described by Mirabelle in this way:

> Depuis un mois, le mardi et le jeudi, je parle de moi à Paule, comme si j'étais un casse-tête aux morceaux éparillés par terre n'importe comment, et je ne sais pas quelle image ça va donner. D'ailleurs, je ne suis pas sûr d'avoir tous les morceaux. J'en ramasse un, au hazard, je le decries à Paule. (Gingras 129)[35]

In *Te Malade Toi!,* it is not Josée who goes through a transformation of a negative self image. Instead, it is Gamache who realizes that her sister only thinks of herself in the positive. Gamache states that:

> Son handicap est moyen et par ce fait même, elle ne se rend pas compte de sa difference. Ce qui fait qu'elle ne peut en être malheureuse. Elle vit comme dans un rêve. Sa vie est belle et grâce à elle, la vie des gens qui la côtoient est plus belle aussi (Gamache 61).[36]

This passage indicates that it is more the people around Josée who go through a circular journey of acceptance towards Josée. Whereas in the other novels,

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[35] "For the past month every Tuesday and Thursday I talk to Paule about myself as though I were a puzzle whose pieces are scattered all over the floor and I don't know what the picture will end up looking like. In fact, I'm not even sure I have all the pieces. I pick them up randomly and describe each one to Paule" (Ouriou 119)

[36] Because her disability is not a major one, she doesn't notice that she's different. It doesn't make her unhappy. She lives in a kind of dream world. To her, life is beautiful. And because of her, the lives of the people around her are also filled with beauty" (Cochrane 61)

specifically *Waiting for Sarah*, it is the character with the disability that must learn to accept their own disability.

In *The Space Between*, it is Jace that goes through a transformation of how he views his younger brother Lucas. Jace is worried that because of Lucas' CDD, Lucas is unable to remember Stefan. After sharing a traumatic moment with his younger brother, Mike realizes that Lucas, despite having severe autism, and never showing any recollection of having an older brother who has died, does indeed remember Stefan. Holding Lucas close, after Lucas has almost drowned, Jace writes:

> I wonder what went through [Lucas'] mind at that moment...I wish I could ask him, wish he could tell me. And then miraculously, he does. "Fan," he says simply. The word catches me, like a stitch when I'm running...I can only hug my brother. Who could never say our older brother's name. (Aker 221)

Jace realizes in this moment, that he has been entirely wrong about Lucas not being capable of remembering Stefan and he becomes closer to his younger brother than he ever has been.

Disability as normality is illustrated by the characters with disabilities through the ways in which they identify their negative self-image and then transistion towards a positive self-image. This positive transition is indicative of a new disability-intertext for the authors to follow when including characters with disabilities into their texts.

Abuse. There were also instances of abuse, both of a sexual and a mental nature, against the characters with disabilities in three of the texts. In *Free as a bird*, during Ruby Jean's first night in the Institution, she remembers that she:

> woke up in the dark an there was a night uniform layin side me an he was touchin me. I dint like that man touchin me like that – nope, not a'tall. So I scratched an bit him hard's I could. He slapped my face, but that dint stop me from tryin to bite him more. (McMurchy-Barber 15)

In *Waiting for Sarah*, Mike, comes victim to a mean prank after someone hung a bumper sticker on the back of his wheelchair with the slogan "Ban Leg-hold Traps" (McBay and Heneghan 27). Further, in *Wild Orchid*, Taylor is called "the freaker" (94) by a young man she shows interest in. In *Disability Hate Crimes*, Mark Sherry emotionally conveys that "disability hate crimes do exist, that they have unique characteristics which distinguish them from other hate crimes, and that more effective policies and practices can be developed to respond to an prevent them" (1). For the authors of the young adult texts, including disability hate crimes into their novels may be another route, albeit a painful route, to explore disability in their future works in order to demonstrate the many branches and facets of disability-intertext.

Humour. On a lighter note, humour does exist in the novels especially regarding the characters with disabilities. Whether dark or hilariously light-hearted, humour regarding the disability of the character manages to appear in some way, shape, or form within the contemporary fiction perhaps to make us laugh during the process of learning. For instance, in *Té malade toi!,* Gamache recounts her younger sister's adventures, specifically when Josée runs away and becomes friends with a six-foot-tall boy. The boy follows Josée blindly throughout the town and Gamache states that:

> Mais la dire escapade de Josée dont je me souvienne, c'est lorsqu'elle s'est poussée du centre des loisirs d'été. Ma petite soeur Josée avait encore une fois fugue mais, cette fois elle avait entraîné avec elle un grad gars de six pieds qui l'a. Vait suivie aveuglément. (28)[37]

The idea that little Josée could evade her family, looking for her for such a long time, while making friends with a "giant" during her adventure, is comically represented in the graphic novel. Also, Brenna includes instances of humour in her text *Wild Orchid*, specifically while Taylor recounts taking a test to see if one has autism. Taylor remembers that:

> I got a total of eighty-five points out of a hundred for my answers to the questions, and at the end of the quiz, everyone with over seventy-five points gets a message that says, "Congratulations, you're definitely autistic!" (Brenna 31)

Taylor then writes in her diary that when her mother first told her she had Asperger's Syndrome, she thought "she was saying, "Ass Burgers." Later, when she asked if I had told anyone at school, I said, "Of course not." I mean, who would go around telling people they had Ass Burgers" (Brenna 31).

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[37] Josée's wildest escapade that I can remember was one summer when she took off from the recreation centre. My little sister had run away again, but this time she had brought a long a six-foot-tall boy who followed her blindly. They walked and walked, and walked some more. Josée managed to lead the boy right across the city" (Cochrane 28)

These instances of humour used in the novels that illustrate characters with disabilities, demonstrates the way in which disability as normality can function positively in a text.

Author's Notes. Finally, in four of the texts, *The Space Between, Free as a bird, Wild Orchid,* and *Té malade toi!,* the authors make an effort to leave some semblance of an author's note to discuss why they have incorporated disability into their works. The author's entry in the acknowledgements section, and efforts taken to leave an authors' note, delves into the author's own personal reality. Further, the author's note is interesting to consider in regards to the idea of background-bodies as discussed before. Gamache writes that "elle était differente dans un monde où la differénce faisait peur! Parce que les gens ne la comprennent pas de la comprendre" (18),[38] and I think this is really a feeling that all the authors have experienced when including a character with a disability in their works. The fact that *differences do frighten people* and that people often do not take the time to understand difference or even try to, presents a threatening environment for the authors to put their works out into the mainstream. Although the authors are able to control to some extent how the characters in the texts react to their characters with disabilities, they cannot control the readers' reaction, nor can they control a person's real life experience when one is faced with disability. What these books do attempt to do though, is to get the conversation of disability stories started. Perhaps the author's notes is added in order to defend the reason why the author has chosen to include a disabled character in their story as a main protagonist so

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[38] Josée is different, in a world where differences frighten people. Because people don't understand her and don't even try to (Cochrane 18).

as to ease the reader into the production of the text that features disability. Maybe one day in the future, the disability-intertext will evolve so that leaving an author’s note is no longer a requirement felt by the authors who place disabled characters at the forefront of their works.

In all six texts, as the characters move out of their constricted circumstances (whether it be their families hold over them, or issues surrounding their disabilities), they ultimately transform into a character that a reader could meet anywhere. Where emotions range from anger, guilt, shame, laughter and love, the characters with disabilities are representative of humanity and disability as normality. Readers may recognize this contextual shift from a character with a disability being usually represented as a stock character into the idea that a character with a disability can be a “real” character. The textual space offered to the protagonists in the six texts are powerful in the manner in which Mike, Taylor, Ruby Jean, Mirabelle and Paule, Lucas and Jace, and Josée are depicted as viable, strong present-day protagonists who are capable of telling his/her own story. What these characters with disabilities represent is the ability for such characters to move authoritatively as a protagonist throughout a text, which was entirely uncommon for characters with disabilities in classic texts. When these texts are examined fully (through close readings), they offer examples that include disrupting the common place of young adult texts and interrogating multiple viewpoints, especially disability as normality.

The Future Disability-Intertext

Boundaries previously found in young adult texts that feature disability are changing, and evolving. This transformation is occurring through the depiction of new types of community and disability as normality. For the six texts examined, the common denominator of the novels is simply the inclusion of characters with disabilities along with “the realistic treatment of these characters as people rather than ‘using’ them as plot devices” (Brenna 119). The time span of the novels does also illuminate certain restrictions to the texts. It is interesting to note that in the novels that take place across a time span of days, “there is no conclusive evidence that this shorter time span affects the ability of the target character to learn and grow” (Brenna 122). What the novels do offer is texts set in a present time. The novels also offer some involvement with past times in the characters’ lives whether through flashbacks, memoir, or diary entries. Further, past tense appears as the preferred way for accomplishing the narration for characters with disabilities that are of high school ages. Some of the books also involve multiple settings which implies the potential of a character with a disability to travel within the context of the novel, an occurrence that contradicts past stereotypes about people with disabilities.

Similar to Brenna’s findings in *Characters with Disabilities in Contemporary Children’s Novels: Portraits of Three Authors in a Frame of Canadian Texts* (Spring 2010), I found that there was a general lack of metafictive elements, and that no use of a fantasy genre or a future tense appeared in the texts. Further, the suggestion that all the characters of the texts in my sample were unspecified white Anglo-Saxons, leaves room for the authors to incorporate ethnicity into their novels. This development would see for the inclusion of ethnicity into the young adult genre that includes characters with disabilities. The idea of "previously unheard voices" in terms of disability in young adult literature falls short of the inclusion of other types of diversity. *The Space Between*, did include a secondary character that is a homosexual, in order to represent other types of diversity. Further, it was determined that the relationship of the character's disability to plot is integrally related in all six texts I examined. The disability in each text appears to be inseparable from the main plot line. Like Brenna, I wonder if future texts will be able to depict characters whose disabilities are simply another aspect of their characters without operating as a plot device (Brenna 211).

At the conclusion of Brenna's research she suggests that authors are not considering characters with disabilities as possible candidates to be protagonists as a junior sleuth (Brenna 135) in the mystery genre. During the final months of my research into the six texts used in this thesis, I was fortunate to find a new text *Ice Rose* (2010) that was recently published by an Edmonton author, Alison Neuman, who is also physically disabled. Interestingly enough *Ice Rose* is a mystery young adult novel that includes a main character Elissa Morris, with a disability (specifically, she is in a wheelchair), who eventually becomes a spy after her father goes missing. *Ice Rose* suggests a change in the previous tradition that may have represented and reflected stereotypical societal attitudes, and is indeed a new evolution to the capabilities of the disability-intertext. Further, *Ice*

Rose makes extensive mention of Alberta. Specifically, the main character Elissa lives in Edmonton only to eventually leave to go to Madisyn Academy, a secret agent training school, in order to find her missing father. Brenna's research indicated that:

> while including a number of Canadian settings, mentioning many provinces by name, the study texts did not make mention of Alberta other than indirectly through a reference to a 'western province,' and none of Canada's territories – Yukon, Nunavut, or the Northwest Territories – were given specific address. (Brenna 209)

Of course, it must be stated that Brenna's research came out in Spring 2010, and Neumann's novel did not get published till September 2010. It is interesting to note how fast the disability-intertext is evolving, and the quantity of books that is being published that include main characters with disabilities, across the country.

Implications of the Intentional Disability

Each story in the sample texts showcases a protagonist who must go beyond the restrictions of his or her society in order to achieve personal enlightenment and/or growth. The genres examined in the texts are rich with diversity, including realistic fiction, historical fiction and mystery. The extensive nature of disability in text and the way disability as normality can possibly be represented in a text is made more apparent when one types the generic *disability* into an internet search engine and immediately receives page upon page of results. Easy accessibility to online discussion forums, blogs and interactive online storytelling is where the twenty-first century is positioning how disability is discussed and talked about or not talked about. With all that in mind, one thing remains remarkably clear: the disability-intertext has yet to waver in its creative power of wonderment and it will continue to inspire. For instance, one PhD researcher, Sarah Lewthwaite, at the University of Nottingham, is focusing on social experiences of disability online, in and around higher education. On her blog "32 Days Remaining," her research focuses on the ways in which the internet-based technologies of "Web 2.0" are changing and perpetuating disability. What Lewthwaite's research offers is a new look into the online world of disability representation. Lewthwaite states that in the online world, "disability is not always reported as the most salient factor implicitly effecting student interaction, however disclosure of disability and an "extra-ordinary" (dis)abled perspective remain central facets contributing to student's negotiation and "management" of identity in online social situations" (no page), perhaps offering insight into the future of disability-intertext representations in the online world.

With regards to social situations in the online world, social thinking is presented in Lewison, Flint, and Van Sluys' (2002) four dimensions framework regarding critical literacy. Their framework consist of "(1) disrupting the commonplace, (2) interrogating multiple viewpoints, (3) focusing on socio-political issues (4) taking action and promoting social justice" (Lewison et al 382), and the six texts examined in this thesis reflect these dimensions. By including disability into the texts, the authors have disrupted the commonplace and have allowed a new viewpoint to be heard in young adult fiction. Multiple viewpoints have been assessed in this thesis by analyzing the characters with disabilities. Further, the authors' have included disability as normality into their texts so as to create a textual landscape that fully includes all aspects of a human experience into the young adult genre.

As a new departure from the conventional themes which run throughout Canadian literature, the use of the disability-intertext becomes important for young adult contemporary fiction's concern with inclusion. However, that is only part of the reason as to why the disability tale has managed to find a place within contemporary young adult fiction. Uniquely, young adult writings and re-incorporation of the disability tale thread in contemporary fiction have led to something that is conventional yet revolutionary. What takes places within the story of the disabled tale and disability-intertext is the hero/ine is able to rise from one level of consciousness to another that is not as irreversible as the transformation itself, but also as spoken of in the present and formulated future or the concept of working through the past, instead of working past it. With regards to stereotyping disability in young adult literature, it is interesting to consider that if modern authors try to "balance" a disability in their characters with a particularly evident gift; it can be argued that writers are moving from one stereotype to another in terms of characterization. In addition, "if authors see all female single-parent situations for these characters as positive, and the rare male single-parent situation as negative, that too may have implications about stereotypical thinking" (Brenna 71). During close readings, what must be taken into account is the genre, point of view, type of disability, degree to which disability was “cured,” family interactions, self-image, and character traits. Further, it was asked what the time span in the novels covered, including tense of story, and whether the relationship of the characters disability to plot was integral. Arguably, the authors in the six texts are examples of young adult fiction that are taking action and promoting social justice by including previously “unheard” voices.

The emerging disability-intertext in Canadian young adult literature is indicative of works about characters with disabilities that are moving from new and provocative to “fundamental” as “other meanings of radical take over” (Dresang, xviii). Overall, the six books I examined in this thesis did not reflect what Keith (2001) describes as the “kill or cure” mentality of authors writing about characters with disabilities in traditional texts, nor did they illustrate a predominance of particular disabilities, unlike the prominence of polio and blindness in classic literature, the later reflected in excess of its actual occurrence due to its metaphorical possibilities (Keith 199). The texts do represent Ato Quayson’s ninth provisional category for aesthetic nervousness, disability as normality. Disability as normality is represented by a new thread found within the six texts I have examined and suggests a changing disability-intertext from previous stock models. This pattern includes special mention to temporality, where the character is allowed to navigate a space that was not previously given to characters with disabilities. Author’s notes are also found throughout the texts indicating a need for the authors to explain their works and justify why they have included a character with a disability as a protagonist. Hopefully as the disability-intertext continues to change, the author’s note will be something of the past and the intentionality for an author to include a character with a disability will not need to be known by the reader. The new disability-intertext also includes a transformation of self-image by the character with a disability from a negative self-image to positive a positive self-image. The self-image is integrally related to the instances of abuse and humour that are also found throughout the texts. Representations of the disability-intertext have been evaluated through the concept of disability as normality for the purpose of exploring the journey of the new disabled protagonist.

Disability as normality has occurred in the text through efforts to make the characters believable and different from the “norm.” This new pattern of disability-intertext may be representative of attempts of trying to “perfect” how disability is represented in literature. The act of applying possible formulaic means for making disability in literature believable contradicts the unique nature of a disability. These are stories that need to be told and the desire for an author to get away from the historic treatment of disability demonstrates that a disability story is in fact more complex than it may first appear to be.

Conclusion

Pour comprendre la differénce, il faut avoir un minimum d'imagination et de générosité... (Gingras 18).[39]

In North America, attempts are being made to follow the principle of inclusion in the classroom, the work place, social policy, government, the arts and the media. Within the realm of literature, one result of this intentional attempt at inclusion seems to be construction of a new pattern of representing disabled protagonists. This pattern is one that is indirectly "perfecting" how disability is conveyed in print. Disability cannot be perfected, however, as each disability is so different from body to body. Further, disabilities can change over time, and someone who is able-bodied can later become disabled, and vice versa with advancements in medicine. Through the intentional inclusions of disability in literature, a new pattern and new model of disability has emerged through the visible efforts of the media, and social efforts of activists. Needless to say, there is value to telling these stories of disability, but one should be wary of conventionality in a pattern of representing disability. Further, this explorative study of the disability-intertext suggests new patterns in which disability is being represented. Textual analysis of a specific novel was not my intent and further research is needed in this area to fully understand the new patterns in the disability-intertext.

What I have attempted to examine in this thesis are instances of the new emerging patterns of the intentional disability-intertext formula. The story of disability is used in the process of individual and cultural identification. This is

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[39] "To understand differences you need to have a good imagination and a generous heart..." (Cochrane 18).

illustrated through the alternative visions of individuals with disabilities who are dancers, singers, or writers. The story of disability within the popular mediums of film and television and intentional acts of inclusion in literature can be read as possible acts at “perfecting” disability representations. Conversely, the story of disability has inspired unconventional visions which have greatly affected the literary canon. Writers have rearranged familiar motifs, reversed plot lines and new patterns to represent characters with disabilities. The new patterns provoke readers into rethinking stereotypical views of disability.

In Chapter 1, my focus began with an exploration of the literary traditions of disability. This exploration included a history and explanation of Disability Studies as a discourse. Beginning with representations of disability from antiquity to present day I was able to provide a working definition of “disability.” Further, by asking “what is Disability Studies,” I was able to analyze images of disability in the media and transition Disability Studies arguments into a discussion about the disability-intertext. Explanations of representations of disability in text, and the disability-intertext provided a basis for an introduction into Michel Foucault’s theory of the abnormal, Ato Quayson’s theory of aesthetic nervousness and Wimsatt and Beardsley’s theory of the intentional fallacy.

In Chapter 2, I analyzed Foucault’s theory of the abnormal body and the background-body and problematized it in terms of a Disability Studies approach. Aesthetic nervousness was explained as my main methodological departure with disability as normality taken as my main consideration for further exploration of the disability-intertext in the sample texts. Finally, Wimsatt and Beardley’s theory of the intentional fallacy was explored in relationship to when disability is indicated by the author. The case study using Heidi Janz's semi-autobiographical historical novel *Sparrows on Wheels* analyzed the intentional fallacy against emerging patterns of the disability-intertext. When disability is indicated by the author (referring to the author's personal experience with disability), it upsets the intentional fallacy, and in my analysis I argued that disability in the young adult genre provides a space for writers to negotiate new frameworks and borders.

In Chapter 3, the disability-intertext was analyzed in six contemporary young adult texts and I put forward questions for future research. These questions related to such things as: disability as normality, temporality, social context, textual landscape, genre, abuse and humour and the inclusion of an author's note. For the authors, the hero/heroines must be successful agents in constructing disabled images free of stereotypes, and all writers mentioned in this thesis have situated their disabled protagonists in the traditional position of storytellers so that they may negotiate their "dis/abilities." Further, the way characters with disabilities are being portrayed in recent Canadian young adult fiction has emphasized the importance of the topic of disability for critical studies. Finally, I proposed that future research and future writings for characters with disabilities could include a fantasy genre, the inclusion of ethnicity and more diverse secondary characters.

Implications of representation of the disabled individual in Canadian young adult literature are important in discussing how the disabled body is viewed in society today and what can be done to develop new views. Through exploring questions of how characters with disabilities convey themselves, have their voices heard, and how the stories are interpreted by the community, I hope that this thesis has demonstrated that it is up to the *listeners and readers* of texts to engage with and construct meanings of texts.

Kroeber's observation that "stories are always retold, reread, [and] that narrative is a repeating form for discourse" (3) highlights the power and importance for the disability-intertext to continue to thrive in young adult literature. In the conclusion of *La liberté? Connais Pas...* Paule tells Mirabelle that "il y a une vie, pour toi, dehors. Elle à toi, ta vie..." (Gingras 132), "that there is a life for you outside. Your life belongs to you" (Ouriou 121). The message that everyone belongs outside, and that everyone has a story to tell regardless of ability, resonates when speaking about disability. Through my comparative method of analyzing the intentional disability intertext in the frame of aesthetic nervousness, it is my hope that the observations made will further the conversation of inclusion, authorial intent, and the treatment/perfection of disabled characters in literature. It is the act of reading literature that can allow us to understand how alike we all are, even in our differences.

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